LONG-TERM CARE: A SINGLE ENTRY POINT FOR THREE POPULATIONS

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FOREWORD

This study was undertaken in response to Senate Concurrent Resolution No. 33 and Senate Resolution No. 27, adopted during the Regular Session of 1995. This study examines, in general, the concept of a single entry point for long-term care services and its advantages and disadvantages. The operation of coordinated systems, including the use of single entry points in other states is also reviewed. The situation in Hawaii is discussed and a recommendation is made for the implementation of a single entry point for long-term care services for disabled children, non-elderly adults, and the elderly.

We extend our sincere appreciation to all who contributed and without whose cooperation this study would not have been possible.

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INTRODUCTION

Senate Concurrent Resolution No. 33 and Senate Resolution No. 27: Senate Concurrent Resolution No. 33 (Appendix A) directs the Bureau to study "the merits of establishing a single entry point for long term care services used by elderly adults and families of disabled children and disabled younger adults in Hawaii." The Bureau "may use models of systems from other states in exploring a system appropriate for Hawaii's environment and population."

The two Resolutions state that:

> [A] "single point of entry" for long-term care services is a method which may simplify access to long-term care services because it provides a local or regional access point where consumers receive information and assistance, assessment of needs, care planning, and authorization of services.

The Resolutions further elaborate that a single entry point ("SEP") also involves "help[ing] individuals become aware of the services available." The focus of the Resolutions appears to be improving *access* to the system. From the perspective of potential consumers, this means an easier, simpler, and faster way to get at long-term care services. From the State's point of view, it may also mean a more efficient way to deliver services.

Limitations and Focus of Study: Both Resolutions specifically recognize that an SEP is "only one component of a comprehensive long-term care system." ***This is a very important point.*** The focus of the Resolutions, and therefore of this study, is a single entry point system and does not encompass the entire panoply of issues of interest in the long-term care field.

Any long-term care system, even if targeted to just one discrete population such as the elderly, is hugely complex and multi-faceted. These complexities are compounded by the addition of two other categorical populations: disabled children and the disabled non-elderly. The many components, precisely because they form part of a system, are necessarily inter-related and inter-dependent. Therefore, it is only natural, upon examining one component, to want to look at the next related component. However, the Resolutions clearly did not intend for an all-encompassing exegesis of a comprehensive long-term care system to be done and, thus, none is attempted.

Although this study focuses on access to a care system which happens to be long-term in nature, interesting long-term care issues abound, however tangentially related to the concept of an SEP. Worthy though they may be, many issues, including those listed here, are examined only if and to the extent that they shed light on a single entry point system:

- The philosophical differences between long-term institutional care and community- and home-based long-term care support services; and differences within the community- and home-based model itself, for example, the merits of using support services in congregate housing vs. group homes vs. own-home situations.

- Long-term care reform: the merits of private vs. public strategies, including the use of private continuing care retirement communities, capitated, managed care, social/health maintenance organizations, individual medical

accounts, home equity conversions, PACE programs (programs for all-inclusive care for the elderly), and substitution of lower-cost hospice care for skilled nursing facility care.

- Long-term care financing, including private or public long-term care insurance, or a mixture of both.
- Quality assurance, including standards and licensing of facilities, programs, and personnel at the federal, state, and local levels and services, including the elusive monitoring of home health and care services, especially in a client's own home.
- Equity issues, including the disparity between rural and urban access to care.
- Programs and efforts to prevent or delay the need for institutional care, including prenatal care programs to reduce developmental delays, thus reducing overall eventual long-term care expenditures for the disabled.
- Funding sources, *per se,* especially maximizing of Medicaid funds through the use of various waivers, rates, and reimbursement methodologies.
- Client rights, including guardianship programs.
- Housing assistance for the disabled and elderly.
- Special education, training, and assisted employment for the disabled.

Regardless of any particular service approach or the actual services provided, consumers must access those services in some way. The focus of the Resolutions and thus of this study is not necessarily what the end-product services are, but how those services are accessed.

Organization of the Study: Chapter 2 reviews the concept of a single entry point, system fragmentation, an SEP as one component of an integrated long-term care system, and how an SEP process can be integrated horizontally and vertically. Three models of administrative structure ("consolidation," "umbrella," and "cabinet") seen in long-term care reform, and which often include an SEP component, are discussed. Next, this chapter examines various obstacles to system integration. How an SEP can act as a gatekeeper in a managed care system is also examined. The heart of any SEP process, and key to efforts at system coordination, are the three inter-related processes of pre-admission screening, assessment, and case management, each of which are examined in turn. However, standardized assessment presents difficulties, which are discussed. Finally, functional and financial eligibility determination and service authorization are examined.

In chapter 3, various types of long-term care services are examined, including Medicaid-funded nursing home care and home- and community-based supports and services. Various long-term care populations are also reviewed. Next, this chapter looks at long-term care services as supports for an individual's functional limitations. The long-term care services continuum, including both institutional and home- and community-based supports is then examined from a variety of perspectives. Home care as informal support by family caregivers is described. Home care as paid personal care and homemaker services follows. Various other alternative services such as adult day care and adult day health services, including a look at the original PACE (Program of All-Inclusive Care for the Elderly) program (On Lok Center in San Francisco) is examined. Hawaii's PACE program and the concept of social/health maintenance organizations are also discussed. Finally, various alternative living arrangements, including congregate housing, adult foster homes, board and care homes, and

adult residential care facilities (ARCHs) are looked at. The Maluhia Waitlist Demonstration Program which routes nursing home-level patients staying in acute care hospitals to certain Hawaii ARCHs is introduced. The thorny issue revolving around the categorical vs. the generic, or functional, approaches to long-term care access, and their respective advantages and disadvantages, are examined. The disabled of all ages, including the developmentally disabled (DD), can also be considered using either approach. How the perception of long-term services may affect the ease of integration or coordination of the long-term care system is examined. Next, living arrangements and various federal programs for the DD population are described. Following this, services to the developmentally disabled are examined. Finally family support services for DD individuals are examined.

Chapter 4 reviews the situation in other states and begins with a discussion of the dearth of literature on single entry point systems for the three designated target populations. Material from Colorado, Indiana, North Dakota, and Texas are presented. In addition, material from a well-known six-state (Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin) study is discussed.

Chapter 5 examines the provision of publicly-funded long-term care services in Hawaii to the three designated populations. Services provided by or through the Departments of Human Services and Health and the Executive Office on Aging are presented. The opinions of the three agencies on the pros and cons of an SEP in Hawaii are also reported.

Chapter 6 offers a brief summary of the concept of a single entry point and the implications for a policy choice between a generic and a categorical approach. It summarizes the advantages and disadvantages of an SEP process. This chapter also offers a number of cautions that policymakers should be aware of regardless of whether an SEP is to be implemented or not. In addition, if an SEP is decided upon, further cautions are raised. Next, existing support for some sort of system coordination is reviewed. Finally, chapter 6 makes recommendations for a two-phase pilot project.

Chapter 2

CONCEPT OF A SINGLE ENTRY POINT

> *"A single access point enhances the potential that clients will receive information on an entire range of possible alternatives ... simply making people aware of their community care options can go a long way in deferring nursing home entry."*[1]

Concept of a Single Entry Point (SEP): An SEP can be viewed in several ways. Basically, it is a "one-stop shop" process providing people with access to long-term care services. However, the concept of "access" can be extended beyond merely how one enters the system to how one actually receives services and follow-up monitoring. Consequently, an SEP -- *as a process* -- can operate independently of the actual types of services provided. That is, an SEP is the funneling process through which potential clients of long-term care services can be screened, assessed, advised, and directed to appropriate services, whatever those services are. Thus, the myriad long-term care services available to the three target populations are not, in themselves, of inherent interest to this study. That is, whether one type of service is better or more appropriate than another is not the issue. *(See section titled "Focus of Study" in chapter 1.)* Rather, the long-term care services provided become pertinent when they demonstrate the ease or difficulty of implementing an integrated SEP process serving all three designated populations. It is in this spirit that the examination of various long-term care services is done throughout this study.

Horizontal and Vertical Integration: An SEP can also be thought of as either horizontally or vertically integrated, or both. Horizontal integration results from a single access to long-term care services across various service departments or agencies. In some states, these may include a state department of aging, department of health, department of human services, other governmental bodies, and perhaps private organizations. Sometimes, services may fill in gaps where different populations are targeted. At other times, services overlap unnecessarily while creating unfilled service gaps.

System Fragmentation: Characteristically, long-term care services delivery is fragmented and mostly a function of how legislation on the federal, state, and local levels has evolved historically. To illustrate, Rivlin and Wiener (1988) evidence fragmentation in just one area of service (home care services) for just one target population (the elderly):[2]

> [M]any programs and agencies at the federal, state, and local levels fund some home care services, creating a highly fragmented financing and delivery system. At the federal level, funding for elderly home care services is available from medicare, medicaid, the social services block grant, the Veterans Administration, and the Older Americans Act. Each program has its own eligibility requirements, benefit coverage, regulations regarding provider participation, administrative structure, and service delivery mechanisms. The result is that it is difficult to coordinate a comprehensive set of home care services.

The effect of long-term care service fragmentation on an SEP process is compounded by the mix of other services in addition to home care. In turn, this is magnified by the addition of two other target populations, each burdened with similar historical problems of fragmented funding of services.

The Executive Office on Aging makes a similar observation in its 1988 report entitled Long Term Care Plan For Hawaii's Older Adults:[3]

> More than eighty Federal, State, and local government programs offer direct or indirect assistance to persons with long-term care needs. Help may be in the form of cash, in-kind assistance, or goods and services. Five programs (Medicaid, Medicare, Social Services Block Grant, the Older Americans Act, and Supplemental Security [Income] offer major Federal financial support for both community based and institutional long-term care.

According to the Executive Office on Aging, at the level of program administration, multiple funding sources cause fragmentation of services in Hawaii which, in turn, gives rise to various negative consequences:[4]

> Unfortunately, the existence of multiple funding sources has resulted in the proliferation of different, often confusing and frustrating sets of eligibility requirements and program designs. In specific terms, some of the service and system difficulties [among others] can be described as follows:
>
> - Service providers have developed and apply different service definitions and standards.
> - There is irregular or little coordination of services among the majority of providers.
> - Standardized service records and complete client information are not available on a Statewide basis.
> - Access to services is often limited due to geographical constraints, particularly on the Neighbor Islands and in the rural Oahu communities, and to the fact that many services are not widely advertised or located in such resources as the phone book.
> - Eligibility requirements vary by program and are inconsistent across the board.
> - There is a lack of full public awareness and understanding of services and programs.
> - Services are often fragmented and do not provide adequate follow-up.

SEP as One Component of an Integrated Long-Term Care System: Discussion of fragmentation normally refers to the entire long-term care system. An SEP is only one component of that system. The concept of an SEP implies some degree of integration of the overall system. However, the existence or the establishment of an SEP neither implies nor guarantees an integrated long-term care system in its entirety. The commonly cited characteristics of a long-term care system are:[5]

(1) Planning and policy development;

(2) System access, client assessment, and local service delivery;

(3) Cost containment and private sector involvement; and

(4) Quality assurance and consumer protection.

An SEP involves the second component (system access, client assessment, and local service delivery) in which equal and easier access is sought for the greatest number. The

Executive Office on Aging identified six major components of the long-term care system as follows:[6]

(1) Clients;

(2) Informal support systems made up of family members and friends;

(3) Formal health, social, personal, and other supportive services;

(4) Coordination or linkages between clients and the service, finance, and program and policy spheres;

(5) Public awareness and consumer education; and

(6) Long-term care finance mechanisms.

According to the latter set of system components, several items (1) through (5) have something to do with an SEP process although an SEP concept itself is not clearly articulated. Components (4) and (5) come closest. Although more than an SEP process is involved in a truly integrated system, it is not within the scope of this study to address full system integration. The four characteristics listed above usually describe state-level system integration. At the *local level,* integration more fully involves the SEP process. At the local level, one local agency serving a specific geographic area is identified and is given the responsibility to:[7]

- Serve as the central access point for clients for all publicly funded long-term care services. This one-stop shopping means that a client's many needs can be met without requiring each client to individually search among all the agencies for needed services.
- Matching the appropriate services to the individualized needs of the client and monitoring their provision through case management.
- Act as the gatekeeper in deciding who will be served by all funding sources. This is done through clear eligibility criteria, client assessments, and preadmission screening programs.
- Conducting local needs assessments and planning activities and encouraging or coordinating development of needed services and programs.
- Assuring the quality of services.

Even at the local level, the SEP process still accounts for only several components of an integrated system. These are the first three items: central access, appropriate services provided through case management, and assessments and screening for multiple purposes including cost containment. However, an SEP is an inherently integrative process. Thus, it works to enhance these multiple and reciprocal activities either at the local or state levels.

At any level, the individual seeking help from a fragmented long-term care system needs easier access:[8]

> The person who is not knowledgeable about the full array of services available for a particular problem needs guidance to reach the appropriate service. Persons in need may reach out to a service because of its prominence or because acquaintances have used it. Selecting an agency or service in this manner would be somewhat like wearing a pair of corrective glasses prescribed for a neighbor because they were helpful to the neighbor's vision. Because of the complexity of

> chronic illnesses, there may be a combination of services that would be more helpful than one or another service alone.

A Horizontally Integrated SEP Process: In any case, a horizontally integrated SEP would attempt to either consolidate or coordinate access to diverse services across authorizing agencies and providers. The difference between consolidation and coordination is one of degree. It is important to remember that an SEP is only a first step to true system integration. As an initial process, an SEP can coordinate, rather than totally consolidate, the process of access to long-term care among agencies. This is particularly true under the ***"cabinet"*** model of state administration. Under this model, existing cabinet level agencies retain their long-term care responsibilities but function under an official interagency coordinating committee, or the like. Such an interagency coordinating committee would be the natural locus for development of any integrated long-term care state policy. There is no need for departmental reorganization. It is generally acknowledged that this form of structure lends itself least to true service integration and coordination, largely being dependent upon personal effort and informal agency head consensus. Support of a state's governor is key under this model. However, this structure requires the least amount of change; the umbrella model requires much more, and the consolidation model entails wholesale governmental reorganization.[9]

Under the ***"umbrella"*** model of state administration, all long-term care services are provided under one single agency, usually a department of health and social services. Different long-term care programs and functions are dispersed among various divisions and bureaus within the umbrella department. Internal responsibilities are shifted in order to increase inter-divisional coordination. An intra-departmental coordinating structure is usually developed to integrate planning, policy development, and resource allocation among the different divisions. Integration of services is fostered by assigning responsibility for programs to one division, using one local access and delivery system, and developing an intra-departmental planning and coordinating committee. Thus, regardless of whether categorical or functional criteria are used to define target populations, all services are channeled through the various divisions of one umbrella agency. *(See chapter 3 for discussion of functional vs. categorical approaches.)* Horizontal integration for system entry is achieved, then, across various state divisions by channeling access through one supervising department.

For example, Governor Bayh of Indiana proposed a plan in 1990 to create a new Department of Health and Family Services under the umbrella model. Three departments -- Human Services, Mental Health, and Public Welfare, and the Board of Health were proposed to be merged. While not specifically addressing long-term care, the plan would result in the umbrella structure necessary to accommodate the coordinated umbrella model. A new Division of Health would administer the Medicaid program, take over facility regulation formerly carried out by the Board of Health, and operate Indiana's sole state-run nursing home. A new Division of Family Services would operate most of Indiana's community-based and social service programs and functions.[10]

Obstacles to Service Integration: However, Indiana wisely acknowledges that under a coordinated umbrella or consolidation model *(see following section)*, integration of either the single entry process or of the entire long-term care system does not occur automatically:[11]

> Simply having all long-term programs under one departmental structure or model however, does not guarantee an integrated state long-term care system. The Governor's plan would need to include the following specific actions to ensure that this integration takes place:

- Agreement on common assessment tools for preadmission screening for nursing homes and for eligibility for community care programs;
- Coordination of a long term care information management system designed to produce usable information for policy development, planning, and resource allocation;
- Coordination of planning, policy development, and resource allocation to ensure that all decisions that impact the long-term care system are made with the full knowledge and participation of affected programs and divisions; and
- Use of a single local client assessment and delivery system for community care services.

All long-term care responsibilities, both institutional and community-based, are placed within one sole-purpose agency under the ***"consolidation"*** model. This normally requires a major reorganization of state government including the possible creation of a new superagency and the dismantling of existing departments. Alternatively, the sole-purpose agency could be incorporated under a larger umbrella department. Long-term care responsibilities and programs that are consolidated may include:[12]

(1) One budget for all long-term care expenditures, including Medicaid and general fund community care funds;

(2) Responsibility for quality assurance and consumer protection for all long-term care recipients served by nursing homes and community and in-home agencies;

(3) Planning, policy development, and resource allocation for all long-term care;

(4) Traditional aging programs funded through the federal Older Americans Act (OAA) funds. Traditionally, Area Agencies on Aging (AAA) case management is funded through Title III of the OAA and through Social Services Block Grants. However, the OAA bars AAAs from directly providing services. AAAs can receive a waiver to provide services if no other provider is available. Rather than provide direct services, AAAs are to perform a planning, coordinating, and funding role, leveraging local dollars with state and federal funds to expand available services. Typically, AAAs provide congregate and home-bound meal programs and transportation services. To a varying extent, AAAs also provide some in-home services;

(5) Certificate of need programs (for example, for new nursing beds); and

(6) Responsibility for administering the local service delivery system, including preadmission screening and case management.

Access to the long-term care system for eligible populations must be through the consolidated-purpose entity. In Oregon, the Senior Services Division manages Medicaid payments to nursing homes, Medicaid home and community services waivers, services provided under the Older Americans Act, and federal and state community care funds for the elderly. All long-term care expenditures for the elderly are consolidated into one budget. Oregon uses AAAs affiliated with local units of government to administer all community care programs. These programs include Medicaid waiver programs and case management and preadmission screening services. AAAs also determine Medicaid eligibility for both nursing home and community care clients. In exceptional cases where no AAAs are available, state district offices carry out case management and screening.[13]

Regardless of the model of governmental structure, an SEP does not necessarily require all eligible individuals seeking care to enter through a single, physical, geographic location. On the one hand, a single local or regional agency with multiple locations statewide can be designated as the entry point. Alternatively, multiple agencies can be designated. In the latter case, the different agencies can retain responsibility for their respective services while coordinating with each other to integrate access to those services through a single, standardized entry process. This standardized process is developed interactively and with the cooperation of all parties involved in the provision of long-term care. It is then administered and overseen by either by a single superagency (consolidation model), an interagency coordinating committee (cabinet model) or by an umbrella agency. The point is: a tremendous amount of work needs to be done to develop integrated and standardized entry procedures for multiple target populations before such an SEP can be implemented.

A Vertically Integrated SEP Process: Vertical integration of the entry process links all services from all sources from the time a consumer becomes aware of available services up to the provision and monitoring of those services. This is a more extended view of the entry process than the mere making of initial contact and taking the first step to obtain services. To make sense, any entry process, SEP or not, involves the following component tasks:

(1) Pre-admission screening for program eligibility (functional and financial);

(2) Assessment (social and medical); and

(3) Case management, including creation of a care or treatment plan, coordination or direct provision of program services, and follow-up monitoring of services.

To these, some would include public awareness and education efforts and information and referral help, ideally prior to a consumer's initial contact at an access point. These, of course, may also be offered when a consumer first enters the system. In any case, the three essential components -- screening, assessment, and case management:[14]

> [a]re inseparable and can be viewed as a triangulation of three processes that are mutually interdependent and supportive of one another. They are not intended to function independently. All three components should come into the process when any one is considered. The application of this process on behalf of any client should result in the most appropriate assignment of services and resources available within the context of any program or community.

States have begun reorganizing community delivery systems to overcome the fragmentation of programs as well as make better use of the new resources allocated to long-term care.[15]

> Usually the components of statewide community care systems are designed to give clients better access to care while adding more control and rationality to the allocation of individual services. These components include client functional preadmission screening, case management and nursing home assessments to determine the need for community care. All are interrelated and are undertaken frequently by the same local agency and staff.

Some express the view that the three processes may be applied to more than just the elderly population:[16]

> It is important to acknowledge, however, that [groups other than the chronically ill elderly] who suffer from chronic illnesses could also benefit from coordinated

> programs designed to respond to their special needs. Identification of such groups -- including people of all ages with physical and developmental disabilities and chronic mental illness -- is helpful in illustrating the broad scope of the problem. The coordinated systems of care for the elderly . . . should be equally useful as models for chronic care services for these other groups as well.

What is less clear is how successful a system can be when dealing with several long-term care populations *within that one system.*

Nonetheless, coordination of these tasks would seem to lead to more complete and appropriate assessments for the provision of appropriate needed care. An integrated process should also help to ensure a smooth and timely transition from one step in the process to the next. The chances of a consumer not being referred to the appropriate agency (cabinet or umbrella models) should be reduced.

Again, coordinating the entry process tasks of screening, assessment, and case management within a single system does not imply a single physical locus. The key is operating under a single entry point *concept* that is based on coordinating or consolidating the various entry process tasks -- whether among different agencies, under one umbrella agency, or within one sole-purpose superagency. Whatever the scenario, it would be naive to predicate an SEP on a single geographical location. That is not to say that an SEP is not susceptible to bottlenecks. The greater obstacle -- and the greater reward -- lies not in maximizing the number of geographical entry points but in the challenge of standardizing multiple criteria for multiple target populations:[17]

> Regardless of the organizational approaches adopted, the issues which must be examined across various programs are the same. They include: designing a single delivery system supported by multiple funding sources; developing eligibility criteria for individual programs to ensure equitable treatment of persons with similar needs and resources; and examining the mix of community care services supported by each funding stream. Ultimately, the goal of these efforts is to create the continuum of care which each individual program rhetorically has embraced but cannot by itself achieve.

Regardless of the model of state government, a coordinated SEP process should help reduce service fragmentation at the level of the individual consumer:[18]

> How programs are organized at the local level is even more important than how state responsibilities *[i.e, which state organization models]* are organized. Older people come in direct contact with local agencies and their differing eligibility criteria, service packages, and funding sources. If state policies are successful, the elderly will have access to appropriate care without having to contact multiple agencies to receive services for which they are eligible. Therefore, most of the study states *[Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin]* have designated a single local agency in each part of the state to serve as the client access point for receipt of all publicly financed community care programs. Centralizing entry helps make the system less fragmented from the perspective of older people in need of assistance, while helping states gain better control of total program costs. Client assessments, pre-admission screening programs, and case management are the key components of access systems for community based care programs. *[Emphasis added]*

Gatekeeper in a Managed Care System: As just noted, an SEP process can also be seen to serve a ***gatekeeper function*** in a managed care system. Even without an SEP, because "[o]lder people actively seek community based care services, while going to great lengths to avoid nursing home placement" and because of the accompanying "piecemeal

financing of community services" great service demand is generated.[19] As a result, there is a need to contain costs by controlling utilization through setting priorities for individual access to care. In addition, one goal of an SEP is to create greater access and thus potentially increase the overall number of consumers. On the other hand, an SEP is well suited to function as a management control over allocation of services. Routing all potential consumers through one system of standardized screening, assessment, care planning, and authorization of services effectively acts to control service utilization.

Some insurers feel that the cost of administering multiple community long-term care services is too high. They also fear uncontrollably high utilization rates, expecting the elderly to actively seek these services while trying hard to avoid nursing homes. In response to these fears, the 1988 study of long-term community care systems in six states by Justice, et al., found that "[i]mproved assessment techniques can effectively limit the eligible population and that case management structures can allocate services to individual clients within overall budget limits.[20]

However, the authors offer a caveat to the automatic assumption that just because case management under an SEP process is conducive to controlling service utilization, that case managers, in fact, will do so. One distinctive feature of the community care systems in the six states studied is the case managers' responsibility to authorize services. Not only do they assess consumers, but they also directly authorize appropriate services for them. Justice, et al., found that:[21]

> State officials note that case managers in entitlement systems may have the opposite incentives, resulting in a tendency to authorize more services than needed. State sponsored training programs can help case managers be more aware of cost containment concerns. Staff of Illinois' Case Coordinating Units report that case managers have slowly become more comfortable with limiting services instead of authorizing a complete package of all potentially available services. As they gain more experience in monitoring the implementation of care plans, case managers get firsthand feedback on the scope of services needed and can make any necessary adjustments.

It appears, then, that overuse of services may result from a case manager's lack of expertise and knowledge of the appropriate long-term care needs of consumers. In a system that incorporates several target populations which may not have identical needs, it may be difficult to perform an accurate assessment. How well an assessment is done and services managed by the case manager depends on how well the SEP process is initially developed. Specific and flexible guidelines within the framework of a standardized process can enable accurate and equitable assessments and authorization of services. If left inflexible, an SEP system may result in excessive service authorization, exacerbated by a fear of not authorizing enough services. A lack of concern for cost containment in *entitlement systems* may also contribute to the problem.

Preadmission Screening -- Financial Eligibility Determination: The first formal step in the entry process is usually called preadmission screening. It can be defined as:[22]

> [a]n assessment used to determine the need or appropriateness of nursing home care that goes beyond financial eligibility determination and physicians' certification of need to include an on-site evaluation of many aspects of a client's status.

Screening is more than just a "loose consideration of 'medical necessity' for nursing home care (as is done in the absence of screening programs)" but is a "comprehensive examination . . . of a person's functional, psychological and medical status with a bias toward

determining whether informal supports combined with formal community services could meet the individual's long term care needs."[23]

First, a potential consumer's financial eligibility is determined. States have not opted for universal long-term care systems that offer care for all regardless of income. Rather, they have consistently chosen to address the long-term care needs only of those, in general, with the greatest financial need:[24]

> In none of the six states was there a philosophical inclination to provide universal public support for community based care without regard to a client's income. . . . There were no protracted debates over whether services should be provided on an ability to pay basis; the only question was how to translate this philosophy [that excludes universal community care] to operational policy.

States have rarely enjoyed the luxury of adequate funding for long-term care, especially community- and home-based care. During a time of federal cuts, initiatives to replace entitlement programs with capped block grants, and struggling state economies, it is hard to imagine extending publicly-funded services to those who can afford them. Aside from financial constraints, some object on philosophical grounds to the government's role in linking consumers to services purchased in the private market. However, some states do partly subsidize sliding-scale fee programs in which private-pay individuals not ordinarily financially eligible may participate. For example, Justice, et al. (1988) argue for the publicly-supported use of case management services by private-pay clients. Case management can help family caregivers sustain their informal care to delay the eventual need of individuals, income-eligible or not, for more intensive, publicly-funded care. Such use of case management services will also avoid a two-class system with two separate entry points.[25]

Nonetheless, screening programs,[26]

> [are] part of an organized access point for long term care services . . . [and] are a logical component of state policies designed to curb the growth of Medicaid institutional expenditures [by avoiding inappropriate placements in nursing homes] and [by apply[ing] the cost savings to an expanded community care system.

In some states, preadmission screening determines financial eligibility not only for persons eligible for Medicaid, but also for those estimated soon to be Medicaid-eligible. Typically, the "countdown" to Medicaid eligibility is set at 60, 90, or 180 days, thus "90-day eligibles" and "180-day eligibles." For example, Maryland's target population is screened for both Medicaid- and 180-day eligibles. Screening in Oregon targets both Medicaid- and 90-day eligibles.[27]

> *(Note: According to the Select Committee on Aging of the United States House of Representatives in a 1987 publication, 50 percent of persons aged 75 and older and living alone would spend down income and assets to federal poverty guidelines within 13 weeks of entering a nursing home. Within one year, almost 70 percent would be impoverished. For married couples aged 75 and older, 28 percent would reach poverty income levels within 13 weeks and 51 percent within one year. The vast majority of persons entering a nursing home is over age 75 and live alone.)*[28]

Table 2-1 outlines how six states screen clients; whether participation is mandatory or voluntary; and whether findings are binding or advisory only.[29]

Table 2-1

CHARACTERISTICS OF PRE-ADMISSION SCREENING PROGRAMS

	Target Population	Mandatory or Voluntary Participation	Binding or Advisory Findings
AR (one quarter of state)	Medicaid	Mandatory	Binding
IL	Medicaid and eligibles	Mandatory	Binding
MD	Medicaid and 180 day eligibles	Mandatory	Advisory
ME	Medicaid	Mandatory	Binding
OR	Medicaid and 90 day eligibles	Mandatory	Binding
WI	Medicaid	Mandatory	Advisory
	All	Voluntary	Advisory

Medicaid Payments for Home Health Services and Nursing Homes: Medicaid eligibility, of course, refers to nursing home reimbursement. Medicaid is required to cover most nursing home services for people over the age of 21. The thrust of many state community- and home-based long-term care programs is to divert entry into costly and highly restrictive institutions. For those financially needy, Medicaid has become the largest payer for institutional long-term nursing home care. Medicaid payments accounted for 51.7 percent of all payments to nursing homes, followed by out-of-pocket payments by private residents amounting to 33 percent.[30] In 1990, Medicaid payments to all nursing home vendors in the nation amounted to about $17.7 billion, or 27.3 percent of all Medicaid vendor payments. In Hawaii, these payments amounted to $78,502,328, or 41 percent of all State Medicaid vendor payments.[31]

For people who are eligible for nursing homes, Medicaid must also cover home health services. Medicaid payments to all home health service vendors in 1990 amounted to $3,403,955,203 for the country as a whole, or about 5.2 percent of all Medicaid vendor payments (which amounted to about $65 billion). Hawaii's Medicaid home health vendor payments amounted to $635,089 in 1990 or only 0.4 percent of all State Medicaid vendor payments.[32] This means that Hawaii's Medicaid payments to nursing home vendors was 124 times larger than the amount paid to home health service vendors in 1990 *($78,502,328 / $635,089).*

States may opt to provide non-medical personal care to all Medicaid-eligible persons through their state plans. In addition, states may obtain waivers for such services which may include personal care, homemaker, and adult day care services.[33] According to the American Association of Retired Persons, 48 states have received waivers to provide home-

and community-based (HCB) long-term care services. In addition, 32 states use the personal care or case management option to provide at least one type of HCB long-term care; 30 states have opted to use both programs.[34]

For 1993, Medicaid expenditures for nursing homes accounted for 62 percent of its long-term care spending. Intermediate care facilities for the mentally retarded (ICF-MR) spending accounted for 22 percent. The Home and Community Based waiver accounted for 7 percent, closely followed by 6 percent for personal care services. Home health services accounted for the remaining 3 percent of Medicaid expenditures.[35] In 1990, the federal government spent about $4.5 billion for all state Medicaid programs in Region 9 comprising the four states of Hawaii, California, Arizona, and Nevada. About seven-eighths of this amount was spent in California. Federal Medicaid expenditures for Hawaii in 1990 amounted to $121,441,000 while California received $3,869,906,000.[36] Per capita federal expenditures for Medicaid for the United States in 1990 was $161.94, but only $109.58 for Hawaii. Corresponding per capita figures for the other three states in Region 9 amounted to: $130.04 for California, $111.40 for Arizona, and $61.24 for Nevada.[37]

Almost one-third of the $450 billion spent annually on health care in the United States goes towards treatment of the elderly aged 65 and older, who represent just 12% of the population. The elderly represent two-thirds of the 8 million Americans who require long-term care. Three-fourths of the disabled elderly live at home and rely on family members or other unpaid caregivers. Some 1.6 million persons or 5% of the over-65 population lived in nursing homes in 1985 at a cost of more than $35 billion. Half of the elderly who enter homes eventually wind up on Medicaid. Private insurance covered only 1% of nursing home costs in 1985.[38]

However, even though the subject is Medicare expenditures, according to a 1989 article in State Government News:[39]

> [I]t is not the elderly per se who are the heavy users of health care financing. It is the very sick and terminally ill, many of whom are also very old. In fact, analysis reveals that a very small percentage of the elderly are responsible for the high Medicare bills. According to the Health Care Financing Administration, in 1983 . . . 2.3 percent of the 65 and older Medicare beneficiaries accounted for 33.9 percent of program expenditures. Less than 10 percent of the beneficiaries accounted for more than 72 percent of the costs. A large portion of these expenditures is laid out for the terminally ill: 28 percent of the Medicare budget -- approaching $25 billion -- is spent on patients who are in the final year of life.

Screening and Functional Eligibility: In addition to financial eligibility, preadmission screening also involves functional eligibility determination. However, in addition to medical need, many state programs also look at a person's functional, psychological, and social status. In many states, one becomes eligible for community care programs only if one is already nursing home-eligible and, in most cases, the community care costs no more or less than nursing home care. The aim is to determine if a person can remain in the community and function successfully with the benefit of formal and informal community support services. Thus, community care programs -- of which screening is a part -- aim to integrate client access to *both* community and institutional care. Preadmission screening determines eligibility for nursing homes **and** informs of community alternatives. "Locating these screening programs in the same local agency that serves as the entry point for community care services increases the potential that clients will receive advice on a range of possible alternatives."[40]

In addition to cost containment, screening for clients' functional capacity allows the system to appropriately allocate long-term care resources through the use of a single entry point. For example, 21 percent of those seeking nursing home entry in Oregon in 1986 were diverted to home care while Illinois diverted 18 percent.[41] Effective assessment can curb inappropriate use of services, conserve scarce resources, and help avoid imposed disability resulting from inappropriate diagnosis and labeling of persons. For example, labeling a person "senile" without a proper assessment may prevent useful rehabilitation. Appropriate assessments may achieve some, if not all, of the following:[42]

- More accurate [medical and social] diagnosis
- More appropriate placement
- Reduced dependence on skilled nursing facilities
- Improved functional status of [clients]
- More appropriate use of medications.

It is only logical for an SEP to locate both types of screening, assessment, and case management in the same local or regional agency where system entry takes place. Doing so enhances system integrity. It also increases the likelihood that clients will receive advice on all the alternatives, thus enhancing the chances of appropriate assessments and provision of services, including nursing home care if necessary. Preadmission screening programs, as a part of an SEP, can help curb the growth of Medicaid nursing home expenditures by offering alternative community care. By placing tighter restrictions on access to nursing homes, an SEP complements many states' efforts to control the supply of long-term care beds.

Assessment -- Capacity for Independent Functioning: After a person is financially screened, capacity to function independently in the community is assessed to see whether the person's level of impairment meets nursing home criteria. The performance measures most often used to identify areas of dependence are the so-called Activities of Daily Living (ADLs). These normally include eating, dressing, bathing, toileting, and transferring (mobility). Instrumental ADLs (IADLs) include activities such as cooking, shopping, and doing laundry.[43] Measures of basic functional capacities are said to be more accurate predictors of the need for long-term care than medical conditions.[44] According to a 1990 evaluation audit by the Indiana Legislative Services Agency:[45]

> Seven ADLs are most commonly used to evaluate functional capabilities. These are the personal care activities: bathing, dressing, eating, getting in and out of bed and chairs (transferring), walking, getting outside, and toileting.[46] Six other activities, or instrumental activities of daily living (IADL), are also utilized. These measure capabilities of home management: meal preparation, shopping for personal items, managing money, using the telephone, doing heavy housework, and doing light housework.

On the one hand, ADLs and IADLs are used to diagnose a person's capacity to function independently. On the other, they also indicate the types of support services a person needs in order to continue functioning independently in the community. For example, an elderly person may exhibit difficulty in the ADLs of dressing and toileting and the IADLs of cooking and shopping. Upon such an assessment, a case manager may authorize personal care services, chore assistance, and meal preparation services -- those that correspond to the relevant ADLs and IADLs.

Of course, an assessment would be incomplete if limited to only ADLs and IADL performance measures. The following are also generally included in an assessment:[47]

1. Cognitive capacity;
2. Social interaction;
3. Family support;
4. Resources in the physical environment;
5. Mental health functioning.

Sample Assessment Tool: Attached as Appendix B is a sample assessment tool used by the Wisconsin Department of Health and Social Services entitled the "Model Long Term Care Assessment Tool," dated May 1995. In addition, the Arizona Department of Economic Security uses a tool entitled the "Arizona Minimum Assessment." This latter form covers the following broad topics:

I. IDENTIFYING INFORMATION:

(1) Personal identification data
(2) Marital status
(3) Educational level
(4) Ethnicity
(5) Primary language spoken
(6) Referral source
(7) Personal/legal status
(8) Current living arrangement (including subsidized housing)
(9) Household composition
(10) Financial eligibility
(11) Current use of housekeeper, home health aide, visiting nurse
(12) Source and amount of income

II. INSTRUMENTAL ACTIVITIES OF DAILY LIVING -- STATUS, SOURCE OF HELP, USE OF ASSISTIVE DEVICES, AND CLIENT NEEDS, WITH SPACE FOR ADDITIONAL COMMENTS, FOR:

(1) Medication use
(2) Meal preparation
(3) Shopping
(4) Financial management
(5) Telephone use
(6) Transportation
(7) Housework
(8) Laundry

III. PERSONAL ACTIVITIES OF DAILY LIVING -- STATUS, SOURCE OF HELP, USE OF ASSISTIVE DEVICES, AND CLIENT NEEDS, WITH SPACE FOR ADDITIONAL COMMENTS, FOR:

(1) Bathing and grooming
(2) Dressing

(3) Ambulation (out-of-home)
(4) Transfer, in-home and out-of-home (moving from chair to bed moving from chair to couch)
(5) Eating
(6) Toileting, in-home and out-of-home

IV. PHYSICAL IMPAIRMENT AND ILLNESS:

(1) Incontinence of bladder or bowels -- none, periodic, or complete
(2) Vision
(3) Hearing
(4) Medical conditions including the following broad categories of disorders:
  (A) Hematological
  (B) Cardiovascular
  (C) Musculoskeletal
  (D) Neurologic
  (E) Pulmonary
  (F) Urologic
  (G) Psychiatric
  (H) Gastrointestinal
  (I) Ophthalmologic
  (J) Gynecological
  (K) General Medical
  (L) Metabolic
(5) Emergency notification data
(6) Previous year hospitalizations, including medications and special diets

V. PROGNOSIS FOR SUPPORT (SOURCES OF SUPPORT, THEIR FREQUENCY, AND ANTICIPATED CHANGES IN SIX MONTHS):

(1) Spouse
(2) Parent
(3) Daughter
(4) Son
(5) Sibling
(6) Other relative
(7) Friend or neighbor
(8) Privately paid help
(9) Community volunteer
(10) Agency

VI. ASSISTIVE DEVICES -- NEED FOR AND PROBLEMS WITH USE:

(1) Eyeglasses
(2) Hearing Aid
(3) Phone amplifier
(4) Dentures
(5) External prosthetic device
(6) Cane/quad cane
(7) Walker/crutches
(8) Wheelchair
(9) Tub/shower seat

(10) Raised toilet seat
(11) Commode chair
(12) Urinal bed pan
(13) Handrails, grab bars
(14) Transfer equipment
(15) Medication reminder system
(16) Colostomy/Ileostomy equipment
(17) Foley catheter equipment
(18) Oxygen therapy equipment
(19) Hospital bed
(20) Emergency notification equipment
(21) Other assistive devices

VII. PSYCHOSOCIAL:

(1) Cognition (memory, concentration, orientation, functioning and self care)
(2) Adequacy of social contacts
(3) Language comprehension
(4) Speech impairment
(5) Behavior -- as noted by client, assessor, significant other, professional or paraprofessional, including:
  (A) Loneliness
  (B) Grief/sadness
  (C) Possible depression
  (D) Possible anxiety state
  (E) Verbal abuse
  (F) Physical assault against others
  (G) Intentional self-harm
  (H) Verbalization of suicidal thoughts
  (I) Unintentional self-harm
  (J) Wandering
  (K) Public disrobing and sexual behavior
  (L) Probable undue suspicions of others
  (M) Probable hallucinations
  (N) Emotional instability

VIII. ENVIRONMENTAL CONDITIONS:

(1) Housing problems (20 itemized potential problems including hot water, heating, home security, stairs, etc.)
(2) Transportation -- availability and affordability of public or private transport for:
  (A) Shopping
  (B) Visiting
  (C) Obtaining medical care
  (D) Other
(3) Current services being received:
  (A) None
  (B) Adult day care
  (C) Attendant care
  (D) Chore maintenance
  (E) Counseling
  (F) Emergency notification system services

(G) Energy assistance
(H) Errand services
(I) Escort to medical care
(J) Escort to other services
(K) Financial budget assistance
(L) Friendly visitor service
(M) Guardianship/conservatorship
(N) Home delivered meals
(O) Home health aide
(P) Home health nurse
(Q) Home maintenance
(R) Home repair
(S) Hospice
(T) Housekeeping
(U) Laundry
(V) Legal services
(W) Medical care
(X) Medical social services
(Y) Nursing care
(Z) Nutrition services
(a) Occupational therapy
(b) Ombudsman
(c) Personal care
(d) Physical therapy
(e) Protective services
(f) Public fiduciary
(g) Recreation/socialization services
(h) Respite sitter
(i) Shopping service
(j) Speech therapy
(k) Telephone reassurance
(l) Transportation
(m) Visiting nurse
(n) Weatherization
(o) Other

Standardized Assessments -- Difficulties: It is obvious that the task of accurately assessing even just one population (the elderly) in order to formulate appropriate service plans can be quite complex. It stands to reason that standardizing assessment of multiple populations increases this complexity. Although different populations, for example, developmentally disabled (DD) children and non-elderly adults, may share many functional limitations with the elderly, clearly some are not universal, particularly IADLs. A six-year-old DD child is not expected to shop, do laundry, or manage a household budget. Neither is an incontinent older person who needs help dressing, bathing, and toileting expected to need special DD education and support to get and keep a first job in the community.

The task of capturing both the shared and unique needs of different populations in any standardized assessment tool is a daunting one. Long-term care community-based programs in most states are dominated by just one population -- the elderly. Even with single, dominant populations:[48]

> Using a standard assessment tool to determine need for community long term care services may seem rather straightforward. However, its development generally entails months of disagreement among health professionals, social workers, and various program administrators over the factors that are most likely to indicate need for their individual programs.

Koff (1988), cites a 1980 study that discussed the difficulty of constructing a single assessment tool:[49]

> Baker (1980), who reviewed fourteen assessment instruments, notes that the proliferation of such instruments and the difficulty in developing a single assessment methodology is understandable in the absence of clearly delineated treatment or care programs and the difficulty of translating assessment findings into care plans. In contrast to acute care, chronic care of the aged shifts from a focus on disease or pathology to a focus on function, and then from function to intervention. Each of these transitions increases exponentially the factors to be considered in a comprehensive assessment, which is further complicated by the many possible variations in intervention.

These difficulties dealing with the elderly population may increase with the addition of other populations requiring similar long-term care. Koff, however, acknowledges that assessments, however difficult to administer, are necessary and beneficial:[50]

> Rubenstein (1983, 1984) suggests that assessment can circumvent inappropriate use of health care services, prevent waste of scarce resources and contribute to avoidance of imposed disability resulting from inappropriate diagnosis and labeling of older persons.

For example, being simply labeled "senile" without the benefit of a proper assessment may prevent useful rehabilitation of that person. A successful assessment may result in a more accurate diagnosis, more appropriate placement, reduced dependence on nursing homes, improved functional status of those assessed, and more appropriate use of medications.[51]

In any case, the construction of a viable assessment tool, especially for *multiple* populations, requires a tremendous amount of cooperative effort among the relevant providers and agencies. The key, however, appears to lie in operating under a standardized *concept* liberally laced with flexibility, rather than adhering to a rigid assessment tool or entry process. For example, a state may begin by mandating minimum substantive standards by which local SEP agencies must perform screening, assessments, and case management. Beyond such mandated guidelines, local agencies can be given flexibility to tailor care plans according to individualized assessments appropriate to, and perhaps unique for, each locale.

For example, in Wisconsin, local county agencies, which make up the sites for a single entry system for five different long-term care populations, are required to address 12 areas of community living. As long as they adhere to these guidelines, they are free to employ their own assessment tools. On the one hand, an urban county opted to adopt a computer-scored assessment tool. On the other hand, a rural county decided that long-term care assessment requires more than computer scoring of ADLs. Instead, it required a social worker to write up a two-page assessment in narrative form of the client that includes addressing the mandated 12 areas of community living.[52]

Wisconsin does not require a standardized assessment tool *(although that state has made available the use of a recommended one).* However, Wisconsin does require that the person conducting the assessment be the appropriate one. Therefore, although Wisconsin

does not mandate any particular combination of assessment personnel, if a nurse, physician, or other person is required in addition to a social worker, they will participate in the assessment.[53] *(Illinois, Maryland, and Oregon allow assessments to be done solely by social workers while Maine requires a nurse review only in its waiver component.)*[54] This flexibility allows initial assessments to be followed up by further specialized assessments, if necessary. For example, a social worker on a site visit may notice not only several ADL impairments but also a need for various physical therapies and home modification. A subsequent specialized "OT" (occupational therapy) assessment is then carried out detailing mobility and transferring impairments. As a result, appropriate therapy services and assistive devices can be authorized. In other states as well, applying a standard assessment tool is often not the only assessment performed. They can function to sort out those with more routine service needs who can be helped with information and referral from those needing more detailed assessment.[55]

Numerical Assessments -- Gatekeeper Function: Oregon is a "consolidation" model state where all components of long-term care programs, both community and institutional, are placed into a single state agency. That state's Senior Services Division within the Human Resources Department manages all such programs and places local administration into the hands of the Area Agencies on Aging.

> *[Note: Area Agencies on Aging (AAAs) carry out the provisions of The Older Americans Act (OAA) of 1965 at the local level. At the state level, the program is administered by offices on aging. In Hawaii, the OAA fixes the responsibility for the development of a coordinated, comprehensive statewide system of older adult programs and services and for statewide planning, advocacy, program development, and policy formulation upon the Executive Office on Aging. Concomitantly, it establishes parallel coordinating, planning, and leadership roles for the Area Agencies on Aging at the county level. In each of the four counties, an Area Agency on Aging is responsible for program development and administration.*[56] *AAAs have a primarily social care, rather than medical care, orientation.*[57]
>
> *The OAA provides for a variety of community and social services for persons aged 60 and over. Nursing home care is not included although supportive services that are often thought of as components of community- and home-based long-term care are provided. These include nutrition, transportation, information and referral, outreach, legal assistance, in-home supportive services, senior employment opportunities, elder abuse protection, and long-term care ombudsman services.*[58] *For 1991, total OAA Title III funds amounted to $750,066,000. Of this, Hawaii received $3,855,000, or about one-half of one percent while California received 9.3 percent. Nationally, programs for congregate nutritional services accounted for 48 percent of Title III OAA funds, followed by 39 percent for supportive services. Home-delivered nutritional services accounted for 12 percent and in-home services, about 1 percent. Ombudsman and elder abuse prevention activities received less than one-half of one percent. The proportion of funding allocation for Hawaii's Title III services closely matched the national allocation.*[59]
>
> *1984 amendments to the OAA specify that the Area Agency on Aging should be involved in "services designed to assist the older individual in avoiding institutionalization and to assist older individuals in long term care institutions who are able to return to the communities, including client assessment through case management and integration and coordination of community services such as pre-institution evaluation and screening and home health*

services, homemaker services, shopping services, escort services, reader services, and letter-writing services, through resource development and management to assist such individuals to live independently in a home environment."[60]
Although the OAA program is not means-tested, states are required to target those with the greatest social or economic need. In fiscal year 1994, federal OAA funds were spent for the following:

- *Title III-B supportive services: $306,711,000;*
- *Title III-C1 congregate meals: $375,809,000;*
- *Title III-C2 Home-Delivered Meals: $93,655,000;*
- *Title III-D Frail Elderly Services (for in-home care): $7,075,000; and*
- *Ombudsman Program/Elder Abuse: $9,018,000.]*[61]

In carrying out client assessments, Oregon uses very specific measures to determine functional eligibility. Along with Illinois, Oregon employs an assessment tool to generate a numeric score. *(See above regarding a Wisconsin county opting for a computerized assessment scoring system.)* Aside from developing care plans and authorizing services, these scores are used as threshold points below which individuals become ineligible. This type of system allows the state more control over utilization rates in response to the availability of funding, care service, and caseload size. For example, Oregon raised the threshold score in 1986 because of limited funds and a growing caseload.[62] This is an example of the gatekeeper role of an integrated SEP process (through use of the assessment tool) that helps control waste and manage the allocation of scarce resources within the long-term care system.

Although numeric scores tend to make assessments more objective and uniform, there is a danger this method may foster rigidity and a sense of complacence. First, assessment staff may feel hampered by a numeric tool in tailoring individualized care plans. Certain scores in certain assessment areas may begin to dictate the development and use of "cookie-cutter" plans. Useful creativity may be stifled: it is not easy to go against hard numbers. Second, standardized rather than individualized care plans may emerge because of the ease of direct cross-referencing between certain scores and set plans. The feeling may arise that a numeric "black box" assessment tool, especially if computerized, is unerringly comprehensive. That is, the work has already been done and there is no need for the case manager to further investigate or fine tune a package of services routinely used in response to a certain scoring pattern.

A lack of standardization, on the level of the assessment tool, may not be a bad thing. It may, in fact, promote needed flexibility. Again, the integrating factor in an SEP is a standard but flexible *concept*, not necessarily a rigidly uniform way of dealing with varying populations with needs that sometimes make a difference. Numeric-scoring assessment tools have their good points. There is no evidence that Oregon's numeric scoring system has compromised individual care plans.[63] Nonetheless, their advantages should be balanced against the potential harm to quality of care. A simple way to offset any built-in rigidity of numeric scoring is to moderate it with additional non-numeric bases for assessment. However, funding will become scarcer for all states for the foreseeable remainder of the decade. As a result, one major challenge will be to balance ever tighter assessment-eligibility tools to contain costs with continued provision of quality long-term care.

Case Management: The third major component of an SEP process, performed after screening and assessment, is case management. Some prefer to term this "care

coordination" to describe the "integration of the many services required by chronically ill individuals."[64] The federal Office of Technology Assessment defines the process of case management according to the five core functions of case management:[65]

(1) Assessing a client's needs;

(2) Developing a plan of care;

(3) Arranging and coordinating services;

(4) Monitoring and evaluating the services delivered; and

(5) Reassessing the client's situation as the need arises.

Case management is one of several components in new care systems that have reorganized the management of long-term care services to establish a single entry point for client services:[66]

> The creation of uniform assessment tools, explicit financial eligibility criteria and case management services all make access to community care more predictable from a client's perspective and more standardized as viewed by program administrators.

One view of case management is the following:[67]

> Care coordination is the process of organizing and supervising the delivery of services to persons whose chronic problems require a program of care that is both comprehensive and coordinated. It provides access to the entire service system and ensures the coordinated delivery of multiple services to individual clients. Basic to care coordination is an initial broad-based assessment of the client's needs. In addition, the care coordination process ensures that a service plan that considers all the available service solutions is written, and that the client is reexamined at intervals.

Some believe that effective case management is the most important component of an integrated long-term care system:[68]

> Case management fulfills two roles: it serves a facilitating role in matching the unique needs of clients with appropriate services and resources to meet these needs, and it serves a gatekeeper function in controlling access to public funds and the costs of services provided.

Typical activities involved in case management includes:[69]

(1) Client outreach and screening for service eligibility;

(2) Assessment to determine client strengths and unmet needs;

(3) Care planning to meet client needs identified during the assessment;

(4) Implementation of the care plan and linkage of the client with needed services;

(5) Advocacy[70] on behalf of the client to promote the delivery and/or development of services needed by the client;

(6) Monitoring the care plan and client progress to ensure services are appropriate to the client's needs; and

(7) On-going evaluation of the client and care plan to identify continued needs and needed changes in the care plan.

Long-term care populations generally have multiple problems often requiring an individual to search out and remain in contact with several providers at one time. Case management helps with this burden as well as providing for continuous care coordination. The following is another typical description of case management functions:[71]

1. Making collaborative arrangements to assure continuity of services regardless of the auspices of the provider;
2. Making necessary care arrangements;
3. Referring to appropriate services and coordinating their delivery;
4. Arranging for items and services covered by insurance;
5. Maintaining a continuous relationship with the individual;
6. Acting as a service broker by matching individual needs and resources; and
7. Ensuring delivery of services.

One observer concludes that "[t]he goals of improved care and control of costs can be directly attributable to the processes inherent in a comprehensive assessment and [case-managed] program."[72] The goals of effective case management systems typically include:[73]

(1) Enhancing quality of care as a result of the coordination and continuity of services;

(2) Access to all other services available within the system;

(3) Provision of appropriate services that are neither more nor less than needed at any one time by modifying the treatment plan as required in response to changing needs;

(4) Allocation of care resources on the basis of clients' needs;

(5) Efficient use of community resources; and

(6) Reduction in the incidence of more costly hospitalization or institutionalization.

The task of carrying out case management functions fall to various types of case management agencies. They can be either public or private. This distinction becomes relevant when agencies that perform assessments and case management can also authorize services, as in the six states studied by Justice, et al. A state can designate a case management agency to act as agent of the state in long-term care programs funded with general funds and state-administered federal Medicaid funds. This designation serves both to help integrate the system and to enhance the managed care approach. In terms of an SEP, this designation of private case management agencies limits access to one entry point that is also not overly stigmatized by being perceived as a public welfare program. Whether public or private, case management agencies generally function similarly.[74]

> Specific functions assigned by the six states to case management agencies vary. However, general areas of responsibility include developing cost effective individual care plans, authorizing needed services, and following up to ensure needed services actually are provided. Most importantly, case management and assessment

> agencies are the only client access point for receipt of services financed through the major community care programs in the study states. *[Emphasis added]*

The core functions of case management agencies are to:[75]

(1) Link people with needed community care provided by a variety of providers -- care is no longer provided by one institution under one roof; and

(2) Control utilization of publicly funded services -- unlike nursing homes, community care services can be packaged in many ways, not all or nothing. The implication is that the package can be tailored and unnecessary parts can be omitted for efficiency.

The case management system brokers fairly similar services over the six states studied by Justice, et al. In general, they include personal care (assistance with dressing, bathing and other aspects of personal care); homemaker services (light housekeeping, meal preparation); and chore services.[76]

According to Justice, et al., the scope of case management activities is affected by:[77]

(1) The locus of responsibility for financial and functional eligibility determination;

(2) The range of existing services and providers;

(3) The emphasis placed on utilization controls through service authorization; and

(4) Whether case management is explicitly defined as a universal benefit for all older people with long term care needs or is limited to those persons financially eligible for publicly funded services.

Functional and Financial Eligibility Determination: Placing financial and functional eligibility determination within case management agencies "creates a single service entry point for older people in need of long term care."[78] Not all states do this. For example, in Arkansas, one of the six study states in Justice, et al., case management is done by the Area Agencies on Aging (AAAs), which also perform financial eligibility determination for state-funded programs. However, Medicaid financial eligibility is determined by the Arkansas Department of Human Services while functional assessments are performed by client assessment teams. Similarly, in Maine and Illinois, Medicaid financial eligibility is determined by the states' Departments of Public Aid and Human Services, respectively. In these two states, both functional assessments and state-funded financial eligibility are performed by the case management agencies ("Care Coordination Units" and AAAs, respectively). In Wisconsin and Oregon, all financial and functional eligibility determinations for both Medicaid and state-funded programs are carried out by the case management agency. In Wisconsin, it is the Department of Health and Social Services; in Oregon, it is the AAAs.[79]

However, in Oregon:[80]

> [l]engthy discussions with HCFA [United States Department of Health and Human Services, Health Care Financing Administration] were necessary to achieve this single entry point since normal Medicaid rules permit a state to either determine eligibility through state employees or through local governmental employees, but not through a combination of both. With the Medicaid program being administered through local offices of the state for all other populations, the case management agencies (part of local government) would not be permitted to determine financial

> eligibility for the elderly long term care population. Ultimately, Oregon was allowed to create a single entry point, but had to agree to a state level paper review of eligibility decisions conducted retroactively.

However, it is not always easy to combine both financial and functional eligibility determination within one access system. It was found that:[81]

> Medicaid financial eligibility determination seems to be the function which is the most difficult to integrate with other access activities. . . . In states with multiple entry points, [attempts to maximize the use of state funds by trying to obtain Medicaid payment when clients appear to be Medicaid-eligible] means that clients must be referred by the case manager to another agency for Medicaid eligibility determination. . . . Depending on the complexity of the eligibility process, significant amounts of a case manager's time can be expended on this task [of assisting older people to complete the required paperwork for Medicaid enrollment]. . . . Older people themselves are the most negatively affected by these multiple referrals in most of the study states. Elderly long term care clients have . . . limited capacities to maneuver through the process.

Service Authorization -- Advocacy and Cost Control: The six state community care systems reviewed in Justice, et al. place the power to authorize services within the local agency performing the entry process tasks of screening, assessment, and case management.[82] Because the assessment process leads to service authorization, the study states have consciously placed this function in agencies that do not directly provide publicly financed long term care services. In four of the six states, assessments are performed by the same agency (and sometimes by the same staff) that provide ongoing case management.[83]

Being empowered to authorize services, case managers doubling as assessment staff reduce necessary bureaucracy and also directly affect program costs and service utilization:[84]

> In managed systems of care financed by state resources and state administered federal funds such as Medicaid, state government can designate case management agencies to act as agents of the state in authorizing needed services. Without an explicit delegation of this authority case management agencies can help older people locate services but cannot directly allocate public resources to individual care plans.

However, service authorization is almost always separated from actual service delivery. This helps to avoid conflicts of interest where case managers are also capable of providing direct services for clients they have assessed. This separation also serves a cost containment function by requiring case managers to act as gatekeepers to control service utilization. At the same time, case managers (and assessment staff) can continue to fulfill an advocacy role by managing and coordinating needed long-term care services for their clients.

However, it is the former function of cost containment that is in the ascendancy. This is so because more and more community long-term care is being offered under Medicaid waivers. Medicaid waiver policy specifies that community care services for program clientele can be no more costly than nursing care. Besides limiting the average cost per case, some waiver programs also place a ceiling on expenditures for individual care plans. Such limits have also been adopted for some state-funded care programs.[85] In some cases, these waiver ceilings have been placed at some lower proportion of nursing home care. For example, Maine had at one time limited per case expenditures to 75 percent of nursing home costs. Arkansas had set the dollar cap at an amount equal to 80 percent of nursing home care. Wisconsin does not impose a ceiling on the cost of services by "requires within each county that on the average, program expenditures per client not exceed the state share of

Medicaid nursing home costs" or 42 percent of nursing home care.[86] Although this seems low, Wisconsin has very generous nursing home reimbursement rates and 42 percent is "still adequate to finance the care of most community clients."[87]

Endnotes

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Chapter 3

LONG-TERM CARE SERVICES

Overview: This chapter examines the various types of long-term care services in the context of home- and community-based care. The relationship between long-term care and various populations that require long-term care is examined. Rather than purely medical treatment, long-term care is discussed in terms of supports for functional limitations. This leads to a review of the concept of a continuum of services which includes both medical treatment and functional social supports. Various ways of categorizing services are presented and the most common classifications of services are discussed. Examples of service continuums are included. Home care, adult day care, adult day health services, and social/health maintenance organizations are touched upon. In addition, alternative living arrangements, congregate housing, and adult foster homes are also reviewed.

How and what long-term care services are selected by a state depends in part on the approach a state takes towards program eligibility. Thus, a discussion and review of the pros and cons of the functional (or generic) approach vs. the categorical (classification by age or diagnosis) is undertaken. The developmentally disabled is reviewed next with this in mind. Finally, various services for the developmentally disabled, including children, are then presented.

Single Entry Point and Long-Term Care Services: Theoretically, the examination of a single entry point as a method of access to long-term care services can be carried out regardless of the types of services eventually provided. *(See discussion in chapter 1.)* An SEP is merely the funnel through which clients pass in order to obtain end services. Pragmatically, what services await at the end of the funnel can affect the operation of an SEP. A chief obstacle to a unified SEP is the differing categorical sources of funding for various populations (determined by diagnosis or age) that are available at both federal and state levels.

As discussed in the previous chapter, Medicaid has evolved into the largest payer of long-term care expenses. However, Medicaid pays only for care that is medically necessary and related. Unfortunately, the continuing preference for long-term community- and home-based care rather than institutional (but medically-related) nursing home care is not covered under Medicaid. As a result, states have had to obtain individual waivers for programs that provide such community care services. Thus, what services offered by a state's long-term care system and how they are funded affect, to some degree, how well an SEP may operate.

One difficulty in integrating a system, including the implementation of a single entry point, is the need to obtain federal waivers. A much larger, possibly insurmountable, problem for many states, is the pooling of differing categorical funding sources that have contributed to the development of historically fragmented systems. A state that has an administrative structure based on the "consolidation" model is best positioned to attempt this. For example, Oregon administers all its long-term care programs through one agency: the Senior Services Division of that state's Department of Human Resources. Such a consolidated structure would be able to reap greater efficiencies from an SEP. However, this is not to say that an SEP *requires* total consolidation of all programs, services, and funding for all target populations in order to work. Integration can be a matter of degree. Coordination of services,

programs, and funding in states not undertaking a major governmental reorganization can still make for a viable SEP process.

Nursing Homes and Community- and Home-Based Long-Term Care: For many who have had no personal experience with the long-term care system, "long-term care" stereotypically means living in a nursing home. For example, many elderly may believe that by remaining at home -- and thus, staying out of a nursing home -- they are avoiding "long-term care." In fact, caring for themselves or being cared for by relatives, friends, or neighbors in their own homes is the major form of long-term care today:[1]

> Of the 12.7 million people needing long-term care, only 2.4 million of these live in institutions such as nursing homes and intermediate care facilities for the mentally retarded (ICF/MRs), while 10.2 million live at home or in community settings. There are 6.2 million people who need help with basic self-care tasks, 2.4 million of whom live in institutions. Of the 5.1 million who are most severely disabled, 1.3 million live in the community and need assistance with three or more self-care tasks.

Furthermore, of the severely disabled older persons living in the community, about 75 percent rely exclusively on informal care supports.[2] An Indiana study reports that:[3]

> [t]he majority of even the very old [aged 85+] are not in a nursing home at any one time. Most live in the community and receive needed assistance from a variety of family and other informal caregivers. Currently, only a very limited number of elderly receive formal paid community based care.

Informal care includes unpaid help provided by family, friends, neighbors, and volunteers to a person who has some degree of mental or physical impairment. This pattern of preference for living in the least restrictive setting supports the view that at-home and community-based care are the mainstream and not "alternatives" to long-term care:[4]

> When state debates focus on long term care system reform, discussions now are likely to highlight ways to expand the availability of community care services rather than emphasize only the detailed nuances of nursing home reimbursement. Older people strongly prefer to receive long term care services in the community. . . . State policymakers are attempting to channel the growth in expenditures to services provided in the community, as the elderly prefer, instead of to continued expansion of nursing home beds.

Long-Term Care and Long-Term Care Populations: According to the United States Department of Health and Human Services:[5]

> [L]ong-term care consists of those services designed to provided diagnostic, preventive, therapeutic, rehabilitative, supportive and maintenance services for individuals who have chronic physical and/or mental impairments in a variety of institutional and noninstitutional health settings, including the home, with the goal of promoting the optimum of physical, social and psychological functioning.

The American Association of Retired Persons considers long-term care as:[6]

> [A] set of health care, personal care, and social services delivered over a sustained period of time to persons who have lost, or never acquired, some degree of physical or cognitive capacity, as measured by an index of functional ability. . . . The need for long-term care is generally defined by limitations in the ability of individuals to perform basic activities of daily living independently, including self-care and household tasks. While most people needing long-term care are elderly, 2 percent are children and 40 percent are working-age adults.

A similarly worded definition is given by the Maryland Health Resources Planning Commission that can be considered generic for the term:[7]

> [Long-term care is] the array of medical, social and support services needed by individuals who, because of chronic illness or disability, need another person's help in caring for themselves over an extended period of time. This includes both institutional and community-based services for persons of all ages.

That state's Long-Term Health Care Committee gives the definition a slightly different cast. Emphasis is placed on financing, organization, and delivery of services as well as the otherwise good health of individuals who need help functioning in its definition of long-term care:[8]

> [Long-term care is the] financing, organization, and delivery of a wide range of medical and human services to people who are severely disabled or limited in their functional capacities for a relatively long and indefinite period of time. In medical terms, long-term care is chronic care: the aim is management, control of symptoms, and maintenance of function. But long-term care also has a vast non-medical dimension, and many individuals requiring long-term care are not sick. They may have been injured, or were born with a developmental disability that limits their activities, but otherwise may be perfectly healthy.

Long-Term Care Populations: Long-term care populations, then, extend beyond the elderly to include the disabled of all ages. Whether or not a state wishes to formally include all possible populations in its long-term care programs is a policy issue. First, the way categorical programs and funding for different populations have developed historically within a state will probably heavily influence policy. For example, adequate funding for a designated but limited population may make it unnecessary to include that group within a larger long-term care population for funding. Conversely, funding may be inadequate but categorical restrictions may prevent their inclusion in a larger group. The patchwork development of funding and programs makes it hard to minimize service overlaps and prevent service gaps.

Second, the degree to which categorical group advocates contend or cooperate will also make a difference. Advocates for an established majority population may feel the inclusion of minority populations (such as AIDS-disabled persons, Alzheimer's patients, the chronically mentally ill, post-trauma patients undergoing rehabilitation, the chemically chronically dependent) may dilute their focus. Minority, majority, or plurality group advocates may wish to augment their roles, perhaps at the expense of other group advocates. Even in an all-inclusive long-term care population group, funds must be allocated in some way among the different sub-groups. *(Wisconsin's response to this problem is to require its Community Options Program to serve persons from the major target groups in proportions which approximate the percentages ("significant proportion") served in nursing homes prior to the program's inception.)*[9]

Third, because "public funds are still inadequate to address all long term care needs . . . states have had to make painful choices in selecting population groups to cover."[10] States like Maryland have recognized that "a fundamental policy question is whether services should be limited to the most impaired or whether a broader group of persons should receive services that only partially meet their needs."[11] The upshot is that for most states, including the six studied by Justice, et al., (1988), long-term care programs will usually "opt to meet the more intensive needs of the most impaired, recognizing that those persons not served may also have significant functional limitations."[12]

Of course, the dearth of funds for long-term care provides an incentive to wring more efficiency out of the long-term care system. States are "changing how older people enter the long term care system and how they become eligible for services"[13] to overcome the fragmentation of existing multiple programs and to make better use of new resources. This may well include the design of an efficient SEP process. Ironically, however, this approach could prove dangerously circular. More long-term care populations will be included in an ever more integrated system in which nursing home-eligible individuals are referred to community-based supports. More people will begin to expect to receive a multitude of in-home or in-community services and to avoid the spectre of a terminal nursing home stay. The danger lies in not having the community resources and funding to accommodate this rising expectation. When a state channels people away from Medicaid-paid nursing homes to "no more costly" or less costly home or community settings, there must be enough supports.

Long-Term Care Services as Supports for Functional Limitations: Obviously, long-term care does not preclude medically-related care. On the other hand, community-based care focuses more on long-term supports to enable daily functioning rather than medical treatment. Home health agencies provide excellent post-acute skilled nursing care. They provide nursing services for people suffering from various chronic illnesses such as diabetes and arthritis. They also help with catheters, medications, injections, and rehabilitation therapy for people who have suffered strokes, fractures, or are recovering from surgery.[14] However, the use of home health services conflicts with the concept of community care even when the former expand beyond the traditional package of Medicare services. Home health agencies usually require all home care to be given under the direction of registered nurses to emphasize a stronger health focus. As a result, some believe home health agencies respond "in a way that is more medically related than necessary, desirable, or affordable."[15] Justice, et al., note the difference between long-term community-based care and Medicare home health services:[16]

> Community care programs complement acute care services by providing generally *non-medical* services delivered by professionals and non-professionals. Medicare's services respond to an *acute care* need which can be successfully treated over three to four weeks; community care services respond to client *functional limitations* that are likely to be present for an extended period of time, perhaps for the remainder of one's life. . . [Medicare's] home health focuses on restorative and rehabilitative care, whereas long term care services seek to maintain current levels of functioning although both provide care in the home.

Medicaid is required to cover most nursing home services for all over the age of 21. For those who are nursing home-eligible, Medicaid must also cover home health services. *(Other home- and community-based long-term care services are optional. States may provide personal care to all Medicaid-eligible individuals through their state plan.)*[17] Skilled home health services are prescribed, triggered by a medical diagnosis, delivered by a health care professional using a clinical focus, and address a person's medical needs, usually short-term following hospital discharge.[18] *(Note: According to Lee (1992), Hawaii had 44 certified home health agencies in 1989, compared to 704 in California, 104 in Arizona, and 42 in Nevada.)*[19]

On the other hand, community-based long-term care services are meant to compensate for a person's limitations in carrying out normal activities of daily living (ADLs) for an extended period. This type of long-term care is based on *functional* need and rely extensively on non-professional social supports.[20] Just what services constitute these supports?

Long-Term Care Services -- A Continuum: The notion of using a continuum of services -- as opposed to discrete, unrelated services -- to address long-term care needs is, by now, a standard concept. One practitioner observes:[21]

> A continuum of chronic care services is the purposeful association of health and social services, each having varying elements responsive to the multiple and diverse needs of a chronically ill person and members of that person's family.

Most services vary by level of care and apply to persons in multiple populations with similar long-term care needs. Other services in the continuum address the specific needs of certain populations and not others. For example, special education, job training, and housing assistance may be appropriate for developmentally disabled adults seeking jobs in the community. But they may not be necessary or appropriate for the disabled elderly. The former may require more help to get and keep a job while the latter may need help only with the social and functional aspects of community living. On the other hand, supported living, including personal care services, may be appropriate for both these populations. For example a young adult with cerebral palsy and a frail elderly individual may both be mentally competent but wheelchair-bound and require personal care several times a week. Both may need food stamps, special travel arrangements, vocational rehabilitation, and emotional counseling.

In some states, services along the entire long-term care continuum can be used to fashion a care plan package. For example, Maine and Wisconsin both avoid defining allowable services under their Home Based Care Program and the Community Options Program, respectively. Almost any service package is possible. Both "explicitly state that there are no disallowed services; only disallowed settings (i.e., services provided in an institution)."[22]

Addressing only services to the elderly, an Indiana report describes long-term care services as falling within three basic categories in a range or continuum as follows:[23]

> Community -- These services are designed to help the elderly maintain independence and to encourage their continued involvement in their communities. These are often not services provided to the elderly, but rather opportunities for independence. At this level, non-governmental agencies and funding sources are primarily involved and often include community groups, service clubs, churches, and senior centers.
>
> In-Home -- As capabilities diminish during the second phase [the first phase of aging being independent, and second, semi-independent, and the third, dependent] and the elderly person becomes more homebound and less able to participate fully in the community, services shift to the home setting. These services seek to support, not supplant, the existing informal support network.
>
> Institutional -- Significantly diminished capabilities can warrant institutional placement when the elderly person requires a level of nursing care, medical supervision, and supportive services that are impractical or not feasible in the home.

A similar range of categories for long-term care, from the least restrictive to the most restrictive is offered below:[24]

> (1) Community Service Model: Individuals live at home but services are delivered elsewhere, e.g. adult day health center or senior center where the emphasis is on daytime social wellness activities.

(2) Congregate Housing and Services Model: Housing is supplemented with congregate services, e.g. 24-hour security, transport, recreation, and meals. Life care communities are a modification of this model where large initial payments are made, supplemented with monthly fees which cover housing and medical care. Group or boarding homes do not provide health care but allow residents to share house duties. Foster adult care is a variation.

(3) Home Care Model: Individuals are homebound (about 5% of the elderly population); individuals may also be bedbound. Services include those of physicians, nurses, social workers, and attendants offering various therapies, personal care, homemaking, transport, and home modifications. Examples of this model include various states' "nursing home without walls" (such as New York's St. Vincent's Hospital and Medical Center). St. Vincent's began as one of the first pilots in New York's Medicaid-funded nursing home without walls program in 1979. It provided a ". . . broad array of in-home services, including not only the physician-nurse-social worker team but also various therapies, paraprofessional care, and medical equipment and supplies, nutritional counseling, heavy chore services and personal emergency response systems. Only persons entitled to Medicaid are eligible, with few exceptions, and the patient's rights to remain eligible are held to rigid norms of cost and service."[25] The aim is to replicate the supportive services usually provided in institutions or congregate housing for those living at home.

(4) Institutional Care Model: Hospitals and nursing homes provide care in this category. Nursing homes provide skilled, intermediate, and personal care. Care can be either for short-term post-hospital or rehabilitation services or for chronic long-term care. "Skilled care is defined by Medicare and Medicaid as that provided in a state-licensed institution (or a distinct part of an institution) that is primarily engaged in giving skilled nursing care and related services to patients who require medical, nursing, or rehabilitation services for an extended period of time but do not require hospitalization. . . . Intermediate care is that provided in an institution licensed by a state to provide health-related care to individuals who do not require the degree of care provided by a hospital or a skilled nursing facility but do require care or services available only through an institutional facility. These facilities are sometimes called supportive nursing care or health-related facilities. . . . Personal care is assistance with such activities of daily living as bathing, toileting, eating, transferring, and ambulating provided to an individual in an institutional setting. Customarily, three or more of these services are routinely provided to each client in order to qualify an institution as a personal-care facility."[26]

Broken down in terms of home- and community-based services and not in terms of models or categories of long-term care:[27]

1. **Rehabilitation**: restores or maintains wellness and physical, mental, and social functioning after accident, injury, surgery, or illness. Usually includes various therapies (occupational, physical, speech, hearing, etc.).

2. **Counseling**: often offered at senior centers, nutrition sites, congregate housing, and nursing homes.

3. **Senior center services**: education, information and referral, counseling, health, employment, recreation, volunteer, and special services including therapy and transport.

4. **Transportation**: from housing to senior centers and for physician visits, church, etc.

5. **Nutrition program**: includes delivered meals.

6. **Home health services:** licensed home health care authorized by physician to restore/maintain health and minimize effects of illness or disability which may include nursing, various therapies, physician services, social work, and counseling. May be supplemented by personal care and homemaker services or be substituted for by the latter two.

7. **Homemaker services:** (also known as chore services) are non-medical. Unlike personal care services, they are limited to services to enhance the physical environment and not the person.

8. **Personal care services:** non-medical help with ADLs and affects the person, not the environment.

9. **Adult day health services:** provided in daytime congregate settings to those not needing institutionalization which include health care, physical and vocational rehabilitation, meals, personal care, and recreational and educational activities.

10. **Spiritual supports:** on-site or via transport to a religious site.

11. **The arts:** local artists perform for the home-bound.

12. **Respite care:** infrequent and temporary substitute care, or supervision of a disabled person in the absence of the normal caregiver or to provide that caregiver with relief. Can be provided through in-patient facilities, home health agencies, adult day care/health centers, and adult night care.

13. **Hospice care.**

From yet another perspective, Figure 3-1 lists an ideal set of services in a continuum of care for the elderly based on options available in Indiana in 1990.[28]

Figure 3-1

Type of Service	Community	Supported Living	Institutional
Housing	-Own home or apt. -Low income housing -Retirement community -Accessory apts.	-Own home -Residential facility -Group home -Adult foster care -Home repair -Weatherization	-Nursing home -Hospital -Sub acute units -Alzheimer's units
Social/ Recreational	-Senior centers -Intergenerational activites -Senior community and church groups -Volunteer opportunities	-Friendly visitor -Telephone reassurance -Social model Adult day care	-Activity programs -On-site child care -Volunteer involvement
Mental Health	-Senior centers -Mutual support and	-In-home counseling -Outreach	-In facility counsleing

	self-help groups	-Friendly visitor	and therapy -Family support groups
	-Clinical services -Volunteer opportunities -Peer counseling	-Caregiver support groups -Respite care	-Alzheimer's units -Staff training
Health/ Support Services	-Congregate meals -Transportation -Preventive health services	-Home health care -Homemaker/chore services -Personal care -Homebound meals -Adult day care -In-home respite care -Transportation -In-home activity aide -Electronic emergency response -Live-in companion -Escort services -Bill paying assistance	-Support services provided as part of total service package
Access Services	-Information and referral -Assessment -Case management	-Information and referral -Assessment -Case management -Care plan development	-Preadmission screening -Reassessments
Consumer Protection	-Adult protective services	-Adult protective services -Agency regulation and licensure -Staff licensure and certification -Staff training -Practice standards -Gatekeeper programs -Guardianship program	-Facility licensure and certification -Adult protective services -Guardianship program -Ombudsman
Public and Private Financing	-Personal funds -Social security -Employment training and placement -SSI and state supplement -Food stamps -Housing subsidies -Older American's Act funds	-Same as Community except employment -Long-term care insurance -home equity conversions -State community care funding -Medicaid waiver -SSBG funds	-Personal income and assets -Long-term care insurance -Individual medical accounts -Medicare -Medicaid

-Tax credits and
exemptions for
caregivers
-Social HMOs
-Life care communities
-Medicare
-Volunteer credits

Figure 3-2 compares the scope of services among four different models of a continuum of services. The first ("Benjamin") is the only model that targets a specific long-term care population (AIDS patients). The second ("Pepper Commission") describes the benefits under a national long-term care proposal. The third ("MHRPC") derives from a state planning document written by the Maryland Health Resources Planning Commission. The fourth ("STEPS") lists the services options for an individual's plan of care used by the Maryland Statewide Evaluation and Planning Services preadmission and annual resident review coding sheet.

Maryland's Committee on Long-Term Care believes that the long-term care service continuum should identify the full range of generic services that all long-term care populations need. The advantages of this approach are that it conceptualizes the broad impact of long-term care conditions and disabilities, it emphasizes the common needs among all long-term care populations, and it focuses on the long-term care system rather than discrete services. In recommending a comprehensive continuum of long-term care services, the Committee did not require all services to be provided under one organization nor did it expect government to provide all of it. Furthermore, the Committee recognized that many persons will not require all services but that with appropriate supports, informal caregivers will continue to be the mainstay of the system.[29] . Figure 3-3 reflects the recommendations for a continuum of services made by the Committee.

FIGURE 3-2

Table 1

	BENJAMIN[1]	PEPPER[2] COMMISSION	MHRPC[3]	STEPS[4]
INSTITUTIONAL SERVICES	Skilled nursing facility, hospital inpatient, step-down care	Nursing homes	Nursing home, extended care, chronic hospital. Domiciliary is sometimes considered institutional	Psychiatric inpatient, chronic care/rehab. Hospital, nursing home, ICF-MR. Acute care hospital
COMMUNITY BASED	Psychiatric care, counseling, support groups, buddy programs Legal services Money management-conservator services Employment counseling, support groups Information and referral, hotline, case management Protective services Alcohol and substance abuse services (education and treatment) Personal care, attendant, buddy program, aide Homemaker-chore worker Congregate and home-delivered meals Board and care, foster care, congregate housing	CASE MANAGEMENT A broad range of personal care services including feeding, transferring and tacks related to personal hygiene; homemaker/chore services (such as meal preparations, laundry, housekeeping, transportations); medications management; and for those able to leave their homes, day care services (for disabled adults and children). Respite services Training of family members on how to deliver home-based care more effectively and support counseling for family members. Skilled nurisng care as well as physical, occupational, speech, and other appropriate therapy	Adult day care Assisted housing (including domiciliary care); Assisted transportation; Case management; Home-delivered meals; Home health care--Skilled nursing; Home health aide; Occupational therapy; Physical therapy; Speech therapy; and Social work; Homemaker/chore services; Hospice; Personal care; and Respite care.	Domiciliary Care Alcoholism/Drug Treatment Support Groups Volunteer Groups Legal Services Hospice Care Counseling Medical Care Psychiatric Outpatient/Counseling Equipment/Supplies In-Home Aide/Companion Adult Protective Services Case Management Allied Health Services GES Team Home Health Nursing Services Adult Day Care House

FIGURE 3-2 (Continued)

Table 1

	BENJAMIN[1]	PEPPER[2] COMMISSION	MHRPC[3]	STEPS[4]
	housing Medical/general transportation Social day care Respite, day care Home renovation, repair Hospice, Home health care, physician visits at home Case management Outpatient clinics			Adult Day Care Housing Gateway I (Senior Info. & Assistance) Socialization Gateway II (Senior Care) Nutrition Financial Assistance Respite Care Transportation Foster Care Other Family Community Residential/Waiver (DD Active Treatment) Medical Assistance Personal Care

NOTES: (1) "Benjamin" identifies the continuum of care by A.E. Benjamin in Perspectives on a Continuum of Care for Persons with HIV I llness, presented at "New Perspectives on AIDS: Progress in Health Services Research," May 17-19, 1989, Miami, Florida.
(2) "Pepper Commission" identifies benefits under the Commission's national long-term care proposal.
(3) "MHRPC" identifies services recommends the Maryland Health Plan Resources Planning Commission.
(4) "STEPS" identifies the services options for an individual's plan of care used by the Maryland Statewide Graduation and Planning Services.

Figure 3-3

A. System Needs

1. Information and referral
2. Preadmission screening
3. Case management
4. Simple coordinated access

B. Inpatient health care facilities

C. Inpatient long-term care facilities

D. Prevention/Early Intervention Services

E. Community-based services

1. Medical Care
   a) practitioners offices
   b) outpatient clinics
   c) home health services
2. Residential services
   a) assisted housing
   b) home renovation, repair, subsidy
3. Day Care
4. Transportation
5. Personal Care
6. Homemaker Chore
7. Nutritional assistance
   a) home-delivered meals
   b) congregate meals
8. Medication management
9. Caregiver supports
   a) respite
   b) training and education
   c) supportive counseling
   d) financial assistance
10. Habilitation and Rehabilitation
11. Employment related services
    a) prevocation and vocational services
    b) supported employment
12. Ongoing socialization
13. Protection and Advocacy
14. Income Maintenance
15. Volunteer services

Utilizing a continuum of care builds in a measure of flexibility when responding to changes in an individual's long-term care needs. However, coordination of any changes in services, especially funding sources, is necessary in order to minimize disruption in care.

Inconsistent Terminology: Confusion may arise from the differing use among states of terminology for community- and home-based long-term care services.[30]

> Categorizing state service options first requires some common definition of terms. Each state used different names to describe essentially identical in-home services (such as personal care, supportive home care, homemaker, in-home aides). . . . These services are typically defined to encompass a wide range of activities from heavy to light housekeeping and from minimal to substantial assistance with bathing, dressing, eating and other activities of daily living.

For example, in the six-state study by Justice, et al., *similar* services are delivered under the rubric of "home care services" in Arkansas, Illinois, Maryland, Maine, Oregon, and Wisconsin. They are: "personal care," "housekeeping/chore homemaker," "personal care in-home aides," "personal care assistance," "home care," and "supportive home care," respectively.[31] These are not identical. Personal care addresses impairments with ADLs such as eating, bathing, dressing, and toileting. Chore services, on the other hand, help individuals who have difficulty with Instrumental ADLs (IADLs) such as shopping and meal preparation. With companion sitter services, a trained live-in person (sometimes another elderly person) ensures that medications are taken and does the housekeeping, shopping, and cooking.[32] On the other hand, in the completely different area of long-term care living arrangements, *different* services address that same need. These are "board and care"; "congregate housing services"; "adult foster care"; "residential care facilities"; "adult family homes"; and "community-based residential facilities."[33] Another listing of alternative living arrangements (for the elderly) include:[34]

- Living in original home
- ECHO housing ("Elder Cottage Housing Opportunity" housing: temporary, detached, usually pre-fabricated units sited near a caregiver's home)
- Shared housing (many elders living in one house)
- Boarding homes
- Retirement centers
- Congregate housing
- Efficiency apartments which include special modifications for the functionally impaired, such as safe appliances, low shelves, emergency call buttons, bath railings, limited entry for security, etc.
- Residential housing
- Living with family members

Home Care -- Informal Support by Family Caregivers: The terminology of long-term care services may cause confusion that is distracting. But it must be noted that home care, as provided by usually unpaid informal caregivers such as family or friends, accounts for about 75 percent of home- and community-based long-term care. Of the 12.7 million individuals with long-term care needs, about 80 percent (10.2 million) live either at home or in community settings.[35] In 1991, 5.3 million persons aged 65 and over who needed help with an ADL or IADL were not institutionalized. Many of these persons do not receive formal home- and community-based long-term care services. They rely instead on informal support given by family and friends.[36] Thus, informal care constitutes a large, if not dominant, portion of long-term care. The point is that informal care is usually unpaid and forms the basis upon which publicly-funded packages of long-term care services are authorized. Although a significant part of the continuum of long-term care, informal care is not a "service" that can be authorized and provided by any program. Most states do not penalize a potential

client by authorizing a reduced amount of support services based on the degree of informal support already available to the client. However, screeners, assessors, and case managers routinely take this into account in fashioning a care plan. Nonetheless,[37]

> Family caregivers are recognized as the primary provider of long term care services, and as such are the target for increased state efforts to provide them with *non-monetary* support in order to sustain their efforts. State policies explicitly establish linkages between informal supports and several aspects of formal service delivery systems. For example, family supports are one factor used in assessing an individual's need for publicly assisted community care services. They are also acknowledged in the frequently articulated care planning goals of "building the formal system of care around existing informal supports." And their views are solicited as part of the preadmission screening process. All of these policies relating to informal supports have become universally accepted principles that are relatively easy to implement. *[Emphasis added]*

Although the role of informal caregivers is recognized, some government officials are reluctant to pay family caregivers due to philosophical concerns over using public funds to subsidize what are believed to be family obligations:[38]

> Where such payment is made it is unvariably [sic] the option of last resort. Usually payments are linked to financial hardships resulting from caregiver activities, such as being unable to seek paid unemployment.

In four of the six states studied by Justice, et al., family caregivers can be paid as providers under some of the major long-term care programs.[39]

Home Care -- Personal Care and Homemaker Services: Where home care in the form of unpaid informal support is unavailable or inadequate, community care programs usually authorize personal care and homemaker services. This is the first major component of home- and community-based long-term care. As noted before, these services address both ADL and IADL-impairments and can go by different names. Depending on the state and the target population, these services may be administered by state or local units or by private nonprofits or even for-profit agencies. Actual services can be contracted out to home care agencies or other private providers.

Personal care and homemaker services enable individuals who need help with one or more ADLs or IADLs to continue living at home or in a community setting. Trained staff go to the impaired person's home to perform various care services. For example, personal care attendants may help clients to eat, bathe, dress, toilet, and get around inside or outside the home. Homemakers or chore assistants may help the the client manage the household budget, prepare meals, and do the shopping, laundry, and housekeeping. Their services may be paid for directly by the authorizing program or by the client through a subsidy. Some states offer these services to private-pay clients on a sliding-scale fee basis. Typically, clients not ordinarily eligible for Medicaid are assisted by these private pay programs. The rationale is that these services either delay or prevent their entry into more expensive nursing homes.

Adult Day Care and Adult Day Health Centers: Non-residential adult day care centers (ADCC) and adult day health centers (ADHC) comprise a second major component of long-term community- and home-based care for the elderly. Elderly who are functionally impaired travel from their homes to a care center to receive services. In general, ADHCs offer more services, including a medical component, than ADCCs.

ADCCs do not provide medically-related services although they may provide general nursing services. "Adult day care is not designed for those who are bedridden, severely disoriented, or potentially harmful or disruptive."[40] They do offer a respite for family caregivers. In addition, they provide active therapeutic treatment as well as needed socialization for functionally impaired elders who find it hard to carry on a normal social life. ADCC services are not cheap, but are cheaper than eight hours of homemaker services.[41] Adult day care can be delivered in various settings: hospitals, nursing homes, senior centers, and freestanding ADCC sites. Typical services provided by ADCCs include the following:[42]

- Social work services
- Meals
- Nutritional counseling
- Speech therapy
- Physical therapy
- Music therapy
- Reality therapy
- Rehabilitation services
- Transport services

Although ADCC care is usually considered a part of community-based long-term care, Wisconsin explicitly prohibits its program funds to be used for adult day care that is provided in *nursing homes*. This policy bolsters Wisconsin's aim to expand *non-institutional* services. In turn, this implies that nursing home-provided adult day care falls within the "relatively well-developed and well financed institutional sector."[43] Most other states support adult day care as a component of long-term care. Factors consistently obstructing the expansion of adult day care in most states include the scarcity of initial and continuing funding and limited community awareness of ADCCs as a viable component of community- and home-based long-term care.

According to Lee (1992), almost 83 percent of an estimated 8.6 million elderly persons who need long-term care lived in the community.[44] In the four states comprising Medicaid Region 9 -- Hawaii, California, Arizona, and Nevada -- there were 433 licensed adult day care centers in 1989. California had the lion's share with 91 percent (392) of all Region 9 ADCCs. Hawaii had 14 (Arizona had 24 and Nevada had 3).[45]

In Hawaii, the Department of Human Services regulates the services and licensing of ADCCs under chapters 17-1417 and 17-1424, Hawaii Administrative Rules, respectively. While ADCCs are not required to, they often serve many ICF-level clients. However, they do not receive Medicaid compensation that ADHCs receive for providing care to these ICF-level clients. ADCCs that wish to receive such compensation must qualify for dual licensing as both ADCCs and ADHCs. They have no difficulty meeting DHS standards for day care, but have found it all but impossible to meet DOH standards even for the relatively less stringent freestanding ADHCs.[46] *(See subsequent section regarding regulation of ADHCs by Hawaii's Department of Health.*

Adult Day Health Centers: ADHCs are also non-residential. An often cited example of a community-based, non-institutional long-term care program (for the elderly) is the On Lok Senior Services center in San Francisco. A non-profit, the On Lok program began in 1973 as an adult day health center. By 1979, On Lok was providing the comprehensive services which distinguish the PACE program (program for all-inclusive care for the elderly). By 1983, full risk and fixed monthly capitation payments were included from Medicare, Medicaid, and private funds.

> PACE is part of a national replication project authorized under the federal Omnibus Reconciliation Act of 1986, as amended, which instructs the secretary of the Department of Health and Human Services to grant Medicare and Medicaid waivers to permit not more than fifteen public or nonprofit private organizations in the nation to provide comprehensive health care services on a capitated basis to frail elderly who are at risk of institutionalization. These Medicare and Medicaid waivers allow PACE to receive a per-person payment each month from Medicare and Medicaid without restrictions on service delivery and fee-for-service limitation. As a result, PACE has the authority and flexibility to consolidate these funds and provide any services ranging from adult day health center to acute hospitalization. . . . Operating within a cost-effective, capitated risk based financing system, PACE charges a fixed monthly payment per person for a complete package of health and social support services. This capitated financing requires PACE to assume full financial responsibility for a client's total long-term care and and for cost overruns. PACE's success depends on aggressive community-based preventive care which maintains the elderly's health and avoids high cost institutional care. . . . PACE is a cost-effective alternative program that addresses the problems of fragmented and costly long-term care by meeting the needs of . . . families who are struggling to maintain their frail elderly in their own homes and avoid institutionalization.[47]

The On Lok program provides long-term care for a population whose average age is 80, two-thirds of whom live alone and half of whom speak no English. To be enrolled, they must be certified by California's Department of Health Services for institutional long-term care. Clients cannot be discharged once enrolled, binding the On Lok program to provide lifetime care regardless of a client's degree of sickness. On Lok now operates three adult day health centers and On Lok House, which is a 54-unit low-income housing complex for seniors. The comprehensive health program also includes in-home, hospital, and (when necessary) nursing home care for some 300 persons.[48]

Entry into the On Lok program involves the usual three-part process of screening for eligibility, assessment, and creation of a service plan upon enrollment. A potential client's age, frailty, other residency requirements are determined. A comprehensive assessment of the client's health is done by a multidisciplinary team of physicians, nurses, social workers, nutritionists, therapists, paraprofessionals, and other support staff. Upon enrollment, a service plan is created.[49]

In the case of On Lok, as opposed to the six states studied by Justice, et al., the multidisciplinary staff not only assess and develop the treatment plan, but they also provide direct services and formally reassess clients quarterly. Services provided by the multidisciplinary team include:[50]

> [p]rimary medical care; dental care, skilled nursing care; physical, occupational, and recreational therapies; social services, nutritional counseling; medical day care; social day care; postdischarge planning; pharmacy services; all health-related transportation; and some in-home services. . . . Essentially, in return for its monthly capitation premium, On Lok pays for and provides every health and health-related service from transportation and social support to acute

> hospitalization. And most of these services are provided directly by On Lok staff. Care by professional medical specialists, institutional care (acute and skilled nursing), and medical specialty services are provided under contract. . . . On Lok is the only long-term care program in the country receiving capitation financing from Medicare, Medicaid, and private individuals, and assuming full financial risk. On Lok's unique service program is made possible through Medicare 222 and Medicaid 1115 waivers. The waivers are normally time limited; but in spring 1986, federal legislation was passed to make these waivers for On Lok permanent. . . . In the fall of 1986, federal legislation was passed to extend this financing model and its waivers to ten other sites around the country.

Although On Lok began as an adult day health center, it has evolved into a program of all-inclusive care for elders, including acute and skilled nursing care, if necessary. The day health care component remains an integral but smaller subset of the PACE concept of long-term care.

ADCCs and ADHCs in Hawaii: On June 21, 1995, the governor of Hawaii vetoed a measure that would have:[51]

> (1) Recognized that ADHCs are a viable alternative to institutional long-term care for elders;
>
> (2) Supported the expansion of ADHCs;
>
> (3) Required the adoption of coordinated rules to:
>
> (a) Guarantee high standards of care;
> (b) Present a rational, unified framework for eligibility and admission, program, and licensing requirements and scope of services for both ADHCs and adult day care centers (ADCCs);
> (c) Regulate ADHCs separately from skilled nursing and intermediate care (SNF/ICF) facilities;
> (d) Require licensing, program, and admission requirements and scope of services of ADHCs to be a superset of the requirements for ADCCs; and
> (e) Ensure Medicaid reimbursement for freestanding ADHCs for ICF-level patients.

Final enactment of this measure would have helped to more fully utilize both ADCCs and ADHCs more effectively in the community care system.

Social/Health Maintenance Organizations for Elders: Another initiative towards the goal of providing all-inclusive care is the operation of social/health maintenance organizations (s/HMO) for elders. Based on the HMO model of managed health care, the s/HMO provides a full range of acute and supplemental medical services on a capitated basis. Elders agree to use specified s/HMO physicians and health services. In addition, elders receive prepaid, case-managed long-term care benefits covering chronic conditions excluded by Medicare and private insurance. s/HMOs offer a single point of entry and eliminate the arbitrary boundary between acute care hospital and physician services and long-term care services.[52] Services usually include homemaker, personal care, respite, adult day health care, transportation, and case management services. Nursing home services are also provided. Four demonstration sites were established: Elderplan, Inc. in Brooklyn; Medicare Plus II in Portland; Seniors Plus in Minneapolis; and Senior Care Action Network in Long Beach.[53] However, enrollment in these sites have been low and has been attributed to elders' unwillingness to give up their personal physicians. In addition, enrollment has been depressed by the low maximum amount of benefits for chronic care. According to Rivlin and Wiener (1988): "At most, s/HMO

enrollment is likely to be a subset of the minority of the elderly who join health maintenance organizations."[54]

Hawaii -- ADHCs and PACE: In Hawaii, there are a limited number of ADHCs, both facility-based and free-standing. The Department of Health regulates ADHCs under rules originally designed for skilled nursing and intermediate care facilities (SNF/ICF). *(Note: According to Lee (1992), the distinction between SNFs and ICFs is no longer used since the implementation of the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203). SNFs were formerly distinguished from ICFs by the heavier level of care needed by their residents -- SNF residents typically required continuous 24-hour nursing care, whereas ICF residents typically required intermittent nursing care.)*[55] Because ADHCs are subject to these more stringent rules, only a handful of ADHCs have been qualified.[56] In 1992, the Legislature found that PACE costs less than what Medicare, Medicaid, and private individuals currently pay for long-term care. It also found that:[57]

> PACE provides a complete package of services that enhances the quality of life for the elderly participant and offers the potential to reduce and cap the costs of the medical needs of the participants. . . . PACE is a cost-effective alternative program that addresses the problems of fragmented and costly long-term care by meeting the needs of Hawaii's families who are struggling to maintain their frail elderly in their own homes and avoid institutionalization.

As a result, the Legislature established the Hawaii PACE demonstration project at Maluhia Hospital in 1992 with the following goals:[58]

> (1) Maintain eligible persons at home as an alternative to long-term institutionalization;
>
> (2) Provide optimum accessibility to various important social and health resources that are available to assist eligible persons in maintaining independent living;
>
> (3) Coordinate, integrate, and link such social and health services by removing obstacles which impede or limit improvements in delivery of these services; and
>
> (4) Provide the most efficient and effective use of capitated funds in the delivery of such social and health services.

Alternative Living Arrangements: A third major component of community-based long-term care is the provision of alternative living arrangements other than institutionalization. Justice, et al., found that:[59]

> Increasingly the lack of support housing options is viewed as a major gap in community care delivery systems. Without a place to live frail older people cannot remain in the community regardless of how well the long term care system is organized. The study states have finally bridged the barriers between health and social service systems in their development of integrated community care programs.

They concede, however, that there is still a need to better link housing policies and long-term care. Most housing programs are federally administered with distinctly different financing and administrative structures. Long-term care systems, on the other hand, are state-managed.

Congregate Housing, Adult Foster Homes, Board and Care Homes, and Residential Facilities: One type of alternative living arrangement is congregate housing. Congregate housing allows states to offer support services without the need to build new housing for the elderly. Existing housing (usually federally assisted) projects are increasingly becoming the homes of frail and impaired older people as they "age in place." Residents continue to occupy their own apartments, in contrast to board and care homes. Rents are often federally subsidized in congregate housing for low income persons. For its part the state, which runs long-term care programs, provides a package of support services such as meals, personal care, and housekeeping. Other services may include emergency call systems (attached beeper with which to call for help); home health care; volunteer visitors; and daily telephone checks.[60] Typically, the target population in congregate housing have only moderate impairments and are not candidates for nursing homes.

In Maine, the same functional assessment tool used for determining eligibility for its Homes Based Care Program and for preadmissions screening is used to determine the need for congregate housing services. Only low income elderly are eligible. In Maryland, moderate income elderly can access the package of support services by paying fees on a sliding scale basis.[61]

Personal care is provided in adult foster homes which can each accommodate a small number of clients. Oregon restricts the number of residents to five per foster home. That state's use of adult foster homes is a major service strategy under its Medicaid waiver program. The program allows current nursing home residents to be relocated to community settings. Adult foster homes are licensed by the local Area Agency on Aging and paid directly by clients receiving Medicaid waiver funding.[62]

Board and care homes, although alternatives to nursing homes, are still considered institutional. They do not offer the privacy of living in adult foster homes and certainly not in living in one's own apartment or in congregate housing. They are, however, preferable to traditional residential care facilities which are larger and have a less family-like environment. Medicaid waivers can be used for care in these residential care facilities. For example, Oregon pays the care facility directly for the package of support services while clients pay for room and board.[63] Arkansas has over 100 residential care facilities and pays a fixed amount to providers for recipients at risk of entering nursing homes. Wisconsin pays for services in residential care facilities only if clients number no more than four, six, or eight under differing circumstances.

ARCHs in Hawaii: In Hawaii, there are about 500 adult residential care homes (ARCHs) with about 400 on Oahu.[64] ARCHs are divided into Type I and Type II. Type I facilities provide a setting for group living for up to five unrelated persons. Type II facilities serve six or more persons. Residents can include the mentally ill, elderly, disabled, and developmentally disabled. ARCHs provide three levels of care (LOC) for which they are reimbursed escalating rates of payment. Although both facility types have the same minimum supplemental state payments, the larger Type II ARCHs have higher reimbursement ceilings than the smaller Type I ARCHs. *(Note: Both Type I and Type II ARCHs are paid supplemental payments by the State of not less than $79.90, $129.90, and $191.90 for levels of care (LOC) I, II, and III. However, Type II ARCHs have higher payment ceilings at $338.90, $477.90, and $579.90 for LOC I, II, and III, as opposed to $284.90, $369,90, and $471.90, respectively, for Type I ARCHs.)*[65] ARCHs, however, are not licensed to care for nursing home-eligible clients. Nonetheless, many ARCH operators claim that they care for ICF-level clients without being reimbursed at the ICF-level.

In 1994, in recognition of this and to relieve the long waiting list for SNF beds, the Hawaii Legislature established the Maluhia Waitlist Demonstration Project (MWDP).[66] *(See chapter 5 for a more detailed discussion of the MWDP.)* The purpose of the MWDP is to establish a *new category* of ARCH qualified to serve nursing facility-level clients. These ARCH residents would then qualify for higher State Medicaid payments -- $927.90 -- of which $30 goes to the ARCH resident for spending money.[67] Actual startup of the program is scheduled for October, 1995.

The number of individuals staying in acute care hospitals in Hawaii -- at a cost of about $2,000 per day -- waiting for nursing home beds is about 400.[68] *(Note: In 1988, Medicaid recipients in Hawaii spent a total of 160,000 days in SNFs, averaging 129 days of care. In 1989, Hawaii Medicaid residents spent 671,000 days in ICFs, averaging 236 days of care. Nationally, the average days of care in SNFs and ICFs were 198 and 262, respectively.)*[69] The MWDP is designed to alleviate the shortage of nursing home beds by routing nursing home-eligible patients from acute care hospitals to upgraded, new-category ARCH facilities.[70] Selected ARCH operators are to be trained to accommodate the types of clients to be targeted. ARCH services for these nursing home-level residents in the MWDP will be supplemented with home health care, case management, and community support services.[71]

In terms of access by different populations, the MWDP does not impose age limits for clients. Thus, the project is not limited to the elderly -- the population one normally associates with nursing homes. Rather, it is open to *all persons* without regard to age who have "been approved by the [D]epartment of [H]uman [S]ervices for nursing home placement at the intermediate care facility or skilled nursing facility level."[72]

Categorical Versus Generic (Functional) Approach: How a population is classified or defined often determines who can have access to services. Consequently, such definitions are matters for policy decisions. Historically, groups needing long-term care have been defined *categorically* on the basis of diagnosis or age, mostly reflecting funding streams. For example, states often have offices on aging to fund elderly long-term care programs, and separate mental health and developmental disability agencies to care for their respective categorical populations.

Advantages of a Categorical Approach: The categorical approach has been in place in many states by historical default. However, its value is not due entirely to historical accident. According to a 1991 study by a Maryland commission, the advantages of the categorical approach include:[73]

- This is the way that most people think of long-term care populations. Nonprofessionals generally become interested in long-term care because they, a family member, or a friend require long-term care services. They help to organize and support an infrastructure for that population.
- These categories describe legitimate differences between populations, ages, and disabilities and the diversity of service needs that should not be ignored.
- Many existing funding streams, such as Older Americans Act funds, are categorical.
- Networks of population-focused advocacy associations already exist. Providers and professionals specialize on the basis of long-term care population.

- Many people believe that the only way to address the specific needs of a given population is to focus on that population.
- Offering service by population category can make eligibility [determination] easier; for example, a person is over age x, or younger than age y, or has a particular diagnosis.

Disadvantages of a Categorical Approach: The categorical approach has its drawbacks, chief among which is the issue of equity of access. The following are often-cited disadvantages of the categorical approach:[74]

- Artificial gaps in services are created because a person may be too young or too old to be eligible for an age-based service or have a multiple diagnosis involving two or more agencies.
- Inequitable treatment results when people with equal disabilities or needs do not receive equal service because they are in different eligibility categories (for example, more or less than age 22, over or under age 65).
- Complex application procedures.
- Fragmentation and duplication of services may well result as each categorical agency develops its own community-based long-term care system.
- This approach encourages population-focused advocacy groups to address their own population's problems separately, even though their problems may be common to many other populations.

The Generic Approach: As an alternative to the categorical approach, generic long-term care services can be provided to different categorical populations based on functional need. For example, regardless of the diagnosis or age of an individual, personal care is almost uniformly required for all persons needing long-term care. The chances are that developmentally disabled children and non-elderly adults need the same type of help as the frail elderly in ADLs such as toileting, bathing, and dressing. In fact, the generic approach would include all other sub-groups requiring long-term care such as AIDS and Alzheimer's patients. Thus, using functional eligibility criteria may imply the need for a policy decision to include those without financial need for services. Functional criteria can also be used to limit the size of the recipient population. For example, increasing the number of qualifying ADLs would limit the population of eligible individuals. On the other hand, lowering them could include, say, the less disabled so that services would slow their deterioration, reduce the erosion of social supports, and lessen other types of disabilities such as depression, incontinence, and falls.[75] Others counter that inclusion of additional subgroups is inefficient and dilutes funding efforts so that services are not maximized for those with the greatest need. Thus, setting the number and types of ADLs used to screen the recipient population is a matter of *policy*.[76]

Advantages of a Generic (Functional) Approach: In any case, the following are typical advantages of a generic, or functional approach:[77]

- Services are more effective and efficient because of the elimination of duplication and fragmentation. One agency could provide services for several categorical populations.
- Services are more equitable because persons with the same level of disability will get the same service, regardless of diagnosis or age category.

- An agency is better able to follow an individual as his or her needs change over time, without disjunctures such as movement from [the] children's to [the] adult services system, or from the adult to the elderly service system.
- It encourages coordination of services and allows pooling of resources.
- By combining populations, this approach may encourage coalitions of otherwise isolated groups to advocate for and protect programs benefiting several categories.

The literature indicates that the trend is toward delivery of long-term care services generically based on need rather than on a categorical basis. Fiscal constraints increasingly felt by the states are also generating support for the generic approach, heightening their belief that categorical programs are probably more costly and inefficient.[78] The following is an example of one state's recommendation on policy regarding this issue:[79]

> The [Maryland] Committee on Long-Term Care believes that equity of access to long-term care services should be a guiding principle of the long-term care system. Individuals with similar needs for long-term care services should have equal access to the needed services and not be denied services because they are targeted to a particular age or disability group. As a consequence of the way long-term care services have evolved, the current [categorical] long-term care system does not meet this test of fairness.
>
> The Committee believes that equitable access can best be achieved when services are organized generically rather than categorically, and when eligibility is determined by an assessment of functional disability. This does not mean that age or specific disability is of no consequence, or that some aspects of the service system would not be organized to provide for such needs as might be peculiar to a particular categorical population.

Of course, as with any policy, the proof of the pudding is in the eating. It is one thing to state policy but quite another to implement it through viable action. An affinity for the generic approach implies the need to integrate the system to some degree, if only the establishment of an SEP. Because services are to be delivered across categorical groups, some measure of integration, or at least coordination, is necessary to screen, assess, and manage previously discrete populations. Once it is decided to do so, a solid foundation needs to be built through careful and thorough negotiations among all the players in the long-term care arena. Interagency agreements need to be reached. Intraagency and interagency activities and procedures -- such as the screening, assessment, and case management processes -- need to be unified, coordinated, or re-structured. Advocacy groups need to be consulted. If no major governmental reorganization is involved (cabinet or umbrella/coordination models) a strong interagency coordinating body with substantive powers needs to be established. Even so, without equally strong leadership and commitment from a state's governor, such coordination efforts may flag. The public, especially those who need long-term care and their families and informal caregivers, need to be educated, kept informed, and consulted. Activities of providers (acute care hospitals dischargers, SNFs/ICFs, home- and community-care providers, benefits coordinators, insurers, state and federal funding agencies, etc.) need to be coordinated.

Disadvantages of a Generic (Functional) Approach: On the other hand, opponents of the generic, or functional approach typically cite the following disadvantages:[80]

- Assessment methodologies that cross age and disability categories must be developed, which will be a difficult task.

- Some people may lose services if limited resources are redistributed across all long-term care populations, and eligibility criteria are tightened.
- Shared service delivery may blur the distinct needs of age or disability categories.
- Managing a system with multiple populations and funding streams, and unequal mandates and entitlements, would be administratively complex.
- Many people believe that to organize service other than by population would mean that the specific needs of a given population would never be adequately addressed.
- Resources available to any one group might be diminished, leading to greater turf [b]attles.[81]

The Disabled as a Functional and Categorical Group: S.C.R. No. 33 and S.R. No. 27 specifically refer to "disabled children and disabled younger adults" in addition to the elderly as target long-term care populations. They are distinct *categorical* populations for the purposes of funding. However, in terms of long-term care needs stemming from *functional* impairments, many believe that the distinctions are artificial. There is some disagreement as to how completely these needs are shared by the three groups. It is only logical to see an increasing commonality of needs as the ages between two groups narrow, and vice versa. For example, a disabled 2-year-old's needs will be more similar to those of a disabled 5-year-old than to a disabled 25-year-old, and even less with frail elders. Disabled "younger" adults in their 50s can be almost indistinguishable in their long-term care needs from the frail "elderly" in their 60s. On the other hand, a disabled 25-year-old's needs may differ significantly from a disabled 60-year-old's, particularly if the younger person requires special training and employment supports. However, as one observer notes, various categorical populations need generic services which, by implication, are more apt to be provided in an integrated system:[82]

> Those likely to benefit most [from case management] include older persons with chronic problems that significantly impair their activities of daily living, younger persons who have neurological or orthopedic impairment due to trauma, the chronically mentally ill, and the developmentally disabled. *[Emphasis added]*

Regardless of age or disability, all those in need of long-term care are functionally impaired in some way. Thus, all require services that address functional impairments.

The functional differences among the three named groups are a matter of degree. As such, they are subject to disagreement. It is these differences that may give rise to conflict among advocates of the three categorical groups over issues such as integration of services and funding, including a single entry point. Unfortunately, long-term care programs -- particularly their funding sources -- have developed historically in a way that address specific categories of people, not their degree of functional impairment.

One reason why the elderly dominate long-term care is that there are more of them who need long-term care than any other group. Only a very small proportion of children and non-elderly adults are functionally impaired. On the other hand, a larger proportion of the elderly eventually become functionally impaired, including some who may have been disabled at an earlier age. However, not all programs treat the disabled as a distinct categorical funding or programatic group. For example, the Maluhia Waitlist Demonstration Project *(above)* is open to all who require nursing home placement at the SNF or ICF level. This does

not preclude non-elderly disabled adults. Practically speaking, however, nursing homes have not been appropriate placements for disabled children.

The Developmentally Disabled: The term "developmental disability" is similarly defined in many states. Generally, it involves a severe and disabling condition that arises in infancy or childhood,[83] persists indefinitely, and causes problems in language, learning, mobility and capacity for self-sufficiency. Chapter 333F, Hawaii Revised Statutes, entitled "Services for Persons With Developmental Disabilities or Mental Retardation" defines "developmental disability" as follows:[84]

> "Developmental disabilities" means a severe, chronic disability of a person which:
>
> (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> (2) Is manifested before the person attains age twenty-two;
>
> (3) Is likely to continue indefinitely;
>
> (4) Results in substantial functional limitations in three or more of the following areas of major life activity; self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic sufficiency; and
>
> (5) Reflects the person's 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.

According to Wright and King (1991):[85]

> Developmental delays result from mental retardation, cerebral palsy, muscular dystrophy, cystic fibrosis, congenital heart disorders or serious heart disease, neural tube defects such as spina bifida, and fetal alcohol syndrome and drug addiction. Infants and toddlers who experience sensory impairment, emotional disorders, or neurologically based learning deficiencies also may have delayed development.

Many developmentally disabled (DD) are children. The federal Children with Special Health Needs Program is a major component of Title V within the Maternal and Child Health block grant. This program provides for specialized health care and support for chronically ill or DD children and their families.[86]

Long-Term Nature of Services and System Integration: Whether or not all services for the developmentally disabled are, *ipso facto*, perceived to be long-term in nature may affect how easily the system can be integrated. If they are so perceived, there will be more common ground for sharing the same or similar screening and assessment tools across current categorical long-term care populations. This should be so even at a lower level of integration such as an SEP. Many core services are the same across various categorical long-term care groups. These are services and supports that address ADLs in a home or community setting. However, as discussed above, different categorical groups have certain unique needs. It is these non-overlapping services that address needs specific to a categorical group that may hamper the establishment of an SEP or the further integration of the long-term care system.

On the one hand, it can be argued that all DD services are long-term in nature because DD individuals:

(1) Suffer "substantial functional limitations";

(2) Have a "severe, chronic disability" which "is likely to continue indefinitely"; and

(3) Need services "which are of lifelong or extended duration."

Certainly, the DD population requires help with ADLs in the same way that the frail elderly do. They may even share some needs for various therapies. In fact, some programs only use functional impairment as the criterion for eligibility and not age (which could group non-elderly DD individuals with the frail elderly).

On the other hand, it can be argued that at some point services become merely facilitating and not integral to the long-term needs of the DD population. Some services may not last indefinitely. In fact, some are designed to terminate at some phase of a DD individual's life. For example, the federal Individuals with Disabilities Education Act of 1990 (P.L. 101-476)[87] provides for the right to a free and appropriate public education for children and youth with disabilities. Specialized support services that see these children through their public education years terminate at some point. Furthermore, only about one million of the nearly four million Americans who have developmental disabilities may require an intensive array of services for most of their lives.[88]

Nonetheless, one could say that everything that supports individuals who need care indefinitely is part of a system of long-term care even though specific supports may not last indefinitely. For example, the Fair Housing Amendments Acts of 1988 and 1990 (P.L. 100-430) prohibits discrimination against and accommodates the needs of the DD population.[89] One of its effects is to assist and protect the housing interests of the DD population, which contributes to the long-term welfare of the disabled.

Thus, the more such services and benefits are viewed as specific to a categorical group, the more difficult it would be to integrate the system across populations. On the other hand, the more support services are viewed as long-term in nature, the fewer the obstacles to a shared system. Although a discrete service or support may not be needed indefinitely, the continuing need for a set of supports in lieu of institutionalization is the current reality for the DD population:[90]

> Community living once was reserved for people with mild or moderate degrees of disabilities. Today, community service systems furnish a wide range of services and supports to thousands of consumers with severe disabilities, including people with substantial medical needs and individuals who may act violently toward themselves or others. Once, these people were thought to require highly structured, congregate-care institutional services. This is no longer the case.

In 1967, there were 350 institutions for the developmentally disabled, housing some 228,500 persons. By 1993, the number of institutions had dropped to 240 institutions, accommodating about 71,000 persons.[91]

Living Arrangements for the DD: In the not too distant past, group homes for the DD were considered one of best ways to integrate DD individuals into society and community life. Group homes were more "homelike" than institutions. However, living arrangements have been trending away from group homes, spawned from complaints that they are not acceptable alternatives to institutions. Some have objected to the "unnatural" environments created by group homes and congregate housing. In the former, six to ten unrelated persons must live together under supervision and are provided with personal care.[92]

> Housing and support services such as home health care, money management and housekeeping are tied together in relatively inflexible programs administered by what some call "paternalistic" agencies still entrenched in the medical model of care for the developmentally disabled. . . [The national trend is to] help people with DD rent or buy their own apartments or homes where they receive individualized services that have proven cheaper for states than the expenses involved in a group home or institution. In such a "supported living" scenario, housing is separated from and no longer dependent on a service agency. Instead, agency personnel come to the individual at home and provide services necessary for care and safety. If the individual's needs change, the services are modified, and the person is able to remain at home.

The pilot federal Community Supported Living Arrangements (CSLA) program helps with personal assistance for shopping, meal preparation, housekeeping, and money management tailored to meet individual needs. *(See subsequent section "Federal Payment Sources and DD Services" for more discussion of the CSLA program.)* A supported living consultant is available to coordinate community services. "[B]ecause of the flexibility and personalized nature of the [CSLA] program, people with even the most severe disabilities -- once thought of as manageable only in an institution -- are now able to live in neighborhoods and communities."[93]

On the other hand, some DD advocates and families of DD individuals have objected to the wholesale move to a home- and community-based, supported living environment.[94]

> "People who want to move toward a model of community living often have an idealized view of community life" asserts Caroline Walsworth of Voice of the Retarded (VOR), an association of individuals and parent groups. "VOR believes that community living is just not for everyone." . . . [Kansas Senator Gus Bogina agrees:] "The philosophy that all clients can be or should be out of institutions is false. There are some people who cannot function in the community either because of profound mental retardation or because they have spent their entire lives in institutions and are, therefore, very vulnerable." . . . [Walsworth says] "there are degrees of mental retardation and multihandicapped individuals who need more protective settings [especially those with high medical needs]."

Those who caution against a total rejection of institutionalization warn that once a facility is closed, the state cannot easily re-open it. Often, structural reorganization has taken place and personnel have been transferred or laid off. Once patients go into the community, a state has less control over the continuation of community provider services, especially if a federally funded provider goes out of compliance.

That there is opposition to a wholesale transfer of the DD population from institutions to the community must be recognized. To the degree that such opposition exists, there may also be a diminution of common ground upon which different categorical groups can agree regarding a unified system of access. For example, some may feel that individuals who should remain in facilities may get left out in a system that emphasizes home- and community-based services inappropriate for them. Will their institutional needs be accommodated in such an integrated system? Of course, SEP processes and fully integrated long-term care systems can, and do, include institutionalization as a matter of policy. The point is that those involved in both policymaking and implementation must make conscious decisions to accommodate differences and differing needs among long-term care populations.

Federal Programs for the Developmentally Disabled: The disparate manner in which federal and state programs address the multiple needs of the DD population contributes to

overall fragmentation of services. The previously mentioned ***Individuals with Disabilities Education Act (IDEA)*** contains Parts A through H. Part B is permanently authorized and provides funds to local education agencies to help pay the excess costs of educating students with disabilities. All other Parts are discretionary.[95] Part H consists of the ***Program for Infants, Toddlers, and Families***. This intervention program aims to help states develop and implement a statewide, comprehensive, coordinated, multidisciplinary interagency program of early intervention services for infants and toddlers with developmental disabilities or with conditions that place them at risk of delays.[96] Federal Part H moneys are not meant to provide direct services although the end result contributes to improved care for young DD individuals. Obviously, services under Part H are not long-term in the sense of extending into the future indefinitely. However, they operate within a phase of a DD individual's lifetime over which the person requires various types of long-term care.

Part B of the IDEA (originally enacted as Title II of P.L. 99-457)[97] provides for the ***Federal Pre-School Program***. Part B requires states to ensure that all eligible children with disabilities, beginning at age three, receive a free and appropriate public education by the 1991-1992 school year. States must meet this requirement to receive federal funds for children counted in preschool under federal special education grant-in-aid formulas.[98] This program is similarly not "long-term" in the normal sense. To the extent that it does not neatly overlap with customary "long-term" care dealing with ADLs available to multiple populations, it may pose problems for service integration.

Medicaid also provides for early intervention services that screen and treat eligible children. Medicaid's ***Early and Periodic Screening, Diagnosis and Treatment (EPSDT)*** service is provided under states' Medicaid programs and covers children from birth to age 21. States are required to provide treatment (such as speech therapy and hearing aids) to correct or ameliorate any physical or mental problems identified during the EPSDT screening and assessment process.[99] The EPSDT program assists the DD population with its overall long-term needs. However, its services cannot be applied to other categorical populations. To the extent that they cannot, they must be taken into account in any effort to create an SEP or to integrate the long-term care system for multiple populations. The point is: every service or benefit that is not generally applicable across long-term care populations may obstruct system integration. How each service is dealt with in an SEP process or an integrated system requires across-the-board consensus.

Medicaid is the most important source of funding for the DD population:[100]

> The vast majority of federal assistance to states to pay for developmental disabilities services comes in the form of Medicaid. . . . State legislatures play a critical role in establishing state developmental disabilities policy, authorizing services, structuring service delivery systems, and deciding how much medicaid will pay for services. . . . Community residential services for adults typically claim the lion's share of each state's community developmental disabilities budget.

In 1993, people with disabilities accounted for 15.5 percent of Medicaid enrollment, but 39 percent of all Medicaid expenditures. Just as in the general population, the disabled population also has a minority that uses the most Medicaid primary care services. Many disabled recipients are more modest users of the health care system.[101] One clue as to why disabled individuals may account for a disproportionately large amount of Medicaid expenditures may be that:[102]

> Primary care physicians have traditionally been fearful of treating patients with disabilities . . . . They have tended to respond to the disabilities and not to the

> immediate medical need. The result is that people with disabilities have a specialist referral rate that is 60% higher than for the general population. They also have longer hospital stays even though people with disabilities don't seem to have different rates of healing.

The federal ***Maternal and Child Health*** block grant enables states to develop or enhance systems to ensure that children with special medical needs have access to primary health care. In addition to intervention services, states have discretion to target some of these funds for primary prevention and prenatal care.[103]

The Crisis Nurseries and Respite Care program is an extension of the ***Temporary Child Care for Handicapped Children and Crisis Nursery Act of 1986 (P.L. 101-127).*** The program funds respite care services for children with disabilities and nurseries for children in crisis due to abuse or neglect.[104]

The ***National Early Childhood Technical Assistance System*** is funded by the federal Office of Special Education Programs. Its purpose is to advise states technically on policy planning and intervention models by analyzing the implementation of Part H of IDEA. ***Regional Resource Centers*** in each federal region have added early intervention specialists to help states develop and implement early intervention and preschool policy.[105]

DD Services: A DD individual may require age-appropriate supports and services that address the individual's long-term needs. Generally, DD services for children include:[106]

> [d]evelopmental, educational, therapeutic, technological, and social services. Early identification and treatment of a child's developmental delays promote the optimal development of the child and prevent the emergence of more severe and costly problems later on. . . . Early intervention services include family training, counseling, and home visits; respite care; speech pathology and audiology; occupational therapy; physical therapy, assistive technology; psychological, nutrition, and case management services, early identification, screening, and assessment services; and health services necessary to enable the infant or toddler to benefit from the other early intervention services.

Children diagnosed as developmentally disabled often receive services in infant development programs that include various therapies. Their families receive social work services and their caregivers receive special training to care for DD children. Case management ensures that DD children and their families receive, or at least gain access to, social, medical, legal, educational, and other services.[107]

"Services" for the developmentally disabled in Hawaii is defined as follows:[108]

> "Services" means appropriate assistance provided to a person with a developmental disability or mental retardation in the least restrictive, individually appropriate environment to provide for basic living requirements and continuing development of independence or interdependent living skills of the person. These services include, but are not restricted to: case management; residential, developmental, and vocational support; training; habilitation; active treatment; day treatment; day activity; respite care; domestic assistance; attendant care; rehabilitation; speech, physical, occupational and recreational therapy; recreational opportunities; counseling, including counseling to the person's family, guardian, or other appropriate representative; development of language and communications skills; interpretation; transportation; and equipment.

DD individuals may also need training in general skills such as learning to budget, shop for groceries, take a bus, and order in fast food restaurants. Because "[s]tates are

moving away from rigid facility-based or program-driven services to more flexible, customer-driven community supports models, many DD individuals live in the community."[109] However, they need various supports. Supported living can be described as follows:[110]

> [S]ervices and supports would be shaped around each person's particular needs and would complement the other assistance that could be obtained through other public programs or "natural supports" (e.g., friends, families, neighbors and other people in the community). This approach is commonly called supported living. . . . In supported living, people pay for their own living arrangements and daily living expenses, using employment income as well as public assistance benefits. . . personalized support strategies are worked out in concert with the person, family and friends, and professionals to identify the combination of services and supports that the person needs. . . once a strategy is worked out, people are linked up with community agencies or individuals who provide various kinds of support.

Under the supported living concept, services are tied to the person, not the residence. Services are tailored to fit the needs of the person. Supported living does not focus exclusively on facilitating functional disability but on enhancing a person's strengths and ties to the community.

Federal Payment Sources and DD Services: The first federal payment option is Supplemental Security Income, which is an income maintenance program that provides a base level of income support for the blind, disabled, and elderly. Parents' incomes are counted for children under age 18 living at home, thus only very poor families qualify.[111]

According to Bauer (1994), Medicaid provides medical services to low-income children meeting eligibility requirements:[112]

> States have the flexibility of choosing 34 different services when designing their Medicaid plans once they have incorporated nine mandated services. Physical therapy, speech therapy and private-duty nursing are all Medicaid-approved services that a state has the option to provide Medicaid-eligible children. These services must be available across the state to all eligible children, unless the state has received a waiver stipulating something different.

Two Medicaid waivers are generally used. First, the Home- and Community-Based Services (aka "2176 waiver") provides support services for Medicaid-eligibles who would otherwise live in more costly institutions. Most often, these services consist of case management, respite care, and homemaker and personal care services. Waivers are negotiated with the federal Health Care Financing Administration (HCFA) for three years and are renewed for up to five years.[113] More and more states have chosen to provide this option.[114]

> As of 1990, 41 states offered services to over 50,000 persons with developmental disabilities through this option. Although the majority of these persons are adults, Medicaid-eligible children with disabilities also benefit from this option.

Second, the Model Waiver Option (aka "50/200 waiver") allows optional services such as home care to be provided that are otherwise not included in a state's Medicaid plan. Services are provided to a small targeted population such as children who are ventilator dependent and who would otherwise need institutional care.[115] The waivers cover 50 to 200 persons in a specific target population. Home care services not normally allowed are reimbursed under this waiver. The 50/200 waiver also requires less information than the Home- and Community-Based Services waiver and is given preference in HCFA review.[116]

Furthermore, the pilot Community Supported Living Arrangements (CSLA) program was added to the Medicaid program in 1990.[117]

> CSLA services include personal assistance, training and habilitation, assistive technology, housing modifications, and other supports that help a person to take greater command of his or her life and take part in more community activities.

As of December, 1993, only California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island, and Wisconsin have operated this pilot program. The CSLA program has less stringent criteria than the HCBS waiver but is federally capped.

In addition, Medicaid's "targeted case management services" makes Medicaid funds available for case management or service coordination for the DD population:[118]

> Service coordinators help individuals access services such as health care, specialized developmental disabilities services, and other generic programs. . . . They help people obtain benefits to which they are entitled (e.g., federal and state income assistance benefits to help them meet their daily living expenses), pull together service plans and identify provider agencies who can meet the person's needs, and conduct ongoing monitoring of the health and well-being of people in the community. Medicaid funding of these services is used to leverage state money in order to improve the availability of service coordination.

There is also the Medicaid personal care option. This option can be used flexibly and broadly to meet DD needs in individuals' own homes. In Michigan and Wisconsin, Medicaid personal care money complements HCBS waiver funding.[119]

Finally, the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) disregards parents' incomes for children aged 18 and below who live at home. This is done ". . . by modifying the state's Medicaid plan in accordance with Section 134 of [TEFRA.] Although 17 states have elected this option, many apply it to a very narrow range of potential beneficiaries."[120] Choosing the TEFRA option consists merely in checking off a box and showing that the state will save money by avoiding institutionalization. However, Only 18 states use this option.[121]

In any case, system integration is hampered by the need for multiple funding sources because no one source is adequate. For example, Medicaid (absent waivers) severely restrict reimbursements for community-based services. Medicaid's intermediate care facilities for the mentally retarded (ICF/MR) requirements prevent facilities that serve fewer than four people from qualifying for ICF/MR certification and reimbursement.[122] Thus, to get flexible, tailored services to integrate the DD population into the community, there is a need to use other funding sources such as:[123]

(1) Expanded use of Home- and Community-Based Services waivers;

(2) Selected use of Medicaid state plan options;

(3) Targeted assistance to providers (to change to new services); and

(4) Flexible payment mechanisms to let consumers choose needed services while having the state pay for them.

Many DD services can also be used by other long-term care populations. For example, those funded by the the Medicaid Home and Community-Based (HCB) waiver

programs, below, are purportedly 40 percent to 50 percent less costly, on average, than institutional care:[124]

> The Medicaid HCB waiver program allows states to redirect Medicaid money that would be spent on institutional services to support a wide array of community services and supports. These include personal care/assistance, skill building, supported living, home modifications, and specialized equipment or assistance technology services to help people live in the community. Such services are furnished in family homes, people's own home[s] or apartments[s], and specialized facilities. The services a person receives via an HCB waiver program are tied to his or her needs for particular kinds of support.

Family Support Services: DD individuals living at home or in the community require family support services. Definitions of "family support" differ but the term ". . . generally means providing services necessary to strengthen a family's ability to provide care at home for a family member with a developmental disability."[125] Family DD support programs are fairly new. Early programs had four components: (1) respite care; (2) services such as case management and parent training; (3) financial assistance; and (4) a combination of financial assistance and other services.[126] According to Wright and King (1991):[127]

> Services most commonly offered are case management, respite care, parent education, home adaptations, special equipment, and transportation. Other services may include information and referral, parent and family counseling, peer support groups, homemaker services, attendant care, chore services, in-home nursing services, future planning, and cash assistance.

The following is a chart illustrating family support services.[128]

Figure 3-4

What Do We Mean by "Family Support" Services

Core Services	RESPITE AND CHILD CARE	IN-HOME ASSISTANCE	ENVIRONMENTAL ADAPTATIONS
	Respite	Homemaker services	Adaptive Equipment
	Child Care	Attendant Care	Home Modification
	Sitter Service	Home Health Care	
		Chores	
	RECREATION	SUPPORTIVE	EXTRAORDINARY NEEDS
	Recreation	Family Counseling	Transportation
	Camp	Family Support Groups	Vehicle Modification
		Sibling Support Groups	Special Diet
			Special Clothing
			Utilities
			Health Insurance
			Home Repairs
			Rent Assistance
			Vehicle Repairs

Traditional Developmental Services	Behavior Management	Medical/dental
	Speech Therapy	Skill Training
	Occupational Therapy	Evaluation/ assessment
	Physical Therapy	Nursing
	Individual Counseling	

In a 1991 study, 46 states were found to provide at least some services or other resources to families who care at home for a family member with a disability:[129]

> More than 30 different services have been identified that offer assistance to families. The most common are respite care, adaptive equipment, and family counseling. Other common services include medical, health, and nutrition services; special clothing; recreation; speech, occupational, and physical therapy; home modifications and repairs; flexible payment for disability-related expenses; and case management. Ten states have a cash subsidy program for families and 17 offer families a combination of financial assistance and support services.[130]

According to Wright and King, current reimbursement criteria for Medicaid services actually encourages institutional or other out-of-home placement for children with disabilities who need support services.[131]

> Many families who need help with support services or equipment are ineligible for Medicaid because their income level is too high, even though they many not be able to afford to purchase the needed services and equipment on their own. If the child is placed outside the home, the family's income is no longer taken into account and the child becomes eligible to receive Medicaid-reimbursed services. This policy creates severe hardship for many families who want their children with serious health problems to live at home.

Endnotes

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23. Indiana 1990, p. 27.

24. Koff, pp. 56, et seq.

25. Ibid., p. 84.

26. Ibid., pp. 65-66.

27. Ibid., p. 36 et seq.

28. Indiana 1990, pp. 28-29. The service continuum was based in part on the Continuum of Care in Indiana, prepared by the State Board of Health, and A Complete Continuum of Care for Older Hoosiers, prepared by the Indiana Association of Area Agencies on Aging.

29. Maryland Report, pp. 13-14.

30. Justice, et al., p. 97.

31. Ibid., Table V-1 "Major Services Supported by State Community Care Programs" p. 98.

32. Pieper, p. 23.

33. Justice, et al., p. 98.

34. Pieper, pp. 14, 18, & 19.

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37. Justice, et al., p. 103.

38. Ibid.

39. Ibid., p. 104. These are: (1) Wisconsin's Community Options Program; (2) Maine's Home Based Care Program; (3) Maryland's Gateway III; and (4) Oregon's Project Independence and the waiver program in Oregon.

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41. Justice, et al., pp. 104-105: In 1988, ADCC services cost from $20 to $35 a day.

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128. Bauer, p. 2, "What Do We Mean by 'Family Support,'" citing Human Services Research Institute, "Family Support Services in the United States: An End of Decade Status Report," February 1990, p. 40.

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Chapter 4

OTHER STATES

> *"[Six states] have successfully integrated their long-term care programs and developed large, statewide community care programs. These states were able to develop statewide community long-term care programs without uncontrollable state expenditures or utilization increases.... [All used t]ight eligibility requirements ... a case management system ... to control service utilization ... standardized assessment tools, standardized functional eligibility criteria, and a uniform access point to the system while allowing service packages to be determined at the local level within specified fiscal parameters. Such local flexibility encouraged creative solutions that built on unique local bases of resources, informal care networks, and service providers."*[1]

Target Populations: Long-term care is a multifaceted subject. Copious literature is available. However, relatively little deals specifically with this study's three target populations as one unified generic population. Most of the literature, not surprisingly, focuses on the elderly. There are relatively more of them who need long-term care. In comparison, material on, for example, disabled children as a distinct group requiring a rationale and comprehensive set of long-term care supports is relatively sparse. As discussed in previous chapters, there are many reasons why the categorical groupings of disabled children, disabled non-elderly adults, and frail elderly have arisen. Suffice it to say that categorical groupings are relatively entrenched.

This is not to say, however, that some degree of generic integration of the long-term care system is not possible. Indeed, there are states that have revamped or extended existing policies to coordinate and unify long-term care services. However, no state has fully and successfully implemented a totally integrated long-term care system based on generic rather than categorical criteria. Again, system *integration* is a matter of degree. Some states have taken steps to improve system *coordination*. However, even in these efforts at coordination, the literature reveals that little has been done to actively incorporate groups other than the elderly.

Single Entry Point (SEP): A parallel situation in the literature exists with the concept of a single entry point. Although some material is available, an SEP process is more often than not the subject of efforts at coordinating services only to the elderly. This is not to say that states are not aware of the possibilities of generic system integration. For example, Maryland has proposed that long-term care resources be allocated based on functional impairment and not categorically based on diagnosis or age. In any case, the idea of a single entry point often appears only tangentially, the focus being on some form of system integration or coordination as applicable to the elderly. Nonetheless, an SEP process implies some degree of system integration *(see chapters 2 and 3)*. To the extent that the broader topic of system integration holds lessons for a coordinated SEP process at a lower level, relevant material from others states is discussed. The remainder of this chapter presents material from Colorado, Indiana, North Dakota, and Texas. Also, material from Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin (the six states studied by Justice, et al.) is included.

Colorado Study

Fragmented System and Need for Coordination: In December, 1989, the Colorado Legislative Task Force on Long-Term Health Care issued the Report to the Colorado General Assembly: Recommendations for 1990. The objective of the Task Force was to "coordinate the state's fragmented long-term health care system into one that is better organized."[2] It acknowledged that long-term care services had previously been fragmented and hard to access -- exacerbated by differing and confusing program eligibility requirements. Some programs were found to be working at cross purposes and residents accessed the system from different entry points.[3] Residents were unaware of the range of available services. The application and assessment processes were burdensome and there were fewer resources in rural areas.[4] It found that home- and community-based care is often more cost-effective than traditional long-term care and is preferred by Colorado's residents. The anticipated growth in demand for such care is expected to pressure the state to better coordinate an increase in these services in an efficient manner.[5] As a result, the Task Force considered:[6]

> [t]hose services designated to provide diagnostic, preventive, therapeutic, rehabilitative, supportive, and maintenance services for individuals with chronic mental or physical conditions in hospitals, nursing homes or other alternative care settings.

Multiple Populations: The Task Force expressed a commonly-held view that although multiple categorical populations need long-term care, the elderly have the greatest impact on the system. According to the Task Force, long-term health care, although usually associated with the elderly and the disabled:[7]

> [is] a need that can be experienced by any person, at any age, in a variety of situations and can prove to be financially catastrophic. The elderly, chronically mentally ill, developmentally disabled, and nonelderly physically disabled are all populations with pressing long-term health care needs. . . . [However,] more to the point, the number of those aged 85 and older -- who are ***most likely*** to need long-term health care -- will increase significantly. This rapidly growing population of elderly over age 85, in addition to the other populations needing long-term health care, is resulting in an unprecedented demand for long-term health care services. ***[Emphasis added]***

Nonetheless, the Task Force studied issues relating to developmentally disabled persons, the disabled chronically mentally ill, the physically disabled, including the frail elderly, and emotionally or behaviorally disturbed persons.[8]

Recommendation for a Single Entry Point: Colorado is one of the few states that explicitly dealt with a single entry point. It argued that a single entry point and uniform assessment instrument "better organizes client entry, assessment, and service delivery for long-term health care. . ."[9] Being assessed for all long-term care needs at one time would make it easier for clients to access the most appropriate services and would link clients to the least costly service required to meet their needs.[10] The Task Force made nine recommendations, embodied in a number of proposed bills, the first of which relates to a single entry point:[11]

> **Concerning a Reorganization of Service Delivery for Persons in Need of Long-Term Care Through a Single Entry Point System, and, in Connection Therewith, Adopting a Uniform Assessment Instrument -- Bill 1**

> Presently, Colorado does not have a single coordinated system for providing long-term care services. Individuals and families needing long-term care services often have difficulty accessing and using the current system. The intent of Bill 1 is to better organize client entry, assessment, and service delivery for long-term health care by providing for a single entry point. A single entry point is an agency in a local community which all elderly and disabled clients must use to obtain needed publicly funded long-term care services. The Department of Social Services will be required to develop and implement a long-term care uniform client assessment instrument, in order to determine appropriate services and levels of care to meet the needs of clients.
> An assessment instrument will be administered to all clients to: assure a uniform single assessment of needs, span all long-term health care services, and integrate the collection of services into a continuum of care. The assessment instrument will also determine payment sources for such care and assist private paying clients in selecting long-term care services. In addition, the single entry point will contain the case management mechanisms necessary to control long-term care service delivery for public programs. [This case management system also operates as a managed care system in which costs are controlled via assessments and assigning of levels of care.]
> The Department of Social Services is required to conduct a comprehensive study by October 1990. This study will focus on the establishment of centralized systems at the local level for: disseminating long-term care information; consolidating long-term care resources; assessing individuals' long-term care needs; and delivering appropriate long-term care under a plan of care which includes case management.

The Task Force found that public expenditures for long-term care were reduced by systems such as an SEP process that "[p]recisely explain eligibility for various aging and medical assistance programs. . ."[12]

Single Entry Point, Common Assessment Tool, and Access to a Continuum of Care: The Task Force recommended an SEP process and a common assessment tool in order to facilitate access to different levels of care in the continuum of long-term care:[13]

> This concept will better organize client entry, and assessment and service delivery by providing clients access to the full continuum of care services. . . establishment of a single entry point in local areas for long-term health care. . . includes the implementation of a standardized client assessment procedure and an instrument to more appropriately and consistently target services to persons most in need. These changes would replace multiple forms and criteria now being utilized. Another feature . . . is targeted case management as a new Medicaid service in order to better manage existing programs and to capture additional federal resource[s] through the refinancing of current state and local dollars.

Providing a continuum of care allows individuals to remain in their homes and communities, maximizing their independence and quality of life. By accessing the system and receiving services through an SEP and based on a common assessment tool, individuals can:

(1) Move from one level of care to another in the continuum of care as their needs change over time with less chance of encountering gaps or barriers; and

(2) Receive more precisely only those services that they need and no more resulting in cost savings.

Case Management and a Single Entry Point: The Task Force compared case management for the developmentally disabled, elderly, blind and disabled, chronically mentally ill, and others. It attempted to identify commonalities among the various case

management areas by examining the structure, definition, [Bfunctions, models, recruitment of case managers, and the consumer's point of view. It concluded that:[14]

> [d]ifferences exist over the role and authority of the case manager, caseloads, rural and urban applications, outreach, access and screening. Thus, there is no available model designed to encompass the range of case management functions.

The implications are clear. Establishing an SEP that incorporates different categorical populations involves resolving many differences. Even in the limited area of case management in an SEP process, Colorado found that no model existed to address these differences. It is only logical to assume that similar differences exist for the screening and assessment components -- and that no model exists either in those two areas, nor for the SEP process itself.

Computer Expert Software System: To facilitate screening and assessment in an SEP process, the Task Force recommended the development and implementation of a long-term care uniform client assessment instrument based on a computer expert software system. This tool is to be used to determine appropriate services and levels of care which meet the needs of clients. It was found that:[15]

> [a]n additional improvement to the long-term care system will involve the use of advanced computer technology to improve the coordination of the eligibility application and determination process. As part of their budget initiative, the Department of Social Services has recommended the purchase of "expert system" software. This software can be used more efficiently to determine various human services program eligibility such as Aid to Dependent Families with Children, food stamps, Medicaid, and can be expanded to the Medicare and Supplemental Security Income programs. All state and federal statutes, and rules and regulations that impact social services programs will be contained in the system. This proposal will more precisely explain eligibility for the various aging and medical assistance programs.

Indiana Study

Long-Term Care Populations and System Integration: According to a 1990 Indiana study, the developmentally disabled, the non-elderly physically disabled, and the chronically mentally ill in that state are served by separate long-term care systems and funding sources (Department of Health, Department of Mental Health, and Department of Public Welfare-Medicaid).[16] As a result, especially with regard to an SEP process,[17]

> Any attempt to consolidate, integrate, or coordinate state long-term care responsibilities should evaluate the extent to which these other systems [that serve the nonelderly physically disabled, the developmentally disabled, and the chronically mentally ill populations] should be involved. The CHOICE [Community and Home Option to Institutional Care for the Elderly and Disabled] program serves many nonelderly, disabled persons, and future Medicaid waivers for the developmentally disabled or the chronically mentally ill could use the same assessment tool and possibly the same case management system. In addition, shared information from the same assessment tool would permit more comprehensive planning for the long-term care system.

Indiana's Department of Mental Health (DMH) serves a significant number of elderly with two-thirds of DMH funds for the elderly going to elderly patients in state mental institutions in 1989. The DMH is involved in the long-term care system because of the 1987

federal requirement to assess all applicants and existing residents of nursing homes to determine whether:[18]

(1) They have a mental illness or developmental disability;

(2) They need active treatment; and

(3) Nursing home placement is appropriate.

However, the DMH gets involved only after applicants get through the preadmission screening process of the Department of Human Services (DHS) and the Department of Public Welfare (DPW). A so-called "Level Two Assessment" which is more comprehensive is needed if a client may be mentally ill or developmentally disabled. (Level One Assessment is for applicants for nursing home placements).[19] The implication is that the addition of another impairment which may not necessarily be shared with other populations may require special actions to address unique needs. This may add to the complexity of successfully implementing an SEP process. *(See below for more multi-agency involvement.)* DMH then makes the final assessment, provides case management, offers placement choices, and develops and coordinates residential placement.[20]

CHOICE -- Indiana's Community Care Program: CHOICE is Indiana's non-entitlement[21] Community and Home Option to Institutional Care for the Elderly and Disabled Program which began in three counties in 1988. CHOICE pays for a variety of in-home services for eligible persons who are at risk of institutionalization. The goal of the program is to provide an alternative to premature placement of disabled persons in nursing homes or other long-term care facilities. Individuals are assessed for functional deficits that place them at risk of institutionalization. If eligible, care plans are developed and appropriate services are brokered by case managers. CHOICE pays for:[22]

(1) Case management;

(2) Homemaker services;

(3) Home health care and supplies;

(4) Home-delivered meals;

(5) Attendant care;

(6) Transportation;

(7) Adult day care; and

(8) Respite care.

Disabled Non-Elderly: The CHOICE program is not limited only to the elderly. CHOICE funds are available for persons with disabilities who are under age 60. This younger segment comprised 18 percent of CHOICE clients in FY 1990, and utilized 21 percent of CHOICE service dollars. In Allen County, 31 percent of CHOICE clients are under age 60.[23] The statute governing the CHOICE Program (IC 4-28-6.1) grants eligibility to a person who:[24]

is a resident of Indiana and is:
(1) at least sixty (60) years of age; or
(2) is disabled;

> and qualifies under criteria developed by the [CHOICE] board as having an impairment that places the individual at risk of losing the individual's independence.

However, CHOICE targets those at imminent risk of institutionalization. To be eligible, clients must have at least one substantial medical condition or at least three activities of daily living (ADL) limitations.[25] Since most people in this group are 85 years of age and older, there may be some practical limitations on the funding of care for the disabled non-elderly. This notwithstanding, CHOICE guidelines and procedures for AAAs require that at least 20 percent of CHOICE case service dollars be used for persons under age 60 who meet CHOICE eligibility requirements. Non-elderly individuals with significant but stable disabling conditions may need CHOICE-funded service over an extended period. Their lengths of stay on the program are likely to exceed those of many elderly clients whose conditions may deteriorate more rapidly.[26]

Medicaid Waiver Program: Indiana also has a "2176 Medicaid waiver" to provide services normally not reimbursed by Medicaid. Services are targeted to Medicaid-eligibles aged 65 or older or disabled and who would otherwise require institutionalization paid for by Medicaid. Service costs must be less than 90 percent of Medicaid nursing home costs. Waiver services include items (1), (2), (4), (5), (7), and (8), above, in addition to home modifications and adaptive aids and devices. Waiver participants are screened with the same screening tool by the same personnel who administer the CHOICE program. Furthermore, the same assessment and care planning tools that are used for the CHOICE program are used for the waiver program.[27] However, because two departments are involved, the DHS and the DPW:[28]

> [w]ill need to work closely together in implementing the new waiver. . . . DHS will be responsible for case manager training, training for independent in-home providers, and provider quality assurance efforts. Claims processing for waiver services will be handled through DPW and the medicaid fiscal intermediary. DPW will be ultimately responsible to the federal government for monitoring and assuring the need for provision of and quality of waiver services reimbursed through Medicaid. CHOICE claims will be processed through DHS. Separate management information, accounting, and auditing systems will be utilized.

The extent of the coordination needed can be seen from a description of the cross-responsibilities among Indiana's state agencies:[29]

Figure 4-1

Indiana Long-Term Care Responsibilities

	Board of Health	Public Welfare	Human Services
Planning and Policy Development	-Certificate of Need (nursing bed supply) -Quality of care policy -Health planning	-Facility reimbursement policies	-Community care policies and planning
Quality of Care/Consumer	-Nursing home certification	-Nursing Home Medicaid	-Quality of community care

Protection	and licensure -Home health agency licensure	reimbursement	-Ombudsman Program -Adult Protective Services
Advisory Bodies	-Health Facilities Council -Indiana Veterans' Home Advisory Committee	-Medicaid Advisory Committee	-Commission on Aging -State Advisory Commission on Aging -Alzheimer's Task Force -CHOICE Board
Service Funding	-Indiana Veterans' Home appropriations -Preventive Health Block Grant Funds	-Medicaid -Medicaid Community and In-Home Waiver Program -Room and board assistance -Assistance to residents of county homes	-CHOICE -Older American's Act Funds -Social Services Block Grant -Older Hoosier's funds -Alzheimer's funds
Local Service Delivery	-Local Health Depts. -Indiana Veteran's Home	-Nursing homes -Residential facilities -County homes -County welfare offices (Medicaid waiver)	-Area Agencies on Aging -Community Care Agencies
Assessment/ Eligibility	-Indiana Veteran's Home	-Department of Public Welfare	-Area Agencies on Aging -Pre-Admission Screening

Single Entry Point: Regardless of system fragmentation, however, an SEP can be implemented in a cabinet system *(see chapter 2 for discussion of the "cabinet" and other models of administrative structure).* Indiana's system is not integrated although it was recommended that it move in that direction. That state has used an objective preadmission screening and case management tool[30] that has increased credibility and awareness of community options. With reference to a single entry point itself, the Indiana Legislative Services Agency recommended that:[31]

> System access, client assessment and local service delivery should be integrated through one local agency. The Area Agencies on Aging (AAA) currently serve this role in Indiana. Case management is the focal point of this local system both facilitating access to needed services and serving as a gatekeeper to state funding. Issues identified include funding for case management, provision of in-home services by AAA's, *[sic]* integration of the RBA [Room and Board Assistance] and ARCH [Assistance to Residents in County Homes] residential care programs into

the local case management system, and the role of the Indiana Veteran's *[sic]* Home.

Indiana's approach reflects multiple aspects of long-term care access. Naturally, improved ease of access is a goal. In addition, it aims at some degree of integration of service delivery and cost savings via a managed care philosophy.

In a 1991 follow-up study, Indiana reported that:[32]

> Recent administrative changes have integrated client access to long-term care funding sources:
>
> - *The AAA case management system has been designated as the single point of entry for most publicly funded long-term care services;*
> - AAA case managers determine who is eligible to receive publicly funded services and serve as brokers of services for clients, utilizing a pool of resources from a number of funding sources;
> - A single screening and assessment tool is used for all funding programs; and
> - Clients receive services through the following process: referral, assessment and eligibility determination, care plan development, brokering of services, and monitoring and reassessment. *[Emphasis added]*

Consolidation of Services and Funding Sources Into Local Agency: Before service integration in Indiana, state and federal funds were available only through the service provider who got funds directly from the state or through AAAs and who had their own intake and assessment processes. AAAs' case management functioned more as an information and referral service than as a gatekeeper which can authorize services. Local service providers determined client eligibility and provided service within funding constraints. The single entry point resulted in two changes:[33]

(1) It pooled more resources and designated the 16 regional AAAs' case management system as the point where clients are matched with services; and

(2) AAA case managers now serve as brokers in purchasing services for clients, using a pool of resources from several funding sources.

Indiana delegates significant authority to AAAs to encourage flexibility in addressing local circumstances. At the same time, the state maintains fiscal and program accountability by linking delegation of authority with specific budget allocations, program eligibility criteria, service cost limitations, and audit requirements. The AAAs, facilitating the single entry point process, are responsible for:[34]

(1) Serving as the single point of entry for clients for most publicly-funded, long-term care services;

(2) Deciding, based on established eligibility criteria, who will be served with long-term care funds;

(3) Matching appropriate in-home and community-based services to clients' individual needs and monitoring service provision;

(4) Conducting local needs assessments and planning activities and, where identified, encouraging or coordinating development of needed services and programs; and

(5) Assuring the quality of in-home and community-based long-term care services.

With this delegation of authority to local AAAs, the DHS's role has become one of planning, monitoring, and providing technical assistance. A model for this new relationship between the state and the AAAs is the CHOICE program. AAAs are local nonprofits which were already involved in providing and funding in-home services. They already had an established case management system and were responsible for screening persons seeking admission to nursing homes. In addition, since AAAs are not "governmental agencies," they do not carry a "welfare" stigma, an anathema to senior citizens. They also have an ability to react quickly and creatively to local needs and circumstances.[35]

Development of an effective system for monitoring fiscal and program accountability of AAAs will be essential. However, this must be balanced against the benefits of encouraging local flexibility and creativity. In addition, the dangers of state-level micromanaging and the cost of imposing unnecessary paperwork and reporting requirements must be resisted. Based on an annual plan, AAAs are given CHOICE budgets, responsibility for developing and reimbursing a network of providers, and flexibility in designing individualized service packages for clients. However, this autonomy is provided within clearly specified parameters of average costs per client, caps on expenditures per client, and clearly delineated eligibility criteria. As AAAs assume increasing fiscal and operational responsibilities, the state must assume greater responsibility for providing technical assistance, consultation, and training.[36]

As part of the SEP process, consolidating scarce funding resources enables the long-term care system to target those most in need. AAAs serve this function in three ways:[37]

- AAAs receive and allocate federal and state funds to local service providers based on an assessment of local service needs.
- AAAs determine client eligibility for state and federally funded in-home and community-based services through their case management system, assess client needs, and broker needed services for these clients.
- AAAs serve as gatekeepers to the institutional long-term care system through the Preadmission Screening Program (PAS).

Preadmission Screening: As mentioned above, Indiana uses a preadmission screening (PAS) instrument that, along with the case management system, is at the core of Indiana's single entry point:[38]

> The appropriateness of all nursing home admissions must be determined through the Preadmission Screening (PAS) process.
>
> - AAA case managers conduct the screenings, using the same eligibility screening instrument as for [other in-home programs,] CHOICE, and the [Aged and Disabled Home and Community-Based Services] Medicaid Waivers; and;
> - The Department of Public Welfare [separate from the DHS] makes the final PAS determinations.

The following summarizes the steps in a preadmission assessment in Indiana's long-term care system:[39]

- A person applies for admission to a nursing home. Referrals may come from hospital discharges, SNFs, families and other informal caregivers, elders agency staff, health providers, etc.

- The nursing home notifies the person that application must be made to the AAA in the area for a PAS assessment.

- The AAA case manager visits the person (in the hospital or nursing home prior to discharge, or in the person's own home if home-bound), conducts an assessment [clients no longer need to undergo multiple assessments due to different funding categories] of the person's need for a nursing home placement using the Long-Term Care Services Eligibility Screen,[40] analyzes the cost of alternative in-home services, and presents the alternatives to the consumer. In greater detail, information is obtained about ADLs, medical and support services needs, and types, amounts, and cost of services that would be necessary if the person is to avoid nursing home placement.

- The AAA case manager reviews the information obtained in the assessment with the three-to-five-member PAS multi-disciplinary team. This team includes the consumer's physician, the AAA case manager, and from one to three other persons who are familiar with the needs of persons seeking nursing home admissions.

- The team decides by majority vote to recommend whether the nursing home placement is appropriate or inappropriate. The person must have one of seven severe medical conditions or three of 16 limitations of activities of daily living to be eligible for placement in a nursing home or for participation in the CHOICE or Medicaid Waiver Program. Response time for the frailest or most vulnerable may be just one day compared to possibly a week for a person with less immediate needs. There are no functional eligibility requirements to qualify for Social Services Block Grant (SSBG) or OAA Title III in-home services funding. However, AAA case managers use the same Screen to target these funds to clients who have at least one of nine limitations of IADLs or who meet at least one of three measures of the lack of informal supports. SSBG and Title III funding must be used before CHOICE or Medicaid Waiver funding for clients eligible under these programs.

- The recommendation is sent to DPW.

- Staff at DPW review the information and the recommendation and make a final determination as to whether the admission will be approved or denied.

- DPW provides written notification to the applicant and the AAA regarding its determination. Since Medicaid requires freedom of choice of providers, a Medicaid-eligible person can still choose to be admitted to a nursing home, if the criteria are met, regardless of the cost of alternative community services.

- If admission is denied, the applicant can appeal the decision to DPW through an established appeals process.

When authorized by the AAA, PAS assessments can be completed after admission to the nursing home under the following circumstances:[41]

- The person is admitted directly from a hospital or inpatient bed of a community mental health center after the assessment is substantially complete, if alternative community and in-home services are not available. The person can remain in the facility without having to complete the assessment for the lesser of the estimated recovery time, plus 25 days, or 120 days;

- If the AAA determines that the person will probably be discharged from the nursing home within 30 days of admission; and
- If the AAA determines that serious harm to the physical or mental health of the person would result if the person must wait for approval.

Denial of Admission to Nursing Homes: The circumstances under which a person can be denied entry to a nursing home consist of the following:[42]

(1) The person's condition does not meet the level of care requirements for intermediate or skilled care as specified in Indiana Administrative Code; or

(2) If requirements are met but alternative community services are available and sufficient and the cost of those services does not exceed 75% of cost of nursing care.

The Preadmission Screening Process -- Benefits: It was argued that the PAS process results in cost savings: "Cost savings occur even when the Medicaid Waiver is used, since the cost of Waiver services must be less than the cost to Medicaid for nursing home care."[43] In addition, in 1989, 219 persons, some of whom were Medicaid-eligible, were diverted from nursing homes to alternative in-home services:[44]

> In 1989, a total of 67 persons were denied admission to nursing homes who either were Medicaid recipients, had applied for Medicaid, or who were expected to apply for Medicaid within one month. If each of these persons had been in a nursing home for a full year at an intermediate level of care, the cost of Medicaid in 1989 would have been approximately $1.25 million. The state cost would have been approximately $450,000. The state cost for home care services for these patients is not known. However, only $122,000 of state funds are currently being spent on the PAS program. The cost savings to the state for diverting private pay admissions are not as immediate. Personal and public funding may be expended for in-home services for these persons if they are diverted. If they had been admitted, only personal funds would be used until the persons had spent down their income and assets to the level of Medicaid eligibility.

Furthermore, aside from cost savings, the Indiana study summarized non-quantifiable benefits of a PAS process (including case management) -- in other words, the single entry point system:[45]

- PAS makes nursing home applicants and families aware of in-home services and funding sources. AAA case managers are responsible for establishing in-home service plans for patients who can remain at home. With CHOICE and Medicaid Waiver funding resulting in the development of more community services, diversions are expected to increase.
- PAS provides an opportunity for persons admitted to the nursing home for only a convalescent stay to begin planning for in-home services when they return home.
- PAS prevents inappropriate use of Indiana nursing homes by Kentucky or Ohio Medicaid-eligible residents [which have moratoriums on nursing home beds].
- PAS provides an informal check on quality of care in nursing homes when AAAs case managers visit nursing homes to conduct PAS assessments. AAAs provide nursing home ombudsman services in their areas.
- PAS provides a means of identifying persons in need of adult protective services.

- PAS creates a greater awareness and credibility among family, the medical community, hospital discharge planners, and others regarding in-home and community-based options.

- The objective assessment of needs provided by PAS helps relieve the guilt of family members for placements of spouses and parents.

- PAS provides a consistent and reliable means of obtaining information on demographic and functional characteristics of nursing home applicants that is useful for planning purposes.

The Preadmission Screening Process -- Disadvantages and Streamlining: On the other hand, it is acknowledged that there are drawbacks to the PAS system. Chief among these are that:[46]

> [t]he process is cumbersome, time consuming, and overly bureaucratic. The oversight function provided by DPW is overburdened, resulting in delays in completing the PAS process. At the local level, a three to five member screening team must be developed and coordinated. Paperwork must flow between AAAs and DPW for each of the 30,000+ PAS assessments conducted annually. AAAs indicated that state funding for PAS does not cover the costs of the program.

As a result, it was recommended that the following steps be taken to streamline the PAS process:[47]

- Eliminate the requirement that a multi-disciplinary team be created to conduct assessments. . . . A screening team consisting of the AAA case manager and the person's physician should be sufficient.

- Eliminate the requirement that DPW make the final determination on all PAS applications. With the new, more objective, screening tool, AAA case managers should be able to make these determinations.[48]

- Change the requirement that placement can be denied when the cost of alternative services is less than 75% of the cost of nursing home care to less than 90%. This requirement would then be consistent with the Medicaid Waiver, which can only be used if in-home services are less than 90% of the Medicaid cost of nursing home care. Such change would reduce the number of forms and cost comparisons required . . . and would establish a direct link between PAS and the Medicaid Waiver.

Case Management -- Functional Assessment and Care Planning: Once eligibility is determined, the case manager uses a functional assessment tool developed by DHS to obtain information about the client's service needs and resources:[49]

> The eligibility determination and functional assessment [are] conducted in the client's home, which allows the case manager to see how the person lives, any difficulties experienced in cooking or housekeeping, home repair needs, and any structural conditions of the dwelling that may prove limiting, such as wheel chair accessibility or bathroom layout.

Based on the assessment, a care plan is developed for each client. Care plans can be very simple -- for example, for clients needing only one service funded through OAA Title III (e.g. home-delivered meals). Or they could be very extensive for persons who need services funded through the Medicaid Waiver. The care plan identifies all of a client's service needs. The case manager and the client, or the client's family, decide how these service needs can be met. Once a client's available family support is identified, services and assistance to be

purchased with state and federal funding can be specified.[50] Funding of in-home and community-based services is not meant to replace existing informal family supports from family, friends, and neighbors but to augment and support them. The care plan includes identification of funding sources including OAA Title III and SSBG funds which are used before Medicaid Waiver and CHOICE funds. The final part of the care plan:[51]

> [i]dentifies the service provider, including whether the service is paid or unpaid, the location of service provision, the amount of services required on a daily, weekly, or monthly basis, and the funding source and amount for each paid service. The care plan also specifies how frequently the case manager will be in contact with the client once the care plan is implemented.

Service Delivery -- Brokering of Services: Once the care plan is developed, the case manager authorizes the purchase of the specified services and arranges with a local service provider for their delivery. Some clients are involved in selecting the provider and arranging the delivery of services. Younger clients and parents of minors eligible for CHOICE funding often are more actively involved. For Title III, SSBG, and the CHOICE program, AAAs are responsible for selecting service providers and negotiating unit rates paid for each service. All providers must meet criteria and standards established by DHS for each service component. These criteria address such factors as staff training, expertise, and supervision. Clients can also use family members (other than spouses), friends, neighbors, or other individuals to provide CHOICE and Medicaid Waiver-funded services, such as homemaker, personal care, or respite care. To be compensated by CHOICE or the Medicaid Waiver, these persons must complete a training program developed by DPW and DHS. *(Under the Medicaid Waiver, clients may choose Medicaid-certified providers. Rates established by the DPW during the certification process must be at or below caps previously set for each service.)*[52]

Monitoring and Reassessment: Fiscal accountability and quality assurance tasks also fall to the case manager who accomplishes this through the monitoring of authorized service delivery. The DHS quality assurance program for in-home services relies on standards for agencies providing the service and on monitoring of direct care staff by these agencies. Monitoring of care provided by non-agency staff is more difficult, especially for clients without regular family contact or involvement.[53]

Clients must be reassessed on a regular basis to assure their continuing eligibility for funding and to make necessary adjustments to their care plans:[54]

> For CHOICE-funded clients, the case manager must have a face-to-face contact with the client within 30 days of the start of services and every 90 days thereafter. At these 90-day intervals, continued eligibility for services is determined, care plans are reviewed, and services are reauthorized. Clients receiving Medicaid Waiver-funded services must be reassessed and care plans reviewed every 90 days.

North Dakota Study

Long-Term Care Reform: In 1987, North Dakota issued a report entitled Long-Term Care: Issues and Recommendations. The study was based on the conviction that a balance of institutional and non-institutional care and support services is the best way of meeting the needs of North Dakota's older adults. The need for an interagency task force to conduct the study is an indication of the major effort that will be necessary to implement long-term care reform that includes an SEP. Members of the North Dakota Interagency Task Force on Long Term Care represent that state's Department of Human Services, Department of Health, and

the Governor's Office. The study based its evaluation of broad issues concerning long-term care in North Dakota and the nation on a needs assessment study of long-term care needs in the Drayton service area. *(Note: Although the Task Force stated that long-term care entails a wide array of social and health services that can be used "by young and old alike," its work dealt only with the needs of "North Dakota's older adults." This likely reflects the circumstances in most states: although efforts are made to include the non-elderly, the dominant numbers of the elderly command the most attention.)*[55]

Findings of Policy: The Task Force felt that the Drayton study ". . . demonstrated a need to examine the structural, functional, financial and social concerns that undermine *[sic]* a comprehensive and fluid long term care delivery system in North Dakota."[56] The Task Force wisely recognized that "the long-term care system is extremely complex and cumbersome" and that they "did not have all the answers to all of the long term care issues or problems."[57] Nonetheless, it did make findings and recommendations, some of which related to a single entry point. In general, the Task Force found that North Dakota needs to express as state policy the following findings relevant to the present study:[58]

- *Access to appropriate long term care services for older adults will be improved through providing a central point of entry.*
- A balanced continuum of long term care services will best meet the needs of North Dakota's older adult population.
- The functional limitations and needs of the older adult population will serve as the principal criterion for the use of long term care services or the development of additional long term care services.
- Families, as the principal caregivers to older adults, will be supported. *[Emphasis added]*

The Task Force contends that the public has limited knowledge of what services are available and how each service fits into the broader continuum of care. As a result, the public does not know how to obtain appropriate services from many different long-term care providers offering different types of services.

Recommendations: The Task Force made several recommendations aimed at streamlining, simplifying, and consolidating North Dakota's long-term care system. To the extent that a single entry point facilitates each of these goals, the following were recommended:[59]

- *A single point of entry to the system of long term care be recognized and used, and that a system of case management be established and used.*
- Federal and state dollars for long term care services be pooled in state government and dispersed on the basis of the functional needs of clients.
- Passage of legislation that will improve access to in-home and community-based services by [among others]:

  (1) Extending eligibility standards through assessments of functional impairment rather than assessing the likelihood of institutionalization;

  (2) Moving to a system of case management within the communities and preadmission assessment of all applicants for nursing home care. *[Emphasis added]*

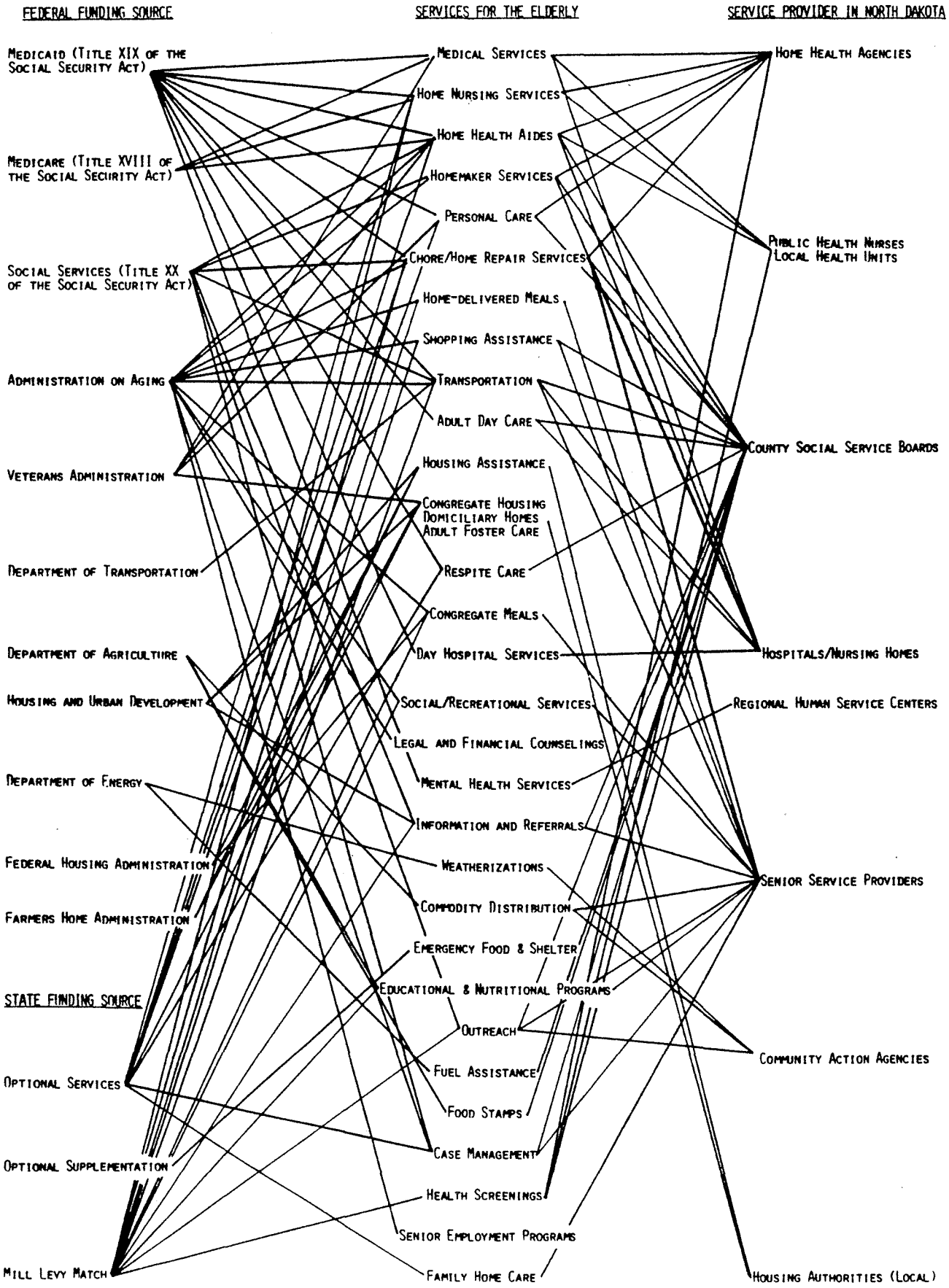
The main impetus for the single entry point recommendation is the ignorance of North Dakota residents regarding the range of services available. Contributing to the difficulty of access to long-term care services is the fragmentation of the system. As discussed in previous chapters, much of this fragmentation developed historically due to categorical funding restrictions. One method to reduce this fragmentation, and also facilitate access, is to consolidate federal and state funding resources so that service delivery can be simplified. A great amount of interagency coordination, however, is necessary. Similar to Figure 4-1 (depicting system fragmentation in Indiana), Figure 4-2,[60] below, is a further example of such fragmentation depicting federally-funded services for elders that are provided by North Dakota providers. Note that this chart does not include long-term care services for other populations nor does it include state-funded programs.

SEP -- Preadmission Screening and Case Management: The SEP recommended by the Task Force is meant to coordinate services among providers and to oversee the pooling and disbursement of disparate funding streams. These goals are to be implemented through statutorily mandated preadmission screening and assessment and a case management program. The assessment team, consisting of at least a registered nurse and licensed social worker would focus on functional limitations. The case manager would match services to client needs and oversee service delivery.[61] Fragmentation and lack of uniformity of service delivery at the county level is evidenced by the availability of different community-care services in different counties. For example, almost every county offers homemaker and home health aide services, but only half offer chore services and fewer still offer adult day care.[62] Similar to other SEP schemes, the preadmission screening teams are recommended to be located in case management agencies, usually under county social service boards. Alternatively, they could be publicly or privately contracted for.

Need For Public Awareness: Another common function of systems with an SEP process -- to be performed by case management agencies -- is the education of the public to make them aware of long-term care service options. The public's ignorance reflects the historical emphasis on institutional care as opposed to in-home and community-based supports. Despite official support for non-institutional services, access to these preferred services may be limited if the target populations and their families are not aware of them. An SEP would contribute to heightened awareness of nursing homes as the "alternative" and community supports as the service of choice:[63]

> Certainly a major reason for the public's limited awareness of the spectrum of services lies in the traditional provision of these services as "alternatives" to nursing home care. A Comptroller General's report to Congress notes that health care professionals tend not to recommend such options "because they do not have the expertise and time to arrange for community care."

Figure 4-2


FEDERAL FUNDING SOURCE
SERVICES FOR THE ELDERLY
SERVICE PROVIDER IN NORTH DAKOTA
MEDICAID (TITLE XIX OF THE SOCIAL SECURITY ACT)
MEDICARE (TITLE XVIII OF THE SOCIAL SECURITY ACT)
SOCIAL SERVICES (TITLE XX OF THE SOCIAL SECURITY ACT)
ADMINISTRATION ON AGING
VETERANS ADMINISTRATION
DEPARTMENT OF TRANSPORTATION
DEPARTMENT OF AGRICULTURE
HOUSING AND URBAN DEVELOPMENT
DEPARTMENT OF ENERGY
FEDERAL HOUSING ADMINISTRATION
FARMERS HOME ADMINISTRATION
STATE FUNDING SOURCE
OPTIONAL SERVICES
OPTIONAL SUPPLEMENTATION
MILL LEVY MATCH
MEDICAL SERVICES
HOME NURSING SERVICES
HOME HEALTH AIDES
HOMEMAKER SERVICES
PERSONAL CARE
CHORE/HOME REPAIR SERVICES
HOME-DELIVERED MEALS
SHOPPING ASSISTANCE
TRANSPORTATION
ADULT DAY CARE
HOUSING ASSISTANCE
CONGREGATE HOUSING
DOMICILIARY HOMES
ADULT FOSTER CARE
RESPITE CARE
CONGREGATE MEALS
DAY HOSPITAL SERVICES
SOCIAL/RECREATIONAL SERVICES
LEGAL AND FINANCIAL COUNSELINGS
MENTAL HEALTH SERVICES
INFORMATION AND REFERRALS
WEATHERIZATIONS
COMMODITY DISTRIBUTION
EMERGENCY FOOD & SHELTER
EDUCATIONAL & NUTRITIONAL PROGRAMS
OUTREACH
FUEL ASSISTANCE
FOOD STAMPS
CASE MANAGEMENT
HEALTH SCREENINGS
SENIOR EMPLOYMENT PROGRAMS
FAMILY HOME CARE
HOME HEALTH AGENCIES
PUBLIC HEALTH NURSES
LOCAL HEALTH UNITS
COUNTY SOCIAL SERVICE BOARDS
HOSPITALS/NURSING HOMES
REGIONAL HUMAN SERVICE CENTERS
SENIOR SERVICE PROVIDERS
COMMUNITY ACTION AGENCIES
HOUSING AUTHORITIES (LOCAL)

Texas Study

Program Audit of Long-Term Care Services: In 1992, the Office of the State Auditor of Texas issued its Program Audit of Long-Term Care Services to the Aged and Disabled. Among other things, the Texas Auditor reviewed the extent, including gaps and duplications, of community programs and services available that offer an alternative to long-term institutional care for the aged and disabled. However, the Texas Auditor specifically excluded a review of programs that target persons with mental retardation or developmental disabilities.[64] The Texas Department of Human Services (TDHS) is responsible for the long-term care system. Current services offered range from congregate and in-home meals to more intensive services such as personal care and those that provide a limited amount of nursing care.[65] The Texas Auditor states that community care programs generally offer services to more persons at a lower cost in comparison to nursing facility care. However, as demand for services increases in Texas, that state must anticipate those needs, including nursing bed capacity. Consequently, planning is essential. Legislative initiatives have also been taken to ensure the delivery of health and human services in a coordinated and integrated manner.[66]

Fragmentation of Services: The Texas Auditor illustrates the degree of long-term care service fragmentation by summarizing as follows:[67]

- **Meals** are provide by five different agencies through eight separate programs.
- **Transportation** is provided by six different agencies through eight separate programs.
- **In-home services** are provided by three different agencies through six different programs.
- **Residential services** are provided by four different agencies through six separate programs.
- **Personal Attendant Services** are provided by two different agencies through three separate programs.
- **Day care/respite care** is provided by five different agencies through three separate programs.

This fragmentation is fairly typical of many states seeking to reform their long-term care systems through coordination or integration of services, funding, and providers. Paralleling similar trends in other states, Texas has moved away from institutionalization to home- and community-based care.[68] The Texas Auditor acknowledges that the TDHS has made large strides in providing such community-based services.

Barriers to Effective Service Delivery: However, several barriers to effective service delivery were identified. One of these was the lack of a uniform method of evaluating the long-term functional needs of elderly and disabled Medicaid clients. Another is that the community care and institutional care programs are treated as separate systems instead of programs on a single continuum of long-term care.[69] Both programs are operated by the TDHS. Although both programs measure functional disabilities of clients, the Texas Auditor found that they interpret the results differently:[70]

> Each system aggregates and assigns different weights to the data, thus the data cannot be compared. As a result, the functional levels of the two populations

> cannot be accurately compared, and the Department loses information that would be valuable for planning for future needs, for determining current range of needs, and for monitoring the consistency of the regional planning function.

Recommendation for an Integrated Service Continuum: According to the Texas Auditor, a more integrated system would help remove some of these barriers. The recommended new system administered by the newly created Health and Human Services Commission would determine client eligibility and increase services. In addition, it would provide needed resources by increasing availability and diversity of long-term care programs in settings that focus on community-based services with options ranging from their own home to total-care facilities. The new system would stress coordination of services between state agencies so that existing community resources can be used for those in nursing homes who would otherwise opt for community living. As a result, the Texas Auditor recommended that:[71]

> All long-term care programs should be integrated into one continuum of care . . . and functional assessments should be made as comparable as possible. We also recommend that this information be used to determine whether long-term care clients are being served at the optimal and most appropriate level.

The Texas Auditor recommended that the TDHS take the lead to develop or utilize a single functional assessment for recipients of long-term care services and by providing guidance to the regions for needs assessment. [72] Implementing this recommendation would further the twin goals of expanding community care services and delaying institutionalization. A uniform functional assessment will also help save money. If Medicaid nursing home patients are functionally assessed or pre-screened before admission, costly inappropriate admissions can be detected and routed to community care options. Clients would also become more aware of all the options in the long-term care system and thus have a better chance of receiving the most appropriate level of care.

However, the Texas Auditor warns that without the necessary uniform data, it would be difficult to plan and budget for long-term care needs, whether community-based or institutional. The implication is that interagency cooperation is needed to obtain that data, assuming that a more integrated system is approved and embarked upon. Thus, the need for a uniform method of screening and assessment. However, no specific mention is made of a single entry point. Furthermore, functional assessments are already being used (their use just needs to be coordinated). Even so, this points to the, by now, familiar troika of coordinated preadmission screening, assessment, and case management that is embodied in an SEP process.

Ironically, the preference for community care gives rise to a pragmatic warning. As an alternative to nursing facility care, community care programs generally offer services to more persons at a lower cost. However, unlike nursing facilities, some community care programs are not eligible for federal matching funds. So while community care programs are perceived as being preferable to institutionalized care in a nursing facility, funding may not be available to meet the demand for services in this area.[73] *(Note: This is a familiar caution raised by several states including Hawaii. The "hype" of home- and community-based care in favor of nursing home care now relegated to "alternative" status must not obscure the need for necessary funding. Policy for the sake of policymaking not backed by hard dollars needlessly raises false hopes for those persuaded of a policy's merits.)*

It was further recommended that a coordinated six-year strategic plan for health and human services be developed. The plan is to include the creation of a continuum of care and the integration of health and human services to provide efficient and timely service delivery.[74]

Medical Services Program for Disabled Children: The Bureau of Crippled Children's Services of the Texas Department of Health administers the Crippled Children's Services (CSS) Program serving chronically ill and disabled children. The CSS is a *medical* services program designed to identify and *medically* assist children who might otherwise be unable to benefit from present or future educational or employment opportunities. To be eligible, children must have severe medical problems as specified by law. They must also be expected to improve medically and functionally.[75] Services provided by CSS program-approved physicians, dentists, hospitals, and ambulatory surgical centers include:[76]

- Initial exams for early identification of children with severe medical problems.
- Medical diagnosis and evaluation.
- Rehabilitation services.
- Limited dental evaluation and treatment.
- Durable medical equipment and supplies (wheelchairs, and prosthetic devices).
- Medications.
- Speech, physical, and occupational therapy.
- Limited transportation.
- Limited meals and lodging.

Access and System-Related Recommendations: In 1987, the Texas Senate Committee on Health and Human Services conducted a study concerning these children's needs and made several recommendations. Of the six major recommendations made by the Committee, two have a bearing on the present study's focus on system access and system coordination:[77]

- Availability and accessibility to regionalized medical case management should be increased.
- Increased interagency coordination is needed to facilitate more cost-effective use of limited funds and provide less fragmented care.

The Committee reported that regional case management centers are effective in providing early identification, intervention, and treatment of early childhood illnesses. The Committee argues that the term "case management" in itself implies the provision of comprehensive, cost-effective, and coordinated treatment and services.[78] To the extent that cases are otherwise not "managed" this is true enough. Although services are still *medically* related, case management for disabled children in Texas also includes the second component of service coordination. The pediatrician who formulates the treatment plan is usually the medical manager. The service coordinator is concerned with coordinating "a broad range of service needs with the family and associated providers."[79] However, it is unclear and somewhat doubtful whether these include the normal set of in-home and community-based long-term care supports. One example of case management assistance given is that of

helping disabled children in remote areas to find the appropriate physicians for diagnosis, evaluation, and medical rehabilitation.[80]

Benefits of Regionalized Case Management: In any case, the Committee argues that regionalized case management results in less fragmented service delivery -- one of the merits of an SEP process. The Committee also contends that regionalized case management decreases hospital days of care and reduces the need for emergency medical services. Parents lose fewer days of work because regional case managers are able to find providers closer to home. In turn, this reduces the overall demand for CSS services.[81] Of course, case management is one of an SEP's three usual components, the other two being uniform preadmission screening and assessment. The "regionalized" aspect of case management referred to implies some degree of integration and uniformity within a specific geographic area perhaps similar to uniform local entry points.

Interagency Coordination: The Committee also recommended more cooperation and coordination among agencies serving disabled children in order to improve service linkage and to optimize the use of public funds. The primary agencies include the Department of Health, the Department of Human Services, the Texas Education Agency, the Texas Rehabilitation Commission, and the Texas Youth Commission. Each of these agencies serves disabled children to differing degrees and for different purposes, resulting in service coverage that is fragmented and duplicative. Families need centralized, comprehensive treatment plans. Interagency coordination (assisted by case management) would make it easier for families to use various resources as well as provide more efficient and medically appropriate treatment.[82]

Consequently, the Committee recommended that the Department of Health be the lead agency in an interagency effort to, among other things:[83]

- Coordinate, design, and implement a medical reporting and tracking system to identify and refer all children with chronic and debilitating conditions to a case management program. The Department of Health should be responsible for coordinating and conducting case management and should include only medical and social services related to the medical condition.
- Identify and eliminate any duplicated screening, diagnosis, rehabilitation, payments, and other health/social services related to the medical condition for children with chronic and debilitating conditions.
- Update interagency agreements.

The Six Study States

Study of Long-Term Care Reform in Six States: In 1988, the National Governors' Association published a study authored by Diane Justice,[84] et al., of long-term care reform in Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin.[85] Although long-term care was examined only in the context of the elderly population, the study's findings are instructive. To the extent that preadmission screening, assessment, and case management are the subject of reform, they are relevant to a discussion of an SEP process.

All six study states have implemented statewide community care systems that have integrated multiple resources and consolidated policy and management control of services at the state and local levels. All states use a combination of resources to support their long-term

community care systems even though it would be much easier to use only one funding stream and thereby avoid the multitude of rules and restrictions that accompany each program. Due to these convoluted restrictions, particularly those associated with Medicaid, no single source is flexible or large enough to support a comprehensive long-term care system.[86] Instead, states use a patchwork of multiple programs financed by multiple funding streams. Most of the study states have designated a single local agency in each part of the state to serve as the client access point for receipt of all publicly financed community care program services. Centralizing entry helps make the system less fragmented from the client's perspective while helping states gain better control of program costs.

Preadmission Screening, Assessment, and Case Management: According to Justice, et al.:[87]

> *Client assessments, preadmission screening programs, and case management are the key components of access systems for community based care programs. [Emphasis added]*

Most of the six states provide services only to those elderly who have functional impairments, as determined by client assessments, equivalent to those required for nursing home admission. However, the scope of preadmission screening among the six states varies widely. One difference is whether only Medicaid-eligibles comprise the required target population or whether a broader population should be included. Another is whether decisions resulting from the screening process are binding or advisory. All states operate case management systems. Three (Arkansas, Maine, and Oregon) have selected Area Agencies on Aging as their case management agencies. Wisconsin and Maryland have designated their county social services departments. Illinois used local agencies chosen on a competitive basis. Case management and assessment agencies are the only client access point for receipt of services through the major community care programs in the study states. By design, the six states allow flexibility in providing different types of publicly funded services.[88]

Advantages of an SEP Process: All six states have expanded community-based care services without generating runaway costs in total long-term care spending. Total costs have risen over a five-year period. However, increases are modest, averaging 6.2 percent annually per person age 75 and older.[89] Several factors contributed to containing overall costs:[90]

- Limiting program eligibility to persons who have multiple limitations in conducting activities of daily living.
- Using a managed care approach to authorize the amount and scope of services needed by individuals.
- Establishing cost sharing provisions for moderate-income persons.

Of course, an SEP process embodying preadmission screening, assessment, and case management is a natural vehicle for implementing tight uniform eligibility criteria. It is also conducive to managing the authorization of appropriate services. Consistency and accountability can be maintained statewide without sacrificing flexibility at the local level in meeting unique individual needs. This was achieved through the use of standardized assessment tools, standardized functional eligibility criteria, and a uniform point of access to the system. At the same time, service packages can be determined at the local level within specified fiscal parameters.

Incremental Approach: All six states developed their systems incrementally. Three (Maryland, Wisconsin, and Oregon) phased in statewide implementation of long-term care

initiatives by geographic area. All added various program components over a period of several years. For example, preadmission screening programs often were added after the supply of community care services was expanded, enabling screening program staff to offer persons seeking nursing home placement some viable community service options.[91] Because the various components of community care are inter-related, undertaking a comprehensive planning process before launching major initiatives is imperative. A broad planning effort also paves the way for multi-agency consensus and coordination. All six states faced difficult decisions in choosing the best local agencies to perform assessment, case management, and direct service delivery. Separate systems providing for social services, aging programs, and health care delivery need to be linked. Such decisions are facilitated by prior broad-based planning efforts involving all players in the long-term care field.

Arkansas[92]

Organization of Community Care Programs: The Arkansas Department of Human Services (ADHS) has responsibility for community-based long-term care services. The Division of Medical Services operates the Medicaid personal care program. The Division of Aging and Adult Services operates the supplemental personal care and alternative care programs as well as those under the Older Americans Act. For the most part, Area Agencies on Aging (AAAs) provide the actual personal care services. Arkansas uses its Medicaid option to cover personal care services and thus has not needed a Home- and Community-Based Service waiver.

Services: Personal care under the Medicaid option is the core of Arkansas' community care program. The alternative care program provides state-funded day care, chore and respite services, and informal caregiver training and support groups. Both the Social Services Block Grant and the Older Americans Act fund some services.

Assessments: The state contracts locally based client assessment teams to conduct functional assessments of all clients seeking Medicaid personal care services, authorize service provision, and refer clients to providers. In part of the state, these teams also conduct preadmission screening for Medicaid clients seeking nursing home care. In the remainder of the state, determination of the need for Medicaid funded nursing home placement is done at the state level and local offices of the ADHS determine financial eligibility.

Accessibility and Coordination: In 1982, legislation mandated the various divisions and agencies involved in long-term care to establish assessment agencies on a demonstration basis. The project's purpose was to test procedures for conducting client assessments and making appropriate provider referrals. Two pilot client assessment teams (in two AAAs) were created to conduct individual functional assessments in one quarter of the state. They also authorized Medicaid long-term care services, including personal care and home health and nursing home care. A local health department and a community action agency provided personal care services. Subsequently, statewide coverage for eligibility determination was allowed the client assessment teams. This mix of agencies and authority required a certain degree of coordination. In addition, state officials cited the gradual, incremental approach as a major factor in the state's success.

Illinois[93]

Organization of Community Care Programs: Administration is centralized. The major components of Illinois' community long-term care system are under the umbrella of the state's large entitlement Community Care Program (CCP). The CCP operates under the state's Department on Aging (DOA). The Department of Rehabilitation is responsible for a similar program for the physically disabled. Both departments work with the Department of Public Aid in developing program rules for Medicaid. Area Agencies on Aging provide contracted administrative support to the CCP such as resolution of billing problems. Direct services are provided through a well-established system of private nonprofit service providers. While several state agencies may be direct providers of service through local offices of the state government, there is no significant human services role for county governments.

Assessment, Case Management, and Service Delivery: All assessment and case management functions are performed by community care units (CCUs) under contract with the DOA. However, they may not provide direct CCP services. About one-third of the CCUs are home health agencies, another third are senior service agencies, and the remaining third are a mix of other agency types. CCUs perform the usual functional assessments to determine eligibility. They also conduct preadmission screening for nursing home care. As a result of the CCP's status change to that of an entitlement program resulting from a class action suit filed in 1982, changes were made to service provision. Since entitlement status acts as an implicit incentive to expand services, entities that performed assessment and case management were no longer allowed to provide direct services. To prevent possible conflicts of interest, CCUs were created to perform assessments and case management, including authorization of services. Other participating agencies which did not opt to become CCUs would then provide direct services.[94]

Maine[95]

Organization of Community Care Programs: Maine's Department of Human Services (MDHS) supervises long-term care programs. The Bureau of Maine's Elderly in the MDHS administers the Home Based Care (HBC) program, and cooperatively with the Bureau of Medical Services, shares supervision of the Medicaid waiver component. The Congregate Housing Program is administered by the former Bureau. At the local level, AAAs administer the HBC and the Congregate Housing programs.

Services: The core of Maine's community long-term care services is the HBC program. The HBC provides a broad range of services to the elderly assessed as meeting the medical and functional criteria for nursing or boarding home care. Because few services are specifically defined, great service flexibility is allowed. In practice, personal care assistance is the most common one. In eight percent of state-funded cases excluding those under the Medicaid waiver, family members can be paid providers -- subject to state approval. The Congregate Housing Program is a small state-funded program which provides meals, housekeeping, and personal care services for low and moderate income elderly living in subsidized housing. The Older Americans Act funds case management for HBC clients as well as for the housing Congregate Housing Program. In addition, homemaker services are provided with limited Social Services Block Grant funds.

Assessments and Case Management: AAA staff perform assessments, develop care plans, and serve as case managers. The MDHS has developed a standardized functional assessment tool. The same functional assessment tool used for determining eligibility for the

Homes Based Care Program and for preadmission screening is used to determine the need for congregate housing services.[96] Hospital discharge workers also use the tool in making referrals to either the HBC program or a nursing home. In addition, AAAs use the tool in preadmission assessments of Medicaid-eligible clients seeking nursing home admission. Financial eligibility for Medicaid is determined by local offices of the MDHS.

Incremental Approach: As with the other six states, Maine's long-term care system developed gradually. The Congregate Housing Program began in 1982. In 1983, the Bureau of Maine's Elderly began a series of demonstrations involving nursing homes in the provision of community care services including adult day care, respite care and some in-home services. In 1984, Maine received approval of a 2176 Medicaid waiver so that federal funds could match state funds previously devoted to the HBC program. This was followed by the Alternative Long Term Care Program which combines the optional Medicaid state plan services of private duty nursing, personal care, and traditional home health services. Clients receiving these services must be nursing home-eligible and service costs must not exceed nursing home costs.

Maryland[97]

Organization of Community Care Programs: Responsibility for long-term care programs for the elderly is divided among three state agencies: the Department of Health and Mental Hygiene (DHMH), the Department of Human Resources (DHR), and the Office on Aging (OA). The directors of these three agencies constitute the Interagency Committee on Aging Services whose statutory task is improve state-level coordination. The DHMH administers Medicaid personal care services and Medicaid reimbursement for adult day care. The DHMH also administers geriatric evaluation services consisting of both preadmission screening and community care evaluations. The DHMH also manages Medicaid nursing home payments. At the local level, Medicaid personal care services are provided by independent contractors. The geriatric evaluation services is part of the county health department.

The DHR is responsible for social services and income maintenance programs, managing In Home Aide Services and case management services and domiciliary care for the elderly. The OA administers the Older Americans Act through local AAAs, which are part of county government. The OA also further administers a sheltered housing program which provides personal are and chore services to frail elderly residents of subsidized housing. In addition, the Gateway II program is administered by the OA as lead agency in collaboration with the DHMH and the DHR. Gateway II provides case management and funds to counties for services to the elderly assessed at risk of nursing home placement.

Equal Access Through Functional Eligibility: In December, 1991, the Governor's Commission on Health Care Policy and Financing issued recommendations on long-term care based on a three-year study. The report was jointly issued with the Committee on Long-Term Care. The Commission investigated the long-term care needs of not only the frail elderly but also those of "persons with serious mental illness, developmental disabilities, AIDS, other chronic conditions, as well as trauma victims and those in need of rehabilitation."[98] As a result, the report recommended that:[99]

> [t]he equity of access to long-term care services should be a guiding principle of the long-term care system. Individuals with similar needs for long-term care services should have equal access to the needed services and not be denied services because those services are targeted to a particular age or disability group. As a

> consequence of the way long-term care services have evolved, the current long-term care system does not meet this test of fairness. Therefore, the Committee recommends that the long-term care service continuum be organized generically, rather than categorically by age or diagnosis, and that, to ensure equal access to services, eligibility be determined on the basis of functional impairment.

Coordinated Care: For more efficient use of resources, the Commission recommended that long-term care be organized into a system of inter-connected care. This calls for extensive coordination among the three agencies that provide long-term care. According to one researcher, "Problems in coordination are a result of three equally powerful agencies, each created for purposes other than long-term care delivery, interested in maintaining or increasing their current levels of service."[100] In practical terms, the Commission recommended the establishment of:[101]

> a State-level coordinating body which is independent from the agencies involved in the provision of long-term care services, but is represented by the secretaries or deputy secretaries of those agencies, so that critical groundwork for integrating policy issues affecting all long-term care populations can be addressed.

The chairperson of this state-level coordinating entity should be appointed by the Governor. This entity is to establish long-term care priorities (both community-based and institutional) and rationalize the use of scarce resources by allocating them between community and institutional services. It should also include multiple populations by prohibiting discrimination by age or disability but recognize the importance of these dimensions in the provision of services. Finally, it should recognize strengths of local jurisdictions to provide coordinated care. Membership in the coordinating body should include all agencies, consumers, and providers to address across-the-board issues. This entity should also be able to budget across agencies for special projects, allocate resources, set standards, and monitor and arbitrate among agencies. However, it should not replace existing departments but only coordinate care across agencies.[102]

The Commission also recommended that the system be tested with a pilot project providing one or more generic community-based services on a functional disability basis. It felt this was prudent before any major reorganization takes place, especially because Maryland has had minimal experience in combining funding streams:[103]

> While some states have accomplished consolidation of services by functional disability, anecdotal information suggests that those states have encountered problems assuring equity of access to services among the long-term populations. Base[d] on California's attempts at consolidating long-term care, interest group struggles can prevent successful consolidation.

Obstacles to Providing Full-Range Generic Services for Multiple Populations: Under a system that provides care based on functional or generic impairment and not based on age or diagnosis, *services and how they are delivered must be defined.* For example, the chronically ill and disabled need an array of medical, social, and support services that are not exclusive to them but are shared with other long-term care populations such as the frail elderly. However, there is an inherent tendency for a population, or its advocates, to identify a particular service as being owned or controlled by that population. This obstacle must be overcome by replacing this tendency with an obligation to coordinate with agencies and populations to provide the service.

Contention between various models of care for dominance also poses a problem. For example, medical care is needed in both the acute and maintenance phases of chronic

illnesses or disabilities. However, a medical model as a priority in the continuum may lead to excessive and unnecessary emphasis on health care. On the other hand, a predominantly social, community care model could possibly lead to insufficient medical care.[104]

How long-term care is financed also affects which type of care model is encouraged.[105] For example, most traditional long-term care services are not medically-based and thus not paid by third party payers. Long-term care providers, then, may be forced to "medicalize" their services in order to be reimbursed. This may adversely affect the appropriate use of the social support model of long-term care.

The issue of whether the *scope of long-term care services should be limited to those actually receiving the care or be extended to informal caregivers*[106] must also be resolved. For example, should training, education, respite care, stress counseling, etc. be included for caregivers? Advocates of different populations need to come to agreement on this issue before any system-wide integration or coordination can be implemented, including a uniform SEP.

How broadly should the needs of long-term care populations be defined?[107] For example, it is undisputed that they need help with ADLs . However, it is argued that some can learn or relearn these daily activities. Should services, then, be limited to assistance with ADLs or include habilitation or rehabilitation that help persons master these activities themselves? Similarly, many with long-term care needs may be able to work if given support. Should prevocational, vocational, and supported employment be included in the scope of long-term care services?

A related issue is the *selection of disability criteria*. This has policy implications for determining the size and composition of target populations. For example, the more ADLs are used for screening, the smaller the eligible population. On the other hand, setting a lower number allows less disabled persons to become eligible on the justification that care will slow their deterioration and delay their need for institutionalization.

Furthermore, the *type of ADL used* also shapes the target population. In addition, not all ADLs may be appropriate for all populations. For example, some ADLs may be inappropriate for children and persons with cognitive disorders (e.g. Alzheimer's patients) or problematic behaviors (e.g. serious mental illness, head injuries, mental retardation). Rather, they may need measures of cognitive impairment rather than depend on ADLs. That is, they may be physically capable of performing ADLs but need instruction and guidance ("cueing") to do so. Assessments based only on the need for active help in ADLs rather than supervisory help (the only type needed by the cognitively impaired or those with problematic behaviors) would generate a much smaller population.[108] One solution is to define them into the picture:[109]

> [a] chronically ill individual [is] one who is unable to perform without substantial assistance from another individual at least two ADLs due to a loss of functional capacity or who has a similar level of disability due to cognitive impairment.

Developing a common assessment tool would be integral to any attempt to provide a full range of long-term care on the services continuum based on functional need. However, any such tool needs to be worked out with full agreement among all populations, advocates, agencies, and providers that address the needs of all groups. Agreement must be reached without unfairly promoting one group's interests or obstructing those of another. This is a task easier said than done.

The overriding obstacle is for categorical populations, advocates, agencies, and providers to resolve all issues of "ownership" vs. coordination in providing specific services along the care continuum. The Commission recognizes this:[110]

> [T]here has been an emphasis on the uniqueness of long-term care populations by age or disability, rather than on the commonalities among these long-term care populations by functional disability. . . . there are numerous barriers that preclude a coordinated approach to long-term care. They include turf battles among the multiplicity of public agencies serving the long-term care population, and the federal rules and regulations tied to Medicaid and categorical grants that prevent effective coordination.

However, the Commission does state that defining service eligibility on the basis of functional disability does not disregard specific diagnosis or diagnostic-specific services. Rather, it focuses on the level of impairment created by the condition. Indeed, even a categorical system needs some way to measure degrees of disability in order to determine eligibility or priority for services.[111]

Access to Information and Entry Into the System: The Commission found that lack of information is a significant barrier to obtaining long-term care services.[112] Information and referral is defined as "a process which links an individual who has an information or service need to the resources which are designed to meet that need."[113] Two relevant issues for access to long-term care services are: how to improve initial access to information and how to improve the way information providers organize their information. However, an information system can be improved without changing the existing structure, functions, or relationships among agencies. That is, it can be improved independently regardless of the system of administration.[114] Furthermore, a good information system can adapt to future changes in the long-term care system itself. On the other hand, an improved information system cannot but enhance equal access, a goal of a uniform SEP process. To the extent that it does, a good information and referral system will aid the operation of a single entry point.

To state the obvious, a good information system must make the information *accessible*. It is no use if those who need it cannot get at it. Just having an 800-line number staffed with specialists is of little use if consumers do not know about it. Therefore, *outreach* is a key ingredient in any information service. The service must be advertised effectively. Furthermore, the circumstances under which an individual needs information are not ideal. A caregiver may be at the point of giving in to the pressures of caregiving. A person may be suffering from the shock of a threatening diagnosis . Or a person may have actually suffered a recent injury or be disoriented in a strange new situation. The information system must be able to handle requests for information from individuals who may not be in top cognitive or emotional form.

In Maryland, the OA's Senior Information and Assistance program is the state's most advanced public-sector information resource for a long-term care population. As such, it may provide a model for other populations or for a generic long-term care information system. The OA provides oversight, information, updates, technology assistance, publicity, and statewide linkage, including a single 800 number that gives the caller entry into the entire system. Services are organized by jurisdiction, through the 24 AAAs, augmented by over 200 satellite sites. Local offices generally offer toll free or collect telephone service and full service at least five days a week during normal business hours.[115] The only other federally-mandated information service is the Child Find Information and Referral Service for children with special education needs, provided by the Maryland Department of Education. There is no clearly

defined information system for the developmentally disabled or for persons with serious mental illness.[116]

Options for a Long-Term Care Information System: The Commission described three options for improving the information and referral system. However, it withheld recommendation of any of the three pending more thorough investigation and wide consultation with consumers and all interested parties in the public and private sectors. Nonetheless, the third option seems the most promising -- that of developing a system with a highly visible access point for long-term care information:[117]

> Such a system would be designed to be a "first call" information number that could provide information, make appropriate referrals, or itself serve as the gateway into the service system.

Possible approaches to implement this concept include:

- Expanding existing programs to serve all long-term care populations.
- Designating an existing or new public or private entity as the principal information and referral source. Maryland could serve as the public partner supplying data, funding, and publicity.
- Organizing access by establishing three information services based on the three major age groups: children, disabled working-age adults; and the elderly.
- Expanding the role of public libraries as long-term care information resources.
- Organizing information services in each jurisdiction or region of the state with wide publicity within each region.

Oregon[118]

Organization of Community Care Programs: Oregon has consolidated all components of its long-term care programs into a single administrative structure at the state level and a highly integrated delivery system at the local level. A single state agency, the Division of Senior Services, manages all of the state's community and institutional long-term care programs. These include Medicaid, a Home and Community Based Services waiver program, the state-funded Oregon Project Independence (an in-home and community services program for elders), and the Older Americans Act. In addition to developing community care systems, the Division licenses and certifies nursing homes, reimburses them for the care of Medicaid clients, and develops policies governing the participation of Medicaid nursing homes.

Oregon's centralized administrative structure reflects the consolidation model in which responsibilities rest in a newly created single-purpose agency. Previously autonomous programs come under one budget which enables clear resource allocation between community-based and institutional care, and reduces the possibility of interagency battles. The expected outcome of such an organizational structure is to improve coordination within programs, reduce duplicative management functions, and develop a policy management strategy.[119] However, gaps in coverage remain, largely due to strict eligibility criteria. Services generally are targeted to elderly and disabled people who are severely functionally impaired and those with low incomes, although some services are not means-tested or are provided on a sliding scale fee basis to people with higher incomes.[120]

Programs and Service Delivery: The Medicaid Home and Community Based Services waiver is the core of Oregon's community care system. Individual client assessments and case management services are financed through Medicaid administration funds. Similar services are provided through the state-funded Project Independence program to those similarly functionally impaired but ineligible for Medicaid. Participants pay on a sliding fee scale. The two programs delineate a half-dozen permissible services.[121] These include in-home companionship services, home-delivered meals, and care services. Services provided in the community include adult foster care, home, residential care facility, specialized living facility, medical, and personal care services.[122]

The major components of the service delivery system include preadmission screening, case management, relocation planning, and risk intervention.[123] The case manager administers the assessment (or by a multidisciplinary team if for nursing home placement) in order to uniformly measure the health and functional abilities of clients. Weights are assigned to data relating to ADLs. Priorities are ranked according to level of need: "A" for highest dependence in three to six ADLs, and "L" for those needing help in two or fewer critical ADLs.[124]

Considerations for System Coordination: Although Oregon's consolidated model is an extreme one, the lessons of that state's re-structuring are relevant for efforts at system integration at lower levels. The dramatic changes required in Oregon's change to a sole agency "generated significant tensions among the state agency, area agencies on aging, service providers and aging advocacy groups."[125] *(Note: In Hawaii's case, the addition of the disabled children and disabled nonelderly adult population merely multiplies the number of agencies, providers, and advocacy groups involved.)* To address the major disagreement that arose, a process called the Negotiated Investment Strategy was undertaken. The interests of the state, area agencies, service providers, and elderly advocate groups were each represented by their own five-member team. These four teams met for a full day every other week for more than six months, at the end of which agreements were reached that successfully clarified the roles and expectations of all parties. It is likely that such broad government and industry-wide negotiations will be necessary in any attempt to realign target populations, funding, services, and service delivery. This is true whether the changes entail a wholesale re-structuring of the long-term care system, or whether only certain components, such as an SEP process is envisioned.

Wisconsin[126]

Organization of Community Care Programs: Wisconsin's long-term care administrative structure is an example of the umbrella model using a generic or functional approach. The Wisconsin Department of Health and Social Services (DHSS) and three units within it (the Division of Health and two bureaus within Division of Community Services) administer all long-term care services in the state. The Division of Health is responsible for Medicaid services. The Bureau of Long Term Support (BLTS) operates the primary long-term care program in the state -- the Community Options Program (COP). The BLTS also provides supportive home care and runs the Medicaid Home and Community-Based Services waiver. The Bureau on Aging administers OAA programs and the Alzheimer's program.[127]

Wisconsin uses an interdepartmental planning and coordinating group known as the Long Term Care Support Management Reference Group. Included in this group are the heads of the following divisions: Medicaid, the aging, vocational rehabilitation, state

institutions, health planning, the developmentally disabled, community services, policy and budget, program initiatives, and the DHSS's deputy director. The group handles broad policy concerns and technical program issues, for example, nursing home reimbursement methodology, eligibility criteria, assessment tools, information systems, and potential Medicaid waivers. Working subgroups address specific areas of interest. At the local level, Wisconsin uses a strong system of county human service agencies to administer community care. These county agencies provide case management, conduct preadmission screening, and determine Medicaid eligibility. At the same time, AAAs administer traditional aging programs.[128]

Screening, Assessment, and Care Planning: An individual is screened at home, if possible, upon a referral. Anyone can make a referral, including the potential client. The COP lead agency provides training to hospitals, nursing homes, home health agencies, community groups, and other potential referral sources on how to refer persons to the COP. An assessment is then scheduled *(see the wait list, below).* Wisconsin defines "assessment" as:[129]

> [a] structured process of interviews which is used to identify the participant's abilities, needs, preferences and supports; determine eligibility for programs and services; and provide a sound basis for developing the care plan. . . . Assessments are conducted in partnership with the participant and his/her family, guardian, or other supports as appropriate.

The assessment usually covers information about the person's:[130]

- Physical, mental, and emotional health
- Ability to accomplish the tasks necessary to daily living and self-care, including the use of or potential for adaptive equipment or skills training
- Level of social participation, including communication skills and educational, vocational, and recreational activities
- Environment, including the physical elements of the home and the extent to which family, friends, and neighbors provide needed service, backup assistance or social or emotional support
- Economic resources
- Personal choices and preferences of lifestyle and service options

A care plan is then developed to address the individual's needs that outlines how each need will be met, who will provide what services when, where, for how long, and at what cost. Upon approval of the individual plan, and subject to funds available, a case manager is assigned to begin arranging the care plan. There is no limit to the amount of Community Options funds that may be spent for an individual as long as the average cost of care for all Community Options participants in the county does not exceed the average state Medicaid share of the cost of nursing home care.[131] The case manager is responsible for on-going monitoring and re-evaluation of the client's situation. In addition, the case manager also monitors service providers, mediates any disputes, and arranges for new providers if necessary.

Multiple Populations and the Community Options Program: The Community Options Program (COP) is the focal point of all federal, state, and local resources devoted to community care services. The state-funded COP is designed to serve all populations needing

long-term care, including the elderly, physically disabled, developmentally disabled, chronically mentally ill, and the chemically dependent. Both children and adults are served. In addition to support services, the COP also funds assessments, care planning, and on-going case management. The state has not defined a particular set of services that can be authorized. State guidelines have concentrated on developing county plans for coordinating existing service programs and involving the client and families in developing individual care plans.

Although multiple populations are served, the COP is designed to serve only those who may otherwise enter nursing homes at a cost that averages no more than that of Medicaid-funded nursing home care. Its purpose is to divert persons from nursing homes, not to include every person who needs long-term care.[132] For example, eligibility is determined by a functional screen which seeks to determine if a person needs a level of care equal to that of a nursing home. If not, then the system will not assess that person. Therefore, although children are eligible, the COP program is not strictly for such young clients because children do not normally need to enter nursing homes. The same is true for the developmentally disabled. In addition, the population of disabled children is relatively very small.

More importantly, according to the Bureau of Long Term Support, although the COP was designed to address five populations, it was never fully implemented because of a lack of funding. The Wisconsin Legislature did not appropriate sufficient funds to carry out all statutorily required assessments for those who may enter nursing homes. There are currently 8,000 on the waiting list for assessment, or about two years' worth. Along the same lines, even if all required assessments were done and people were routed away from nursing homes, there are not enough community services and funding for them, thus raising false hopes.[133]

Targeted Groups and Significant Proportions Served: The COP is required to serve persons from the major target groups in proportions which approximate the percentages served in nursing homes prior to the program's inception. These percentages are termed the "significant proportions" that Wisconsin statute requires to be maintained.[134] The table below shows the statutorily required minimum significant proportions that must be served and the actual point-in-time proportions served on December 31, 1992.[135]

Targeted Group	Minimum	Actual
Frail Elderly	55.0%	57.8%
Developmentally Disabled	14.0%	17.0%
Physically Disabled	6.6%	15.1%
Chronically Mentally Ill	6.6%	8.5%
Alcohol or Drug Abusers	0.0%	0.5%

Actual proportions have always met the statewide minimum significant proportions since program inception.

Medicaid Waivers: Wisconsin also has four *2176 Medicaid waivers*: two for the developmentally disabled and two for the elderly and physically disabled. The largest waiver is the Community Integration Program. Counties may access this waiver program on behalf of older people when there has been a reduction of licensed nursing home beds in the county.[136]

Other Community Care Programs: Although the COP is the core of Wisconsin's long-term community care services, that state operates several other support programs that address the long-term needs of multiple populations.

The *COP-Waiver (COP-W)* program is Medicaid-funded and provides community services to the elderly and physically disabled in lieu of building new nursing home beds.[137] The COP-W is a limited entitlement program whose services are limited to those having federal approval. Non-financial criteria that must be met include requiring skilled nursing facility (SNF) or intermediate care facility (ICF-1 or ICF-2) levels of care. Only specified services are reimbursable:[138]

- Case management
- Care management/service coordination
- Supportive home care
- Adult day care
- Day services
- General and institutional respite care
- Daily living skills training
- Communication aids
- Interpreter services and adaptive equipment
- Housing modifications
- Substitute care (excluding room and board)
- Counseling and therapeutic services
- Transportation
- Personal emergency response system
- Protective payments and guardianship services
- Home delivered meals

(Note: Specific services are authorized in non-COP programs. In the COP itself, any services, equipment, or adaptive aid necessary to keep a person safely in the community, including assessment, care planning, and case management, are allowed.)

The *CIP II* program (community integration program) is also Medicaid-funded and provides community services to the elderly and physically disabled persons after a nursing home bed is closed. Like the COP-W, the CIP II is a limited entitlement program. The same need for SNF or ICF levels of care must be met. Only specific services are reimbursable (the same as for the COP-W) except for case management.[139]

The *CIP IA-DD* is another Medicaid-funded community integration program that provides community services but is targeted to persons relocated from developmentally disabled (DD) centers. This program pays higher per diem rates than other waivers and has a better capability to serve children although DD adults are also included. Consumers have a choice of providers but program participants are strictly limited to those specified in the waiver. Reimbursable services are limited to those specified:[140]

- Adult day care
- Respite care
- Institutional respite
- Supportive home care
- Transportation
- Prevocational services
- Daily living skills training
- Personal emergency response system
- Communication aids
- Adaptive aids

- Home modifications
- Adult family home
- Foster home (children)
- Community-based care treatment facility
- Counseling and therapeutic services
- Day center services treatment
- Case management/service coordination
- Supported employment (excludes supported employment and prevocational services for diverted individuals)

Community services are also available to the developmentally disabled, both adults and children, through the *CIP IB-ICF/MR* program. Like the previous programs, this one is also Medicaid-funded. As in the CIP IA-DD program, above, participants must be relocated or diverted but from ICF/MRs other than DD centers and certain nursing homes beds which would have been converted to ICF/MR status. Consumers also have a choice of providers. However, diversions often require county matching funds. In addition, prescriptive definitions limit coverage flexibility and services are restricted only to those specified in the approved waiver. Services are the same as for the CIP IA-DD program.[141]

The *Katie Beckett* program allows for Medicaid eligibility for children up to age 18 with physical and/or developmental disabilities who live with their families instead of in hospitals or nursing homes. Children must otherwise require a level of care provided by hospitals, nursing homes, or DD centers. This is an entitlement program but neither the income nor assets of parents are counted. Only Medicaid card services are reimbursable; additional services must come from other programs. Cases are processed at the state level and county contacts are limited.

The *Community Support Living Arrangement (CSLA)* program is a Medicaid benefit program for DD adults. The CSLA program provides supported living services to individuals living in their own homes or the homes of relatives in counties which successfully competed for funds. This program uses medical assistance funds for long-term supports. Importantly, participants need not meet institutional level of care requirements. The consumer is granted a high degree of latitude in directing the choice of services provided. Person-centered planning is emphasized. However, there are only limited funds for this program and all federal funds require a 40 percent county match. Authorized services include supportive home care, respite, daily living skills training, housing modifications, communication aids, adaptive aids, counseling, transportation, and personal emergency response systems.[142]

Lastly, the *CSP* program provides a range of treatment, rehabilitation, and support services for persons with severe and persistent mental illness through an identified mobile community treatment team of clinical and support staff. This program's mobile emphasis is designed for persons who may not access traditional mental health outpatient services. A team approach is used to prevent clients from entering institutions. Only adults meeting clinical criteria are eligible although older adolescents are occasionally admitted. Participants must also have significant functional impairments for living in the community. Funds are limited and counties must fund the state share of Medicaid. It is also difficult to hire sufficient qualified staff in some areas of the state. Reimbursable services include almost all services that are identified on the treatment plan except direct vocational and social recreational services. Allowable services include:[143]

- Assessment
- Treatment planning
- Crisis intervention services
- Symptom management

- Medication prescription, administration, monitoring, and documentation
- Psychiatric and psychological services
- Family, individual, or group psychotherapy
- Rehabilitation services
- Activities of daily living
- Case management for coordination of all services

Effect of COP and Medicaid Waivers on Nursing Beds: Wisconsin reports that the COP and the Medicaid Waivers have had a significant effect on the utilization of nursing home beds. The actual census of nursing home residents in Wisconsin rose steadily from just above 25,000 in 1974 to 38,965 in 1980. After the inception of the COP in 1981, the census began to drop and continued dropping with the addition of the community waiver programs. In 1992, the census had fallen to 33,100 against a conservatively projected 49,952 if the various programs had not been implemented.[144]

Cost of the COP: The cost of care for most individuals in the COP was reported to fall within a range of costs comparable to the average rate for nursing home care. Admittedly, some individuals receiving COP or waiver services incur very high costs. However, nearly 80 percent of all participants had average monthly COP costs in the range of $0 to $1,900 while less than five percent averaged monthly service costs above $2,900. Nearly 95 percent of all expenditures were in the $0 to $1,900 range, averaging $727 a month for all COP, waiver, and Community Integration Program-II participants.[145]

County Administration: Wisconsin appoints or contracts with a lead agency in each county. By design, they are all county governmental units although they can subcontract with private agencies either for profit or nonprofit. COP funds are meant to be funds of last resort. Thus, it makes sense to put the COP program into the hands of those agencies already operating with other funds that can be used first. Each county lead agency must address all five target populations. Most are county departments of social services, mental health, developmental disabilities, or some combination. If a county agency originally did not cover all five target populations, they may develop interagency agreements with other agencies or contract out for expertise. County governments were chosen also because they already have administrative and service delivery structures in place and have links with other support services such as public nurses. Furthermore, their staff are already somewhat trained in the assessment process.[146]

Program Flexibility: Other than requiring only that twelve areas of living must be addressed, the counties are given great flexibility. County units may use one standard assessment tool but they are free to append specialist assessments, if necessary. For example, one large urban county used computer assessment scoring. On the other hand, assessment in a rural county consisted of two pages in story-narrative form describing the client's situation. The latter's rationale was that it is more important to know the person than to impersonally assess scores in twelve areas. The key is flexibility. An assessment is meant to see if a person can stay in community. If so, it seeks to identify obstacles preventing the person from doing so. The program then helps to remove those obstacles.[147]

The operating principle is that there is one standard concept, not one standard inflexible tool. Nor does it mean using the same person to assess all five populations. In fact, to assess an elderly person, an assessor whose knowledge is limited to disabled children will defer to someone else knowledgeable about the elderly. Wisconsin requires counties to use specialists to assess the correct people if necessary. Flexibility extends to allowing county units to determine the composition of the assessment team. They may use just one assessor or a team. Disagreements arise even now over whether only specialists in one

target population can assess members of that specific population. However, many believe that many basic needs can be assessed by someone not keyed to a specific target population. In Wisconsin, assessments are not the be-all and end-all. In any case, initial assessment are often followed by further, more specific, assessments.[148]

It must be underscored, however, that program flexibility is made possible in large part because of the state's ability to totally finance its community care system. Without constraining regulations that accompany federal funding, Wisconsin has been able to put forward a policy that addresses multiple populations requiring long-term care. Justice, et al., report that:[149]

> Even after five years of operation, there is very little debate on whether separate systems should be established for each population group. In part, the generic approach has been preserved by the advocate groups who believe that the program is more likely to grow if the various interests all unite. At the same time, however, there is some discussion of earmarking portions of the state's large community aids grants to counties, with designated amounts to be spend on social services for certain client groups.

Other States: All long-term care services in *Arizona* are managed by case managers who screen for financial eligibility and medical and functional needs. The state's functional screen is designed to target those at immediate risk of institutionalization. The long-term care component of the demonstration Arizona Health Care Cost Containment System is meant to provide acute and long-term services to eligible residents. Arizona receives a set amount from the federal government for each eligible participant, regardless of the amount of services used. Arizona pays contractors on a fee-per-person basis instead of a fee-for-service basis. Thus, contractors bear the risk of excessive use and have an incentive to control costs. The long-term care component of the program was not implemented until 1989 for the elderly and physically disabled populations.[150]

California's Linkages program helps match home-based community services with adults who otherwise might be placed in an institution. Services are provided from thirteen sites that each receive $300,000 annually from the state general fund. Case management services include assessing the person's needs, planning for care and, if necessary, funding services. The cost for enabling persons to remain in their homes is $134 a month each, one-tenth the typical $1,435 required for a month's stay in a nursing home. The program served 3,800 persons from 1987 to 1988.[151]

Kentucky's Personal Care Attendant Program, established in 1985, subsidizes in-home attendant care to the severely handicapped elderly. The handicapped person hires, supervises and pays the attendant. The cost per handicapped person averages $6,000 a year, $10,800 less than institutional care. Estimated state savings amount to about $2 million for the 195 elderly handicapped served annually.[152]

Mississippi's Community-Based Long-term Care Program provides services to the frail elderly. Services include homemaker, home health aide, case management, transportation, group meals, home-delivered meals and adult day care. Many of the 7,800 persons served aged 60 or older might otherwise have been forced to enter an institution for care. The program has served more than 20,000 persons at an estimated cost of $9 million since 1985. The program's innovative features include regional-level coordination of local agencies and planning for new resources.[153]

Summary: A single entry point (SEP) implies some degree of system integration. Obviously, an SEP does not embody total system integration nor is this study interested in such. As pointed out earlier, integration is a matter of degree. Some system components can be coordinated, such as an SEP process, without total system integration. All the states examined have attempted to coordinate their fragmented long-term care systems. However, none of the states examined have specifically focused on a single point of entry. All states have touched upon screening, assessment, and case management as instrumental to their long-term care reform. These three processes, used together in a coordinated way, can facilitate system access and form the basis of a single entry point.

The issue of using either a functional or a categorical approach to long-term care affects the successful implementation of an SEP process. A functional approach makes it much easier. However, there are many obstacles -- structural, philosophical, and political -- to adopting a purely functional approach. A subset of this issue is that of inclusion of additional target populations. The more populations, the more difficult it would be to work out the differences among them all. However, if a functional approach is adopted, there is little justification to exclude any group that needs long-term care.

Implementing a continuum of services is a common theme. Home- and community-based care is becoming more acceptable as cheaper ways to provide the least restrictive care. However, states have recognized the importance of and need for institutional facilities. A continuum of care concept includes *all* services, community-based and institutional.

Many of the states recognized that major efforts at broad policy planning is necessary prior to any attempt at implementing system integration. This is so not only because of the fragmented system inherited from years past but also because of the ingrained attitudes regarding turf held by bureaucrats and advocates. Cooperation from all groups must be achieved. More importantly, strong and continuing executive leadership and commitment to change is needed since change implies reform, however slight, as with implementing an SEP process.

Endnotes

1. Indiana, Long-Term Care and Local Service Delivery, Indiana Legislative Services Agency, Evaluation Audit, May 1991 (hereafter "Indiana 1990"), p. 42, referring to the 1988 6-state study of Arkansas, Illinois, Maine, Maryland, Oregon, and Wisconsin by Justice, et al.

2. Colorado, Report to the Colorado General Assembly: Recommendations for 1990, Legislative Task Force on Long-Term Health Care, research publication no. 344, December, 1989, p. 5.

3. Ibid., p. 27.

4. Ibid., p. 3.

5. Ibid.

6. Ibid., p. 5.

7. Ibid., p. 3.

8. Ibid., p. 8. Also, (p. 23): The Task Force recommended considering the special needs of Alzheimer's Disease ("dementia") patients in the development of rules for a single entry point, thus addressing the need for a more intensive needs assessment for dementia patients.

9. Ibid., p. 4.

10. Ibid., p. 27.

11. Ibid., p. 11.

12. Ibid., p. 17.

13. Ibid., p. 27.

14. Ibid., p. 28.

15. Ibid., p. 19.

16. Indiana 1990, p. 34.

17. Ibid.

18. Indiana 1990, p. 35.

19. Ibid., p. 59.

20. Ibid., p. 35.

21. Indiana, Long-Term Care and Local Service Delivery, Indiana Legislative Services Agency, Evaluation Audit, May 1991 (hereafter "Indiana 1991"), p. 44: The funding level for CHOICE is established by the legislature. The cost of a statewide CHOICE program is a legislative decision based on an evaluation of the need for the program, as well as a determination of how much Indiana can afford to spend.

22. Indiana 1990, pp. 31-32.

23. Indiana 1991, p. 37.

24. Ibid., p. 39.

25. Ibid., p. 40.

26. Ibid., p. 50.

27. Indiana 1990, pp. 32-33.

28. Ibid., p. 33.

29. Ibid., Exhibit 13. "Indiana Long-Term Care Responsibilities," pp. 33-34.

30. The preadmission screening process began operation in 1984. (p. 77)

31. Indiana 1990, p. 3.

32. Indiana 1991, p. 2.

33. Ibid., pp. 27-28.

34. Ibid., pp. 5-6.

35. Ibid., p. 63.

36. Ibid., p. 64.

37. Ibid., p. 9.

38. Ibid., p. 4.

39. Ibid., pp. 29, 30, & 72.

40. Ibid., p. 30: Previously, separate assessment tools were used for PAS, CHOICE, the Medicaid Waiver, and Title III/SSBG services [Title III is Older Americans' Act 1965 funds for support services.] The Eligibility Screen is designed to minimize unnecessary paperwork. The case manager works progressively through the Screen, so if a person meets one of seven severe medical conditions criteria and, thus, is eligible for PAS, CHOICE, or the Medicaid Waiver, eligibility questions regarding activities of daily living or informal supports can be skipped.

41. Ibid., p. 73.

42. Ibid. However, (p. 76) it is reported that "only a very small number of PAS applicants" are denied admissions to nursing homes. "In FY 1990, only 219, or 1% of all PAS applications for admission to nursing homes were denied."

43. Ibid., p. 76.

44. Ibid., pp. 76-77.

45. Ibid., 1991, p. 78.

46. Ibid., p. 79.

47. Ibid.

48. The DPW would become involved only when the placements were denied, when the applicants are Medicaid-eligible, and when Level 2 assessments (more comprehensive assessment for clients who may be mentally ill or developmentally disabled) are required.

49. Indiana 1991, pp. 30-31.

50. Ibid., pp. 31-32.

51. Ibid.

52. Ibid., p. 32.

53. Ibid.

54. Ibid.

55. North Dakota, Long Term Care: Issues and Recommendations, January 1987, Interagency Task Force on Long Term Care, Bismarck, North Dakota, January, 1987 (hereafter "North Dakota study"), p. I-1.

56. Ibid.

57. Ibid.

58. Ibid., pp. i - ii.

59. Ibid., pp. iii-iv.

60. Ibid., p. II-6.

61. Ibid., p. II-7.

62. Ibid., p. II-13.

63. Ibid., p. II-14, citing: Comptroller General's Report to the Congress of the United States, Entering a Nursing Home, Costly Implications for Medicaid and the Elderly, PAD - 80 - 12, November 26, 1979, pp. iv, 66-70.

64. Texas, Program Audit of Long-Term Care Services to the Aged and Disabled, Department of Human Services, Office of the State Auditor, Austin, Texas, May, 1992, (hereafter "Texas Audit") p. 29.

65. Ibid., p. 33.

66. Ibid.

67. Ibid., p. 53.

68. Ibid., p. 15: In 1979, the TDHS was ordered to close its ICF II nursing home program and expand community care services in an effort to delay institutionalization.

69. Ibid., p. 16.

70. Ibid.

71. Ibid., p. 17.

72. Ibid., p. 19 and in a letter dated May 5, 1992 by Lawrence F. Alwin, Texas State Auditor, to the Legislative Audit Committee.

73. Texas Audit, p. 33.

74. Ibid., p. 18.

75. Texas, Report on Crippled Children's Services Program, Senate Committee on Health and Human Services, report to the 70th legislature, 1987 (hereafter "Texas children's study"), pp. 1 & 3.

76. Ibid., p. 3.

77. Ibid., p. ii.

78. Ibid., p. 6.

79. Ibid.

80. Ibid., pp. 8-9. However, the study also mentions that disabled children who do not need special education classes may need "related services." According to federal law, "related services" can be used only to assist a disabled child to benefit from special education classes. Therefore, such services are not required for those who can function in a regular classroom. Nevertheless, Texas rules do authorize local school districts to provide special support for such children while attending regular classes. An example of "related services" is transportation. (p. 14)

81. Ibid., pp. 6-7.

82. Ibid., p. 12.

83. Ibid., p. 17.

84. Diane Justice is the Director of the Center for the Advancement of State Community Care Programs, National Association of State Units on Aging.

85. The study was supported by a grant from the Office of the Assistant Secretary for Planning and Evaluation through an interagency cooperative agreement with the Office of Research and Demonstrations of the Health Care Financing Administration, United States Department of Health and Human Services.

86. Diane E. Justice, "What States are Doing to Help Elderly," in State Government News, Council of State Governments, vol. 32, no. 3, March, 1989, p. 23.

87. Diane Justice et al., State Long Term Care Reform: Development of Community Care Systems in Six States, National Governors' Association Center for Policy Research, Health Policy Studies, Washington, D.C., April 1988, p. iv.

88. Ibid., pp. iv-v.

89. Ibid., p. vii.

90. Ibid.

91. Ibid., p. ix.

92. Material in this section is from Justice, et al., pp. 5-10.

93. Unless otherwise noted, material in this section is from Justice, et al., pp. 10-14.

94. Justice, et al., p. 96: Illinois uses a tightly defined list of three services supported by its CCP. However senior companion and home health services are also provided on a very limited basis as part of demonstrations funded with state general revenue funds.

95. Material in this section is from Justice, et al., pp. 14-18.

96. Justice, et al., p. 107.

97. Unless otherwise noted, material in this section is from Justice, et al., pp. 18-22.

98. Eugene M. Feinblatt, chairman, Maryland Governor's Commission on Health Care Policy and Financing, in letter dated December 30, 1991, to Governor Donald Schaefer.

99. Maryland, Report of the Governor's Commission on Health Care Policy and Financing: Joint Recommendations of the Governor's Commission and the Committee on Long-Term Care, Governor's Commission on Health Care Policy and Financing, vol. v, December 20, 1991, (hereafter "Maryland Report") p. 1.

100. Ibid., p. 51, citing Justice, et al.

101. Ibid., p. iii.

102. Ibid., pp. 56-59.

103. Ibid., pp. 61-62.

104. Ibid., p. 8, citing A. E. Benjamin, "Perspectives on a Continuum of Care for Persons with HIV Illness," presented at New Perspectives on AIDS: Progress in Health Services Research, May 17-19, 1989, Miami, Florida; and John Douard, Chronic Illness: A Problem of Passive Injustice, unpublished, 1991.

105. Ibid., p. 8.

106. Ibid.

107. Ibid., p. 9.

108. Ibid., pp. 20-21.

109. Ibid., p. 21.

110. Ibid., p. 54.

111. Ibid., p. 19.

112. Ibid., p. 73, citing: (1) West Virginia Research and Training Center, College of Human Resources and Education, Statewide Assessment of the Needs of Severely Handicapped Individuals in Maryland: Final Report, Morgantown, West Virginia, August, 1989; and (2) Office of Technology Assessment, Confused Minds, Burdened Families: Finding Help for People with Alzheimer's & Other Dementias, United States Congress, OTA-BA-403 (Washington, D.C.: U.S. Government Printing Office, July 1990.

113. Ibid., citing Maryland State Department of Education, Division of Library Development and Services, "Focus: Information and Referral," in Library Keynotes, vol. 7, January 1976.

114. Ibid., p. 73.

115. Ibid., p. 80. Two other models for information and referral systems are those of Illinois and Massachusetts. The Illinois DIAL system defines its target population as anyone with a physical, mental, or emotional disabling condition, and the Massachusetts Information Center for Individuals with Disabilities defines it clientele as the Massachusetts resident "of any age who has a disability, illness, injury or special need." (p. 84)

116. Ibid., pp. 82-83.

117. Ibid., p. 86.

118. Unless otherwise noted, material in this section is from Justice, et al., pp. 23-27.

119. Maryland Report, p. 48, citing the Institute of Medicine, Health Services Integration: Lessons for the 1980s, A Report of the Committee of the Institute of Medicine, June, 1982.

120. Ibid., p. 49.

121. Justice, et al., p. 96.

122. Texas Audit, p. 42.

123. Justice, et al., p. 89: Oregon funds risk intervention case managers for private pay clients who receive less intense services.

124. Texas Audit, p. 42.

125. Justice, et al., p. 25.

126. Unless otherwise noted, material in this section is from Justice, et al., pp. 27-32.

127. Maryland Report, p. 49.

128. Indiana 1990, pp. 40-41.

129. Wisconsin, Community Options: Guidelines and Procedures, Department of Health and Social Services, Division of Community Services, Bureau of Long Term Support, October, 1994.

130. Wisconsin, "Information," Department of Health and Social Services, undated, p. 4.

131. Ibid.

132. Telephone interview of October 3, 1995 with John Lorimer, Director, Bureau of Long Term Support, Wisconsin Department of Health and Social Services, 608-267-7284.

133. Lorimer interview.

134. Wisconsin, "Information," Department of Health and Social Services, No. 103b, January 27, 1994, (hereafter "Wisconsin 'Information' 103b"), p. 1.

135. Ibid., p. 2.

136. According to the Department of Health and Social Services, the Medicaid waivers allow the use of both the state and federal parts of what Medicaid would pay for nursing home care to be used for community care. Several other state and/or federally funded long-term care programs are now in place (Family Support Program, Community Support Program, Katie Beckett program, Community Integration Programs, Community Supported Living Arrangements, Exceptional Expense Supplement to SSI, etc.).

137. Wisconsin, "Comparison of Some Long Term Support Programs in Wisconsin" February 1995 (hereafter "Comparison chart").

138. Ibid.

139. Ibid.

140. Ibid.

141. Ibid.

142. Ibid.

143. Ibid.

144. Wisconsin "Information" No. 103b, p. 7. The figures exclude developmentally disabled residents but include mentally retarded residents. The decline in the nursing bed census was also attributed to termination of medical assistance funding for ICF-III and ICF-IV levels of care and a moratorium on new medical assistance-funded nursing beds in 1981.

145. Ibid., Figure 8 "Range of Monthly Community Options Service Costs," p. 10.

146. Lorimer interview.

147. Lorimer interview.

148. Lorimer interview. For example, an anecdotal illustration: an unsteady elderly person was seen by a social worker who triggered an Occupational Therapy assessment (which is much more specialized) that recommended home modifications and mobility appliances.

149. Justice, et al., p. 32.

150. Texas Audit, p. 43.

151. Keon S. Chi, "New Approaches Aid Elderly," in State Government News, Council of State Governments, vol. 32, no. 3, March, 1989, p. 17.

152. Ibid., p. 25.

153. Ibid.

Chapter 5

HAWAII

Organization: Part I of this chapter presents a partial look at the provision of publicly-funded long-term care services in Hawaii to the three designated populations. Many state agencies are involved in this. The primary agencies involved are the Departments of Human Services and Health, and the Executive Office on Aging. Consequently, program and service information from these three agencies is presented. In Part II, the three agencies express their own views on the pros and cons of a single entry system in Hawaii.

PART I

The Department of Health

Access to the Long-Term Care System by Multiple Populations: The Department of Health (DOH) described how members of each of the three designated populations may access the long-term care system. There is no single entry point. The largest population -- *the elderly* and their families -- currently access the system through the Aging Network (AN). The AN is comprised of the Executive Office on Aging (EOA), the county Area Agencies on Aging (AAAs), and their contracted service providers. Prospective clients may call the relevant AAA, the EOA, or service providers. They may also call the Department of Human Services (DHS) or the DOH. In case of a hospital discharge, the medical discharge social worker or the person's family members would begin to explore post-discharge options. The DOH also cited a potential problem of access relevant to Hawaii's population -- that of "language access." Many of Hawaii's elders do not speak English. They may also hold beliefs concerning long-term care practices and expectations that are culturally very different from prevailing societal beliefs. The DOH argues the need to address these beliefs regardless of the structural model of access to services.[1]

As for *disabled children*, entry to the system is gained through a variety of access points. Access may be through the medical system where an initial diagnosis is made. During early childhood, the child's family may access special educational services in the schools. Later in life, they may access supportive services from the DHS for an indefinite period. Access may be through DOH's programs whose services include information and referral, care coordination and social work, developmental screening and evaluation, medical and related health services, early intervention services, respite care and family support, and parent-to-parent services. It appears that entry can be gained through any of the following DOH programs:[2]

(1) Zero to Three Project, including the Hawaii Keiki Information Services System;

(2) Children with Special Health Needs Program through the intake nurse; and

(3) Preschool Developmental Screening Program.

According to the DOH, *disabled non-elderly adults* gain access to the long-term care system in a similar way, that is, through the medical and social service system. Act 341,

Session Laws of Hawaii, 1987, created chapter 333F, Hawaii Revised Statutes, relating to services for persons with developmental disabilities (DD) or mental retardation (MR). Section 333F-2, Hawaii Revised Statutes, requires the DOH to "develop and administer . . . programs and services for persons with developmental disabilities or mental retardation within the limits of state or federal resources." It is interesting to note that even back in 1987, these programs may include the "development and implementation of a program for single-entry access by persons with developmental disabilities or mental retardation to services."[3]

According to the DOH, the DD population comprises a small but visible group in contrast to the larger but hidden population of disabled due to injury, accident, or illness. Members of the latter group tend to be cared for in their own homes and often fail to be counted for inclusion for services.[4]

Access and Eligibility to DOH Programs and Services for the Elderly: The DOH's Maluhia Home Health Center (Center) currently operates several programs. The *Maluhia Home Health Care (MHHC)* program makes available skilled home health care that is reimbursed by the client's medical insurance (Medicare, Medicaid, Hawaii Medical Service Association (HMSA) and HMSA Quest).[5] Clients must be home-bound (though not necessarily bed-bound),[6] have insurance, and meet insurance guidelines for participation. Services must be deemed medically necessary, be provided part-time or intermittently, and a physician must approve a plan of care. Actual services include skilled nursing and complex nursing procedures which include tube feeding, nasopharyngeal and tracheostomy aspiration, insertion of catheters, wound care, ostomy care, heat treatment, administration of medical gases, rehabilitation nursing, and venipuncture (collection of blood specimens).[7] Services also include home health aide services, medical social services, and physical, occupational, and speech therapy services. Access is by referral to the Home Health Care office through contact by the client, a physician, or a referral agency. If found eligible, the client is assessed and services rendered.[8]

The *Maluhia Waitlist Demonstration Project (MWDP)* is a Medicaid waiver program established in collaboration with the DHS through its Community Long-Term Care Branch (CLTCB).[9] Medicaid-eligible elders or disabled adults in acute care hospitals who require care at the nursing facility level but who are waitlisted for nursing home placement are eligible. Although there are no age restrictions, in reality there are no disabled children in the program because younger children are not usually waitlisted for nursing homes. There are over 350[10] hospitalized patients waitlisted for nursing homes in Hawaii (mostly on Oahu). However, adult residential care homes (ARCHs) have continuously had about 300 empty beds (about 15 percent to 20 percent of capacity).[11] MWDP participants are routed to qualified ARCHs[12] as an alternative to nursing home care. *(All ARCHs, including those not specially qualified in the MWDP program, are licensed by the DOH's Hospital and Medical Branch.)* Access can be through the social work department of hospitals or nursing homes. Applicants are screened and assessed for eligibility. The potential client meets with a Maluhia ARCH operator and the discharge team in a discharge planning meeting to determine a feasible match. The Center provides administrative oversight and case management and dietician services. The MWDP service package includes:[13]

(1) Housing: ARCHs are used to provide health and assisted living services and client supervision;

(2) Case Management: Continuous health and social assessments and coordination and monitoring of a comprehensive group of services are carried out;

(3) Home Based Health Services: These are intermittent therapeutic services that provide home assessments, teaching, continued monitoring of clients and caregivers, e.g., physical, occupational, and speech therapies, and dietician services;

(4) Personal Care Services: Personal care services are provided beyond what ARCHs are now required to provide, including assistance with ambulation, mobility, transfer, bowel and OPbladder control, toileting, bathing, dressing, grooming and feeding, meal preparation, medication assistance, chore services, essential errands and maintaining health records;

(5) Other Services: These include respite care, specialized medical equipment and supplies, adult day health care, environmental modifications, and transportation, if and when appropriate.

The Center also operates the *Maluhia PACE Hawaii Project* and is its focal point. In 1981, Maluhia established Hawaii's first adult day health center (ADHC). Today, this is known as the PACE program. The term PACE refers to a Program for All-Inclusive Care for the Elderly. PACE's 60 participants are being served by an interdisciplinary team of health care professionals. Prevention, regular medical supervision, and overall general fitness are the key components of the model. Through PACE's preventive and rehabilitative services, the program hopes to stabilize chronic conditions and prevent complications from diseases and reduce expensive hospitalizations.[14] Participants must be Medicaid-eligible, age 55 or older, reside in urban Honolulu, and be at the SNF or ICF level of care. About 87 percent live with their families while the rest live alone. The average participant is diagnosed with five to six medical conditions and 66 percent suffer from mental and cognitive impairments related to dementia or stroke.[15]

Participants engage in social activities, receive medical care, nursing, and rehabilitation therapies and treatment at the Center. They are closely supervised and their health status is monitored by the PACE interdisciplinary team. Services include:[16]

- Adult day health center[17]
- Dental care
- Durable medical equipment
- Nursing
- Podiatry
- Rehabilitation therapies (physical, occupational, recreation, and speech)
- Audiology
- Dietary consultation
- Home care/personal care[18]
- Optometry
- Social services
- Transportation
- Primary medical care
- Prescription drug coverage
- Skilled nursing home acre
- Incontinence supplies

The PACE program hopes to prove that for a fixed price ($2,100 per month) below that of nursing homes, participants can be cared for by emphasizing the use of adult day health care in combination with other services such as home care services. The $2,100 rate is about

20 percent less than the average monthly Medicaid rate expended on the aged population for their health and long-term care. Nursing home monthly rates range from $3,500 to $8,000. For private-pay clients, participation in PACE represents about a 40 percent savings over private nursing home costs. For services exceeding traditional Medicare and Medicaid benefits, PACE costs less than what Medicare, Medicaid, and private individuals now pay for long-term care.[19] However, the PACE program was constrained by Medicaid cost-sharing to about 49 slots. As a result, all slots have been filled. However, more patients are needed to make the program cost-effective. Thus, the PACE program has been marketed to private-pay individuals at $2,100 per month.[20]

To gain access to PACE, clients must call the program's intake at Maluhia directly.[21] Screening determines eligibility (existence of physician's order certifying nursing home level care; Long-Term Care Evaluation Form 1147; income information for private-pay patients). An assessment of the patient's social and medical situation is conducted and a plan of care is drafted. Case management is then provided.[22]

As mentioned above, the Center's *adult day health center* has now been incorporated into the PACE program. Some of the original ADHC clients have opted not to enroll in PACE but only avail themselves of the ADHC's services including routine nursing care and monitoring, social services, maintenance activities, lunch meals and snacks, and social activities. Although services continue, Maluhia is no longer accepting clients interested only in ADHC services.[23]

As for institutional care, the DOH's *Community Hospitals Administration* is responsible for the State's community hospitals, most of which offer *long-term care beds.* Only Maui Memorial Hospital and the Hana Medical Center do not have long-term care beds. All the others in the system (Hilo, Honokaa, Kau, Kauai Veterans Memorial, Kohala, Kona, Kula, Lanai Community, Leahi, Samuel Mahelona Memorial, and Maluhia Hospitals) offer long-term care nursing services. *(Maluhia Hospital is well-known for its 158 nursing home beds for both SNF- and ICF-level patients.)* The *Waimano Training School and Hospital (Waimano)* in the DOH's DD Division is an institutional facility. Although non-elderly disabled are eligible for admission to community hospital facilities, most have been located at Waimano because of that institution's special purpose and specially trained staff. Kula Hospital has ICF/MR beds for children. *(Leahi Hospital specifically admits "medically indigent persons who are suffering from chronic disease"*[24] *and is considered a long-term care facility. Leahi patients are considered functionally disabled or limited and remain if they are best served through institutional nursing home care.)*[25]

Other services and programs for elders, exclusive of those provided to persons with Hansen's Disease and by the DD Division, include:[26]

(1) Operation Assist, a two-year demonstration case management project run by the Public Health Nursing Branch for the elderly in East Honolulu using non-social workers (no M.A. in Social Work)[27] is scheduled to end in the near future;

(2) Communicable disease and immunization activities;

(3) Health promotion and education services;

(4) An alcohol and drug project on Maui for elders;

(5) A geriatric psychiatry training program at the Hawaii State Hospital;

(6) Dental health services to long-term care institutions; and

(7) Nearly statewide case management for elders provided through the public health nurse system.

The *Office of Elder Health* in the Personal Health Services Division was eliminated last year due to a lack of any real accomplishments. The envisioned intradepartmental coordination it could have provided did not materialize. Replacing it is an Aging, Long Term Care, and Disability Coordinating Committee which meets monthly to promote such intradepartmental coordination.[28]

Access and Eligibility to DOH Programs and Services for Disabled Children: While many of the services provided by or assured through the *Family Health Services Division (FHSD)* support disabled children, the DOH does not consider most FHSD-provided services long-term in nature. *(See discussion in chapter 3 under the headings "Long-Term Nature of Services and System Integration" and "Federal Programs for the Developmentally Disabled.")* Although disabled children need a set of services lasting a lifetime, not all types of care may be needed indefinitely. Even if they are, the duration of the provision of FHSD services depends upon the child's needs, age, and the program's services.

According to the DOH, children with special health needs are those "who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally." Thus, disabled children are only part of a much larger group of children with special health needs.[29] Accordingly, services to disabled children are only a part of a larger set of services to children with special health needs. In addition, many children with special health needs are not functionally impaired even though they may require continued services and follow-up over a long period of time.[30]

The DOH's Children with Special Health Needs (CWSHN) program assists families to obtain specialized medical care and other services for children with special health needs. Services include:[31]

- Care coordination services
- Specialty physician services
- Nutrition services
- Social work services
- Speech pathology and audiology services
- Outpatient x-ray, laboratory, and diagnostic tests
- Dental and/or orthodontic services for cleft lip and/or other craniofacial conditions
- Medications related to the eligible medical condition
- Transportation to and from neighbor islands to major treatment centers on Oahu
- Specialty clinic services

(See accompanying footnote for more information on services provided by the CWSHN Branch.)[32] The types of services, available by program, are as follows:[33]

Programs: (1) 0-to-3 --> Zero-to-Three Hawaii Project for children up to age three

(2) **CWSHN** --> **Children with Special Health Needs Program for those up to age 20**

(3) **PDSP** --> **Preschool Developmental Screening Program**

- *Information and referral:* Hawaii Keiki Information Services System **(through 0-to-3)**
- *Care coordination and social work:* **0-to-3 and CWSHN**
- *Developmental screening and evaluation:* **0-to-3 and PDSP**
- *Medical and related health services (including nutrition, speech pathology, audiology, physical therapy, occupational therapy, and/or psychological services:* **CWSHN; 0-to-3; and PDSP**
- *Early intervention services:* **0-to-3**
- *Respite care:* **0-to-3**
- *Family support services; parent-to-parent services:* **0-to-3**

The Zero-to-Three Project for those who are developmentally delayed or biologically or environmentally at risk, and their families, also provide newborn hearing screening, nutritional services, psychological evaluations, and social work.[34] The PDSP program focuses on the development of children aged three to five. Services include training to preschool staff in the administration of developmental screening for these children and consultation, interpretation, and follow-up services for those children identified by the screen. Children access the system by being referred by their parents, public health nurses, physicians, preschools which do not provide such screening, and by other agencies.[35]

Most children with medically fragile conditions either reside in Waimano or are placed in long-term care facilities for older adults. According to the DOH, although the DHS-operated Nursing Home Without Walls waiver program serves a small number of these children, there are not enough slots.[36]

Access and Eligibility to DOH Programs and Services for Disabled Non-Elderly Adults: According to the DOH, most of the long-term care services for the non-elderly disabled provided by the DD Division are available to disabled children as well. The *DD Division* (recently placed within the Health Resources Administration) oversees the Community Services for the Developmentally Disabled Branch (CSDDB). The CSDDB provides:[37]

- Eligibility determination for DD Division services
- Diagnostic services
- Service acquisition
- Case management
- Case coordination
- Residential and program placements
- Family support services including counseling, advocacy, family networking, family and community networking, self-advocacy and case management
- Adult day activity programs
- Limited recruitment and certification of residential homes either directly or through the purchase of services with general funds or through the maximization of federal funds

As mentioned above, there is no age criteria for service eligibility. Only those who are developmentally disabled or mentally retarded may receive services. Access is by application for service through the CSDDB's Central Intake and Diagnostic Services Section. The individual's mental retardation or developmental disabilities are assessed and evaluated.

On the institutional side, *Waimano* -- a certified ICF/MR and nursing facility -- provides 24-hour residential services for persons with developmental disabilities or mental retardation who cannot be sustained in a community setting. Residents are severely and profoundly mentally retarded who have intense medical conditions or challenging behaviors,[38] or both. Their conditions require extensive care which call for intensive supports and skills training. Skills training emphasizes the following areas: communication, self-help (eating, dressing, bathing), mobility, and social relationships.

Act 189, Session Laws of Hawaii 1995, effectively closes Waimano as an institution by June 30, 1998.[39] All Waimano residents are to be moved to appropriate non-institutional community settings. As a result, Waimano will no longer be admitting residents on a long-term basis. According to the DOH, Waimano has been reducing its census and plans to use a short-term crisis shelter to accommodate emergencies and provide respite for care providers. The DOH is very concerned about the needs of Waimano's residents, particularly those with challenging behaviors, who must moved to small residential homes. These Medicaid-funded small, community-based residential homes -- ICF/MR(c) -- need to be staffed 24-hours-a-day by trained persons who can handle challenging behaviors. Essential supports must also be in place. These include the crisis shelter, respite services, day programs, transportation to day programs, and timely access to medical specialty and therapeutic services. In addition, Home- and Community-Based Services waiver services will continue to be available.[40]

Waimano also operates a *Medicaid waiver community-based supports program* for about 200 persons with mental retardation living in the community, many of which are ex-Waimano residents. Services include day programs for the medically fragile and behaviorally challenged. Again, there are no age restrictions so that both children and non-elderly adults may receive services with the CSDDB determining eligibility.[41]

Neither the *Commission on Persons with Disabilities* nor the *State Planning Council on Developmental Disabilities* provides long-term care services. Both advocate for accessible, appropriate long-term care services for children and adults. The Commission addresses the significantly larger population of persons with disabilities, regardless of the type. The Council is concerned only with persons with developmental disabilities.[42]

The Department of Human Services

Community Long-Term Care Branch (CLTCB): The CLTCB operates under the DHS's Med-QUEST Division and serves the long-term needs of the elderly, the disabled, the DD/MR population, and the catastrophically ill. Client eligibility criteria include:[43]

- DHS doctor-certified need for acute, nursing facility, or ICF/MR-level of care
- Medicaid eligibility
- Non-Medicaid-eligible (for non-Medicaid programs)

- Determination by the CLTCB that needed services are below authorized expenditure ceilings
- Approval of client's personal physician that home care is safe with appropriate services

Populations Served: The definition of the DD population is basically the same as that used by the DOH.[44] This population is relatively small -- the prevalence rate in Hawaii is 0.9 percent and only ten percent of this group are Medicaid-eligible.[45] However, the disabled are defined differently from the DD population. According to the Rehabilitation Act of 1973 (as amended in 1978), a handicapped individual is any person who:[46]

- Has a physical or mental impairment which substantially limits one or more of such person's life activities;
- Has a record of such impairment; or
- Is regarded as having such an impairment.

Again, only about ten percent of this group are Medicaid-eligible.

The CLTCB also serves the catastrophically ill -- persons not necessarily born with debilitating disabilities. The CLTCB defines a catastrophic illness as:[47]

> [a]n illness experience for which a person incurs medical expenditures in excess of $5,000 during a single calendar year including expenses that are the sum of out-of-pocket and third party payments. Additionally, those medical expenses exceeding 15 percent of gross family income could be called catastrophic expense. The current range of possible catastrophic illnesses includes such widely divergent illnesses as heart and kidney disease, mental illness, and cancer. For the purposes of identifying current target populations for community long term care services, the focus will be primarily on identifying clients who are diagnosed with HIV and those who are technology-dependent [w]hose cost of care commonly exceeds $20,000 - $30,000 per year.

CLTCB Programs: The CLTCB operates several programs. Chief among these is the *Nursing Home Without Walls (NHWW)* program which began in 1982. *(Note: The CLTCB also operated a non-Medicaid component of the NHWW program until August 31, 1995 when state budget cuts forced its termination. It had served 51 gap group disabled clients who paid up to $1,200 per month for the same services as in the NHWW Medicaid component. The CLTCB also operated the Hawaii Centers for Independent Living Personal Care Program with a $184,000 budget for gap group disabled to find and pay for at-home nursing care. This program also terminated August 31, 1995 due to budget cuts.)*[48] The NHWW program provides an array of health, social, and environmental services tailored to clients' individual needs in their own homes that are otherwise available only in institutions. The severely and chronically ill and disabled in the NHWW program must be able to be maintained at home with reasonable assurance of health and safety at less than institutional costs. The primary services used are personal care and skilled nursing. The range of NHWW services, depending on local resources, include:[49]

- Case management
- Environmental modifications
- Personal care
- Skilled nursing
- Home delivered meals
- Moving assistance
- Non-medical transportation
- Adult day health

- Home maintenance
- Nutritional counseling
- Homemaker services
- Respite care
- Emergency alarm response system

Although it was originally thought that most clients would be elderly, the NHWW program now serves all age groups. Understandably, the largest proportion (43 percent) of clients is comprised of the oldest age group -- those age 65 and older. However, adults aged 18 to 49 comprise the next largest proportion at a substantial 31 percent. Those aged 50 to 64 make up only 13 percent while disabled children accounted for another 13 percent. In other words, children and non-elderly adults make up 44 percent -- almost half -- of the NHWW population.[50] The program's waiver has been renewed by the Health Care Financing Administration for five years to 1997 which authorizes an increase from the 350 clients served in 1993 to 500 clients over the five-year period. Even so, the NHWW program maintains a waiting list of over 300 individuals statewide. More importantly, the CLTCB states that it cannot serve the approved increase in clients because of insufficient funding. In 1993, the average annual cost per NHWW client was $11,694, roughly half the average institutional cost of $23,028.[51]

The CLTCB also runs the *Home and Community Based Services* waiver consolidated program for the developmentally disabled and mentally retarded. Clients must be Medicaid-eligible and require ICF/MR-level of care. As with other waivers, service costs must not exceed institutional ICF/MR care. Services are provided directly by the DOH and qualified private providers and individuals to clients living in care, foster, domiciliary, or their own homes. Services include case management, habilitation, respite care, environmental modification, adult day health care, personal care, and skilled nursing. Over 500 individuals were served in fiscal year 1993 on Oahu and Maui, of which one-third were deinstitutionalized from an ICF/MR facility upon admission to the program. Two-thirds were residing in the community.[52]

Finally, the CLTCB operates the *HIV/AIDS Community Care Program* which began in 1988. This waiver program has been approved for five years through May 31, 1997. Services are similar to those provided by other CLTCB-run programs. The additional eligibility criterion, naturally, is a diagnosis of HIV/AIDS infection.

The CLTCB does not operate but rather provides administrative oversight for the following four programs:[53]

(1) Foster Family Community Care Program (a waiver program, similar to the MWDP, for individuals age 55 and older to demonstrate a cost-effective community-based residential alternative for people who would otherwise be institutionalized);

(2) Developmentally Disabled/Mentally Retarded Program;[54]

(3) HIV Community Care Program (on Oahu); and

(4) Non-Medicaid Personal Care Program (for chronically ill and disabled clients who receive subsidies to independently hire, manage, and train personal care attendants).

In addition, the CLTCB has developed a *Home Health Training Unit* to train home health aides to meet the increasing demand for personal care services. The unit trains

personal care/home health paraprofessionals in a ten-week course consisting of 170 hours, achieving a 70 percent course completion rate.[55]

Family and Adult Services Division -- Project Malama: Aside from the CLTCB in the Med-QUEST Division, the Department's Family and Adult Services Division had been operating *Project Malama* as part of the *Hawaii Long-Term Care Channeling Demonstration Project (Channeling Demonstration).* Project Malama was closed October 1, 1995 due to state budget cuts.[56] The Channeling Demonstration aimed to promote state long-term care planning for the disabled elderly and to institute a local channeling and case management project to prevent and delay institutionalization. Project Malama provided the channeling services to disabled and impaired elderly who wished to live, despite their disabilities, in the community and not in institutions. Channeling refers to the appropriate routing to and use of existing long-term care organizations and systems for the benefit of clients. Its primary elements are assessment, case management (including care planning and arranging for and monitoring of services), monitoring of clients, and reassessment. Thus, Project Malama did not directly provide services; it only coordinated them.

By way of background, the U. S. Department of Health and Human Services established the National Long-Term Care Channeling Demonstration in 1980. Hawaii was among twelve states chosen to participate in the project. The National Channeling Demonstration was created to develop and test methods to maximize the efficient use of existing long-term care resources. Channeling projects had the following objectives:[57]

(1) To marshal and direct long-term care resources in a community so that overall costs are contained;

(2) To increase access to a wider range of services than is currently available;

(3) To match services used to the identified needs of clients;

(4) To concentrate public resources on those persons with the greatest need for subsidized long-term care;

(5) To stimulate the development of needed in-home and community services which do not exist or are in short supply;

(6) To reduce the unnecessary use of public long-term care services, including costly medical and institutional services;

(7) To promote efficiency and quality in community long-term care delivery systems;

(8) To promote a reasonable division of labor among informal support systems (including families, neighbors, friends), privately financed services and publicly financed care; and

(9) To maintain or enhance client outcomes, including physical and mental functioning and quality of life.

Project Malama first began accepting referrals on May 10, 1982. By June, 1983, it had received 424 referrals and had served a cumulative active caseload of 264.[58] Participants had to be age 65 or older and unable to care for themselves for six months or more. They had to live in the catchment area and have caretakers who find it difficult to continue providing care. If they were in hospitals, they must have been eligible for discharge within three months.[59] Income was not an eligibility criterion and participation was voluntary. At

the time of its closing, Project Malama had been operating with $500,000 in state funds.[60] It had served 389 clients during the fiscal year that ended June 30, 1995.[61] It also purportedly had a waiting list of about 100 individuals.[62]

The then Department of Social Services and Housing stated in 1983 that channeling and Project Malama were:[63]

> [a] departure from current general practice because *it attempts to establish a single entry for accessing long term care services, promotes client-focused services*, and introduces an altered set of relationships among health, mental health and social service agencies to *help clients gain access to a wider array of services than is usually available. [Emphasis added]*

The fact that such a project existed purely to help coordinate services to address the long-term care needs of the elderly is testimony that access to services is not easy. According to Dorothy Ono, Director of Project Malama:[64]

> Have you ever tried to apply for services? Do you know how complicated it can be to get a home-delivered meal or bathing services? The linking up takes a lot of time, effort, and expertise. Many of these people will be lost without us there to do the monitoring and to be an advocate and make sure everything happens.

The Family and Adult Services Division also runs the Senior Companion Program which trains seniors to become companions to other seniors. This is a federally-funded, non-Medicaid program which pays seniors a stipend for working as senior companions.[65]

The Executive Office on Aging

Functions of the Executive Office on Aging (EOA): The EOA's mandate covers all elderly persons age 60 and older. It administers funds received under the Older Americans Act (OAA) and from state purchases of service and grants-in-aid directed primarily at the provision of home- and community-based care. It also sets standards and establishes contractual agreements with providers for services. The EOA is also the state unit responsible for planning, coordination, and advocacy for social services and other needs of the older population in compliance with the OAA.[66] *(See "Note" in chapter 2 under section titled "Numerical Assessments -- Gatekeeper Function" for detailed discussion on the role of the EOA under the OAA.)*

Services: The EOA does not provide direct services. Services that are funded through the OAA and other sources are available throughout the State through a network of public and private agencies. These agencies provide nutrition services (home-delivered and congregate meals), access services (information and referral, transportation, outreach, and other services), in-home services (chore, friendly visiting, telephone reassurance, and other services which enable elders to live independently at home), and legal services.[67]

Also, for a number of years, the EOA had operated a Case Management Demonstration Project in conjunction with the DOH. The EOA designed, evaluated, and monitored the program and the DOH carried out the actual case management activities. The project is phasing out and a final report is to be published soon.[68]

Statutory Duties of the EOA and Administrative and Program Support: By statute, the Director of the Executive Office on Aging (EOA) has the following functions, duties, and powers:[69]

(1) Serve as the principal official in state government solely responsible for the performance, development, and control of programs, policies, and activities on behalf of elders;
(2) Oversee, supervise, and direct the performance by the director's subordinates of activities in such areas as planning, evaluation, and coordination of elder programs and development of a statewide service delivery network;
(3) Assess the policies and practices of other agencies impacting on elders and conduct advocacy efforts for elders;
(4) Advise the governor on new legislation, programs, and policy initiatives and conduct such liaison as would be required to implement them;
(5) Serve as a member of advisory boards and regulatory panels of state agencies in such areas as income maintenance, public employment, retirement systems, certification of health care facilities and programs, social service and medical assistance, and housing and employment, among others;
(6) Administer funds allocated for the executive office on aging; and apply for, receive, and disburse grants and donations from all sources for elder programs and services;
(7) Establish a clearinghouse for complaints of persons regarding services to elders, or operations of state and county agencies affecting elders, investigate the complaints, and refer the complaints and the director's findings to the appropriate agency for corrective action;
(8) Adopt, amend, and repeal rules pursuant to chapter 91 for the purposes of this chapter;
(9) Employ and retain such staff as may be necessary for the purposes of this chapter, in conformity with chapters 76 and 77; and
(10) Contract for or grant such services as may be necessary for the purposes of this chapter, including master contract with other state agencies receiving federal and state funds for programs and services for the aging, and purchase of service agreements with appropriate agencies.

The EOA also engages in various planning and administrative activities as well as community assistance and program management. Its planning and administrative services division is responsible for the:[70]

(1) Preparation and submission of programs and budgets;
(2) Preparation of an annual evaluation report on elder programs for the governor and legislature;
(3) Preparation of studies and analysis;
(4) Maintenance of personnel records;
(5) Management of contracts and agreements entered into by the executive office on aging with public and private vendors, consultants, and suppliers;
(6) Monitoring the purchase of service agreements with public and private agencies and rendering technical assistance to elder program service providers; and
(7) Establishment and maintenance of reimbursement systems for services provided by agreement with federal, state, and county agencies, as well as private groups.

The EOA's other division, the community assistance and program management division, engages in the following activities:[71]

(1) Legislative research and development as well as liaison on state and federal legislative matters;

(2) Conducting public affairs programs on elder affairs programs, projects, and needs;
(3) Development and implementation of educational, recreational, and cultural programs for elder persons;
(4) Provision of technical assistance and liaison with community groups, organizations, and independent programs of benefit to the elders;
(5) Development and implementation of active programs of consumer protection and pre-retirement counseling;
(6) Establishment of a statewide information and referral system, and an annual inventory of elder programs and service agencies;
(7) Technical assistance and liaison for the purpose of establishing elder-controlled local service delivery systems providing comprehensive services and employment opportunities for elders throughout the State; and
(8) Development and management of federally funded programs and special projects under the Federal Older Americans Act and other federal sources.

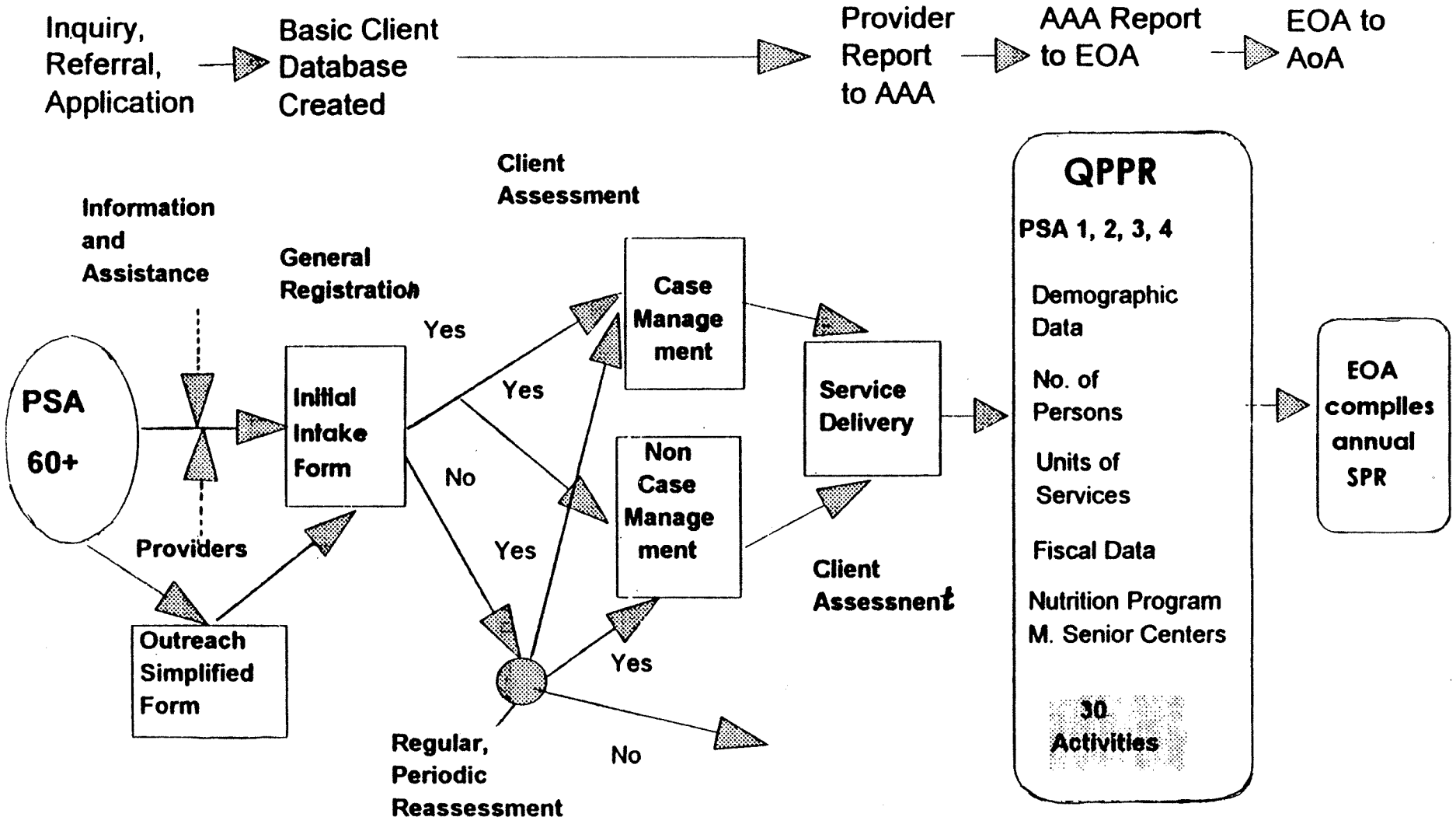
System Access: The EOA's access services include information and referral to long-term care services, outreach to seniors, and transportation. According to the EOA:[72]

> Elders gain entry to the system in a variety of ways. This office is engaged in wide-spread publicity and community education which includes long term care. We have brochures and other printed information and media materials which advertise our services. There is widespread distribution of our information and referral numbers and our Toll-Free national information services which undoubtedly draw many seniors to us for access to the system. Some simply go directly to providers when they feel the need is there. Physicians are a common source of entry into the system. Referral sources for the case management demonstration project were varied. Other long term care agencies, senior centers, county I and R services, hospital discharge planners were all among those referring to this project.
>
> Usually, low income seniors will go directly to the Medicaid program. It is our understanding that when nursing home admission is sought, that the client is referred to Medicaid and a cost-share arrangement is made after determination of eligibility in anticipation of the spend down of assets which qualifies the client.

The following figure from the EOA illustrates how clients are processed through the system.[73]

Figure 5-1

Data Collection Flow Chart: Existing System



Yes: Client needs a service.
No: Client does not need a service.

PART II

View of the Department of Health: The DOH states that:[74]

> [f]rom a national perspective, there is **no consensus** as to the efficacy of a single entry point to publicly funded long term care services or to programs for older adults and disabled persons.
>
> **It is most important to note that the establishment of a single access point in this state will do little to alleviate one critical fundamental shortcoming; i.e., the lack of an adequate supply of affordable, appropriate, quality home and community-based services and of an adequate supply of institutional nursing home beds to which to refer individuals and families. It would be morally challenging for the State if, once able to "enter" the system, its clients were to find that there are no appropriate services to which they can be referred or which they can afford.**

The DOH cited the recent conclusion of representatives from ten states judged by the Council of Governors' Policy Advisors as having exemplary programs for their aging populations that states cannot expect the use of a single access point to provide a "silver bullet" for service delivery dilemmas. It emphasized the pointed rejection of the single access model by the representatives from Florida, which has a very high number of elderly residents. Florida reportedly refrained from the single access approach when "practical, negative consequences became defeating and unacceptable, that is, long waits and lines" were created for the at-risk elderly.[75]

Recommendations of the Department of Health: According to the DOH, rather than treating the single access model as the panacea via which populations in need of long term care can be best served, the following four other approaches should be developed. Paraphrased, these are:[76]

(1) **Additional home and community-based services must be expedited.** Government cannot be expected to subsidize all costs, thus clients with resources should begin to cover all or a part of the costs for their home- and community-based care. More providers need to understand that they must seek reimbursement from clients who can pay for their services.

(2) **A coordinated management information system with the use of a uniform intake form and with immediate access information and referral capabilities must be developed.** As many agencies as possible should be networked by computers. They should use standard forms with special supplements for differing populations, as needed.

(3) **A uniform, coordinated, case management system must be developed.** Clearly articulated policy on case management and its use is needed. For example, if private sector service or insurance entities acting as case managers who authorize services also act as direct providers of services, the resulting conflict-of-interest issues must be resolved.

(4) **A Long Term Care Ombudsman for home- and community-based services must be established.** The OAA mandates such an ombudsman only for institutional care. One is also needed to assure quality of care for home- and community-based services.

The DOH makes several additional points (paraphrased below):[77]

- Vulnerable individuals will likely have to pay a greater share of the costs of their long-term care, institutional or home- and community-based, because of federal budget cuts.

- Research suggests that a segment of frail and vulnerable individuals with high levels of functional disability requires nursing home care for whom home- and community-based care is inadequate. The latter type of care cannot totally replace the former. Most persons in need of nursing home beds in Hawaii have much more exacerbated functional limitations than may be the case in mainland facilities. Nursing home residents in Hawaii tend to have three to five functional limitations.

- There are quite a number of these individuals in Hawaii who cannot get into a nursing home bed because there are not enough to go around.

- As the reliability of Medicaid funding erodes, nursing homes are already beginning to admit only those judged wealthy enough to pay for institutional care for the long term.

- As federal Medicare SNF cuts become a reality, hospitals will no longer continue to indefinitely accommodate patients who are waitlisted for long-term care facilities. A significant number of hospitals and nursing homes may close throughout the nation as a result of increasing fiscal constraints. This would be disastrous in Hawaii where more capacity is needed.

- The need for consistently available, quality hospital discharge planning will increase as more patients are anticipated to be discharged back to their own homes due to Medicare cuts. Current discharge planning occurs unevenly; it should be a routine core service that adequately prepares patients for discharge to some sort of long-term care.

- The need for more nursing beds in Hawaii must not be overlooked. Relatively few of the 1,000 CON-approved[78] beds are expected to become reality. Past fiscal disincentives militating against the construction of these beds due to the State's inability to provide more matching funds for Medicaid-reimbursed beds will only be fueled by anticipated future federal cuts.

- The shortage of beds is the inevitable reality facing a person accessing the long-term care system regardless of where entry is obtained.

The DOH: Advantages and Disadvantages of a Single Entry Point: An *advantage* of an SEP conceded by the DOH is that it "may be easier for the consumer to identify." In addition, there may be some inherent efficiencies if the entry point has bilingual and other language resources and a multidisciplinary capability. However, the DOH cautions that such an entry point needs to be negotiated among the various entities currently serving as access to the system.

As for *disadvantages,* first, the DOH feels that an SEP may cause longer waits for individuals to receive services. Second, an SEP does not increase either institutional or home- and community-based services. Third, it does not assure quality of care. Fourth, it does not "ensure coordination or appropriation of existing services if discharge planning is not consistently available and if case management is not utilized judiciously."[79] According to the DOH, aside from an SEP, the State also needs -- as a requisite component of a state health system -- a coordinated, integrated information system.[80]

View of the Department of Human Services: The DHS believes that a single entry point for the three designated populations can be implemented but it would be difficult.[81]

According to the DHS, the basic medical needs are the same for all three populations. Although some needs are different, it believes they can be worked out. All agencies and advocacy groups involved need to work out criteria for screening and assessment. Most of this work must be reduced to written guidelines and working screening tools, etc., so that individuals or teams performing actual screening and assessment need not be expert in all three populations. The DHS feels that the priority should be on health and medical needs -- who gets long-term care beds. Entry through the SEP must be mandatory for all public-pay clients regardless of whether institutional or home- and community-based services are authorized. The DHS also feels that the State must show a strong commitment to the SEP and provide strong leadership to make the system work.[82]

The DHS: Advantages and Disadvantages of a Single Entry Point: On the subject of Senate Concurrent Resolution No. 33 and Senate Resolution No. 27 (1995) (S.C.R. No. 33 and S.R. No. 27), the DHS testified regarding the *advantages* of an SEP: it could possibly simplify access to services, reduce the need for multiple assessments for each service utilized, and provide for more efficient use of resources.[83] Currently, access is often hit-and-miss, often depending on who one knows: a provider, a friend of a provider, someone in government, etc. Nonetheless, the DHS cautioned that, because of inadequate funding, the system probably could not handle a sudden increase in clients resulting from enhanced access and better-known services due to increased public awareness. However, this is not strictly a disadvantage because the extent of program funding is independent of the type of access model. A possible *advantage* of an SEP could accrue if Congress authorizes states to mandate certain long-term care arrangements. For example, reduced federal funding may be accompanied by federal authorization for states to manage their own long-term care resources. In turn, states may wish to allocate their institutional and community-care resources by requiring even private-pay individuals to pass through a certain uniform screen.[84]

The DHS acknowledged that differences do exist among the three populations and they may be hard to work out in any standardized tool. This could be a *disadvantage. (Note: If ease of implementation or amount of effort are goals, then the difficulties involved in working out differences would be a disadvantage. However, assuming that the required effort is put in, the degree of difficulty no longer remains a disadvantage for an SEP. Whether it stands up in actual use will depend on how well differences have been ironed out.)*

The DHS cautions that shared screening and assessment tools must not be made too complicated. The need to encompass three target populations leaves open the danger that shared tools become unwieldy. The need to establish common ground may compromise the needs of some populations, a *second disadvantage*. Individual programs offered by various agencies and supported by various advocacy groups for differing populations may be weakened. A further *disadvantage* of an SEP is the possibility of creating another layer of bureaucracy.

View of the Executive Office on Aging: The Executive Office on Aging expressed its opinion on the pros and cons of establishing a single entry point for the three designated populations:[85]

> *We do not believe it is feasible to establish a single-entry point to all ages and disabilities because of the complexity of the needs and resources available for each.* [We] do believe that better coordination will result in easier access for all clients. This includes cross training and cross referrals for the three groups. We are attempting to

> establish easier access for older adults and this is no easy task given the complexity of the system and the number of players. *[Emphasis added]*

On the subject of S.C.R. No. 33 and S.R. No. 27, the Executive Office and Aging testified with regard to an SEP that:[86]

> Responding in a comprehensive, caring and knowledgeable manner requires substantial experience and training. The conditions and needs of vulnerable children, young adults, and older adults who are impaired can vary widely and require specific approaches tailored for individual needs. Accordingly, the capacity of any entry point is limited, in part, by the training and experience of the staff, the adequacy of funding, and the level of awareness of the patient and his or her family.

The extent of the cross training that may possibly be needed can be seen from the EOA's identification of the players involved in providing for the long-term care needs of, in this case, just the elderly. Depending on how an SEP is actually set up, these may include:[87]

(1) The EOA & the county AAAs;
(2) The Department of Commerce and Consumer Affairs;
(3) The Department of Education;
(4) The Department of Health;
(5) The Department of Human Services;
(6) The Department of Labor and Industrial Relations;
(7) The Department of Transportation;
(8) The University of Hawaii;
(9) Federal agencies and programs including Social Security; and
(10) Private programs and services.

The EOA: Advantages and Disadvantages of a Single Entry Point: The EOA did not cite any clear advantages of an SEP. It did point out that any movement towards some form of consolidation could be a cost-saving measure. The EOA cites experiments in Indiana that coordinated different funding sources for in-home services to the elderly that significantly reduced costs. However, the EOA expressed uncertainty that this would work for combined groups, citing different goals and outcomes for the three designated populations.[88]

The EOA does not believe an SEP is feasible. Rather, it believes in better coordination among agencies and providers, expanded use of technology for sharing information, and using standardized intake and/or referral forms. However, the EOA acknowledges that older adults consistently prefer obtaining services through one phone call, one intake form, and one centralized location. According to the EOA, increased linkages, especially using an electronic system, offer a mechanism for accomplishing this. The implication is that the convenience and simplified access that clients want can be achieved through system coordination without implementing an SEP.[89]

An important question was raised by the EOA concerning the meaning of "single access."[90]

> If it ["single access"] means that one entity would accept, screen and determine interventions or referrals for long term care, then there is a problem about the management of a pool of resources, funds or entitlements and the case management aspect. We have seen evidence that those who case manage clients may best serve them by having no affiliation with direct services to avoid a bias in referrals.

That is, it is reasonable to infer the following *disadvantages*. First, conflicts-of-interest may arise if case management agencies which authorize services in an SEP are also allowed to provide direct services. Second, it is difficult to pool differing categorical funding streams. Third, it is difficult to manage previously separate screening, assessment, and case management services to create a coordinated delivery system. *(Note: See the final chapter for discussion on the difference between* one standard concept *in an SEP as opposed to* one entry point using an inflexible tool *where entry is limited by geographical location or to a single-constituent agency whose expertise some may feel is not appropriate for all groups.)*

The EOA lists several further *disadvantages* of an SEP. First, rural communities fear exclusion if an SEP means they must access the system in a more central location. They fear simple access may work in reverse for them, making it more difficult. Second, an SEP may slow down service delivery and lengthen existing waiting lists and create bottlenecks.[91]

The EOA reports that 16 states have "single entry points" for senior services with the term used to mean the pooling of common funding sources. According to the EOA, 29 states consider access and care coordination key policy issues. It further reports that many appear to be moving toward adopting a single entry point concept, but only for elder programs, not for all age groups and types of disabilities.[92]

Endnotes

1. Memo dated November 17, 1995 from Jeanette C. Takamura, Ph.D., Deputy Director of Health, to Wendell Kimura, Director, Legislative Reference Bureau, p. 4.

2. Ibid., p. 5.

3. Hawaii Rev. Stat., sec. 333F-2(c)(5).

4. Takamura memo, p. 6.

5. Takamura memo, Maluhia attachment, p. 1.

6. Ibid. A condition must exist whereby there exists a normal inability to leave home. Leaving would require a considerable and taxing effort, absences must be infrequent or attributable to the need to receive medical treatment. Such absences do not indicate that the client has the capacity to obtain the health care outside rather than in the home.

7. Ibid., p. 2.

8. Takamura memo, p. 7.

9. The MWDP was established by 1994 Haw. Sess. Laws, Act 165.

10. There are 400 waitlisted for nursing homes in acute care hospitals each incurring daily costs of about $2,000. Telephone interview with Cullen Hayashida, Assistant Administrator, Maluhia Hospital, September 6, 1995.

11. Hawaii, Maluhia Waitlist Demonstration Project: 1995 Legislative Report, Maluhia Long-Term Care Health Center, Department of Health, January, 1995 (hereafter "Waitlist Report"), p. 1.

12. Contracts with the Department of Human Services to train 12 ARCH [Boperators have been approved and a memo of agreement with Medicaid and the DHS regarding payment has been signed. (Hayashida interview)

13. Waitlist Report, Attachment C-2.

14. Hawaii, PACE Hawaii at Maluhia (Program of All-Inclusive Care for the Elderly), annual report, Department of Health, Community Hospitals Division, 1995 (hereafter "Maluhia annual report"), executive summary.

15. Ibid.

16. Ibid.

17. Almost all (99 percent) of PACE program participants use the adult day health center but, of course, they are not limited to the day health center's services. Hayashida interview.

18. About 36 percent of PACE participants receive home care services on a regular basis. This includes bathing, grooming, meal preparation, and light chore services. Grocery shopping and escort services are also available especially to those who live alone. Maluhia annual report, p. 2.

19. Ibid., pp. 2-3.

20. Hayashida interview.

21. Takamura memo and Hayashida interview.

22. Hayashida interview.

23. Takamura memo, pp. 8-9.

24. Hawaii Rev. Stat., sec. 323-68.

25. Takamura memo, pp. 9-10.

26. Ibid., p. 11.

27. Hayashida interview.

28. Takamura memo, p. 11.

29. Takamura memo, Disabled Children Attachment, p. 1.

30. Ibid., p. 3.

31. Ibid.

32. Peter G. Pan, Care of High Risk Infants in Hawaii, Legislative Reference Bureau, Report No. 9, (Honolulu: 1989), pp. 52-53:

    Services for children with special health needs in Hawaii are based on medical categories. Coverage is restricted due to limited funds and is shaped by historical funding precedent. Patients up to age 20 receive services under the following medical categories:

(1) Severe asthma;
(2) Heart disease;
(3) Eye surgery;
(4) Hearing loss;
(5) Myelodysplasia;
(6) Birth defects;
(7) Seizure disorder;
(8) Orthopedic problems;
(9) Cleft lip & palate;
(10) Metabolic disorders;
(11) Cerebral palsy; and
(12) Genetic conditions.

33. Takamura memo, pp. 12-13.

34. Takamura memo, Disabled Children Attachment, pp. 1-2.

35. Ibid., p. 2.

36. Takamura memo, p. 14.

37. Ibid., pp. 14-15.

38. Challenging behaviors range from self-injury such as biting or hitting oneself, to physical or sexual aggression toward others. Takamura memo, p. 15.

39. 1995 Haw. Sess. Laws, Act 189.

40. The DD Division provides match funds for the Medicaid-funded ICF/MR(c) facilities as well as for the HCBS waiver program while private providers deliver actual services. Takamura memo, p. 16.

41. Ibid., p. 15.

42. Ibid., p. 17.

43. Hawaii, Annual Report, Department of Human Services, Long Term Care Branch, 1993, p. 9.

44. Hawaii Rev. Stat., sec. 333F-1.

45. Long Term Care Branch annual report, p. 10.

46. Ibid., pp. 10-11. The DHS acknowledges that its use of this definition overlaps the "handicapped" with other populations.

47. Ibid., p. 11, partially citing Birnbaum 1978, p. 7.

48. Ann Botticelli, "Home-care program cuts protested," in Honolulu Advertiser, August 1, 1995.

49. Long Term Care Branch annual report, p. 12.

50. Ibid., p. 13.

51. Ibid.

52. Ibid., pp. 14-15.

53. Ibid., p. 5.

54. Interview of September 27, 1995 with Department of Human Services staff: Alan Matsunami, Community Long-Term Care Branch Program Director and Leslie Tawata, Community Long-Term Care Branch Acting Administrator: The DOH selects clients and sends application forms to the DHS. DHS then certifies clients at the ICF/MR level. Clients then choose from nine providers and DHS pays the bills. DOH is responsible for finding providers. However, because of Medicaid, it is the DHS that signs contracts with providers. The DHS has done some monitoring but intends to relinquish this role and have the DOH resume monitoring in the future. Clients are placed variously in care homes, foster homes, and natural homes.

55. Ibid., p. 24.

56. Botticelli article.

57. Hawaii, Progress Report of Project Malama, May 1982 - August 1983, Department of Social Services and Housing, Long Term Care Channeling Demonstration Project, Contract #HHS-100-80-0137, December, 1983 (hereafter "Project Malama report"), pp. 2-3.

58. Ibid., p. 5.

59. Ibid., p. 7.

60. Botticelli article.

61. Ann McDuffie and Christopher Neil, "Budget ax wounds elderly, immigrants," in the Honolulu Advertiser, August 7, 1995.

62. Letter to the Honolulu Advertiser from Donna Grain, September 6, 1995.

63. Project Malama report, p. 6.

64. McDuffie and Neil article.

65. DHS staff interview.

66. Memo of September 14, 1995 from Marilyn R. Seely, Director, Executive Office on Aging, to Wendell Kimura, Director, Legislative Reference Bureau, p. 1.

67. Hawaii, Four-Year Area Plan on Aging, Executive Office on Aging, (for the period October 1, 1995 to September 30, 1999) p. 43. Many other services are also listed ("not an exhaustive list") that are provided at differing geographic sites throughout the State. These are described by each county submitting their respective four-year plans which are compiled by the EOA into the state plan and include: case management, chore, respite, adult day health, Alzheimer's day care, personal, escort, transportation, information and assistance, housekeeping, outreach, education/training, recreation, telephone reassurance, visiting, volunteer, elder abuse and neglect, legal, health maintenance/promotion, adult day care, Alcoholics

Anonymous, Ke Ola Pono No Na Kupuna, AARP, Kuakini Parkinson's disease, diabetes education and support, Mended Hearts/Stroke Club, day hospital, exercise, self-help, interpretation, comprehensive individualized services, housing assistance, Lanakila Multipurpose Senior Center, money management, Emphysema Hui, asthma education, Long Term Care Ombudsman, credit counseling, literacy, home-delivered meals, Senior Community Service Employment, hospice, emergency response, outpatient and family interdisciplinary consultation, nutrition counseling, shopping, companion, immigrant, advocacy, mediation, guardianship, veterans, foster care, adult protective, retirement, home health, and mental health services. (pp. 44-63)

68. Seely memo, p. 1.

69. Hawaii Rev. Stat., sec. 349-3.

70. Hawaii Rev. Stat., sec. 349-5(b).

71. Hawaii Rev. Stat., sec. 349-5(c).

72. Seely memo, p. 2.

73. Seely memo, Attachment.

74. Takamura memo, pp. 1 & 3.

75. Ibid., pp. 1-2. On March 10, 1995, the DOH submitted testimony on S.C.R. No. 33 and S.R. No. 27 stressing that the needs of those requiring long-term care are diverse, implying that an SEP may have difficulty in successfully addressing those needs. On April 7, 1995, the State Planning Council on Developmental Disabilities warned in testimony that an SEP "is only one component of a comprehensive long-term care system, but a very important one that has impact on improving consumers' access to appropriate levels of health care services."

76. Takamura memo, pp. 2-3.

77. Ibid., pp. 3, 4, 5, & 10.

78. Nursing home beds must receive a certificate of need (CON) approval from the State Health Planning and Development Agency pursuant to chapter 323D, Hawaii Revised Statutes.

79. Ibid.

80. Ibid., pp. 6-7.

81. DHS staff interview.

82. Ibid.

83. Testimony submitted by the DHS on Senate Concurrent Resolution No. 33 and Senate Resolution No. 27, Eighteenth Legislature, State of Hawaii, April 18, 1995.

84. DHS staff interview.

85. Seely memo, p. 2.

86. Testimony submitted by the Executive Office on Aging on S.C.R. No. 33 and S.R. No. 27, Eighteenth Legislature, State of Hawaii, March 10, 1995.

87. Hawaii, Long Term Care Plan For Hawaii's Older Adults, Executive Office on Aging, Office of the Governor, July, 1988, p. 8.

88. Seely memo, p. 2.

89. Ibid., pp. 2-3.

90. Ibid., p. 2.

91. Ibid.

92. Ibid., p. 3.

Chapter 6

RECOMMENDATIONS AND RESERVATIONS

> *"In order for the controlled access concept to be effective, especially in the broker model ... it is critical that the organizational interests of participating groups be recognized. These participants are expected to give up some portion of their autonomy, so they are entitled to have a reciprocal relationship by which they gain access to clients [and] are rewarded for participating in a quality program..."*[1]

Concept of a Single Entry Point: Creating a single entry point (SEP) to the long-term care system is not the same as totally integrating that system. Therefore, arguments cited as disadvantages of total system integration do not necessarily apply to the creation of an SEP. As mentioned several times in previous chapters, *total system integration* is an extreme measure. However, the system can be integrated by varying degrees. For example, *system coordination* can entail less than full-scale integration, as with the creation of an SEP.

It is important to remember that an SEP is only one component of the long-term care system and is only a first step. Thus, an SEP *coordinates* access to long-term care, but does not necessarily integrate other components of the long-term care system. An SEP often involves the coordination or consolidation of screening, assessment, case management, and authorization of services functions. Occasionally, an SEP also involves pooling of different categorical funding streams. Although it is an obvious option, states have used SEP systems without undertaking major governmental reorganization. Several SEP states have not had to create new single-purpose agencies or abolish multiple existing long-term care agencies to accommodate a coordinated system of access.

On the other hand, creating an SEP for several populations does imply a shift in policy away from a categorical approach toward a generic approach based on individuals' common functional limitations. Many states have not had to fully face this problem because their SEP systems focus on only one major population -- the elderly. An SEP for multiple populations makes more sense when common functional criteria are used. Accordingly, arguments pro and con for an SEP parallel those for a generic approach to dealing with multiple populations.

Advantages of a Single Entry Point: A good SEP may make it easier for members of targeted populations to gain initial entry into the long-term care system. If an SEP can adequately handle and process multiple populations, ***entry should be easier and more equitable for members of all populations.*** Access is facilitated to the extent that those in different categorical populations are not turned away or required to undergo multiple screenings and assessments in an SEP. Access is made more equitable in that all members of designated populations can enter the system with equal ease. However, this assumes that a solid foundation has been successfully laid for the operation of the SEP process. A key, and difficult, task is the working out of uniform screening and assessment criteria among all involved parties that adequately account for the needs of multiple populations.

A local or regional SEP providing centralized access may make access easier. However, centralized access cannot mean the use of only one central site or the use of sites located only in centralized areas. Routing everyone this way would create unnecessary

bottlenecks and may actually reduce ease of entry. Obviously, more than one site is needed, including access points located in remote areas. Instead, centralized access means access through a centralized *system*.

However, ease of entry does not depend entirely on an SEP process. Effective publicity in a multiple-point access system may also facilitate entry. In other words, effective publicity and outreach activities are appropriate in all entry systems, including an SEP.

A good SEP can also ***simplify the entire process of obtaining appropriate services***, beginning with entry into the system. An SEP is conducive to the coordination of the inter-related functions of pre-admission screening, assessment, case management. SEP systems usually locate these inter-related functions in the same local agency so that the entire process is simplified. Pre-admission screening for multiple populations simplifies financial and categorical or functional eligibility determination. Subsequent assessment builds on the previous screening; and case management follows from the prior two steps. This means clients need not be subject to multiple screens and assessments administered by different agencies, each of which may have a slightly different mandate or service orientation. Neither will they need to be repeatedly referred to other more appropriate agencies and possibly go through additional screens. Case managers are often empowered to authorize services although most are not allowed to also provide direct services to preclude conflicts of interest. Service authorization by the case manager adds to the overall degree of coordination in the system.

Concomitantly, if an SEP is implemented successfully, ***long-term care program resources can be more efficiently allocated***. The different services of various agencies and providers become available on the continuum of services to multiple populations as necessary. Although an SEP makes the most sense if based on a generic approach, an SEP need not necessarily require the consolidation of categorical funding streams. If it should be decided to do so, this funding consolidation would make it ***easier to allocate long-term care funding resources more efficiently***. However, this is a very difficult task. Funding consolidation involves coordination of a type that is different from the coordination of screening, assessment, and case management, which are inherently inter-related.

However, an SEP that espouses a generic approach ***encourages the consolidation or coordination of resources to meet the needs of multiple populations***. This is true regardless of how the population universe is limited by policy to some combination of sub-populations (e.g., the elderly, disabled children, and non-elderly) eligible for generic coverage. Any movement toward cost savings that may be possible through such coordination and consolidation of functions and funding should be welcome as state revenues continue to lag.

Upon exposure to the system at entry, prospective ***clients will be more likely to become better informed of all appropriate and available alternatives***. A family reluctantly seeking nursing home admission for a frail elderly relative may discover that a package of home supports may enable that person to remain at home and at less expense. In addition, because an SEP is amenable to dealing with multiple categorical needs, ***there is a greater chance that a client will receive appropriate services from a full continuum of services***. Without a coordinated SEP, seeking and obtaining precisely the right service or mix of supports can be a hit-and-miss prospect. An SEP also ***facilitates the flexible delivery of services along this continuum according to changes in a client's level of care needs***. As needs change for the better or worse, an SEP client need not exit one program and be screened, assessed, and evaluated for another. Through the case manager, a client can more easily

switch to more appropriate services or supports. This may include switching from a nursing home to community supports and vice versa. Or it could entail the removal of transportation or chore services as a person improves with physical therapy. Another example involves young disabled persons who are making the transition to real life after a period of special education and training:[2]

> At this point, specific mechanisms need to be in place to link the exiting [young disabled] students with community services and supports; otherwise, the students risk falling through the cracks or being placed in a segregated program or facility.

A coordinated SEP can provide the required coordination of all family support-related activities undertaken by various agencies to help them make the transition.

An SEP can also contain costs ***by acting as a gatekeeper in a managed care system***. Through clearly articulated screening and assessment criteria, the case manager can authorize only those services that are needed to reduce excessive service utilization. The gatekeeper function depends on articulated criteria -- the tighter they are, the fewer people will receive services, or the fewer services will be authorized and *vice versa*.

A good SEP ***encourages the achievement and maintenance of uniform standards for services while remaining flexible in responding to differing needs***:[3]

> [T]he six states [in the Justice, et al. study] have shown that some aspects of community care systems can be tightly structured and uniform statewide without compromising their ability to flexibly respond to individual service needs. Uniform assessment tools, explicit financial eligibility criteria, and system entry channeled through case management agencies have all made access to community care more predictable from a client's perspective and more standardized as viewed by program administrators. Yet, the actual services provided often are very loosely defined, giving local program managers considerable latitude in tailoring service packages to individuals needs.

One charge sometimes leveled at SEPs is that they do not assure quality of care. However, this type of objection may be somewhat off the mark. An SEP is not specifically designed to assure quality, just as it is not specifically designed as a mechanism to assure the adequacy of long-term care funding, although both are desirable. One could charge the status quo with the same shortcomings. On the contrary, one could actually argue that ***an SEP is conducive to quality assurance because of the emphasis on coordinated screening, assessment, and case management***. As one researcher points out:[4]

> The challenge to states is to develop methods for enhancing quality care without making [quality assurance] standards so inflexible and rigid that delivery systems cannot respond optimally to the diverse needs of individual older people.

An SEP also ***enhances efficiency and equality in the delivery of long-term care services***. All procedures in an SEP are carried out usually by the same staff under a standardized concept that coordinates the inter-related tasks of screening, assessment, and case management. This reduces inconsistencies in eligibility and functional assessments at all the various points of entry throughout a state. More consistent and coordinated screening for eligibility determination should result in more equitable access for multiple populations. More consistent and coordinated functional assessments should result in more efficient and appropriate provision of care.

A standardized SEP concept could designate one regional agency (with local offices throughout the region) as the entry point. It could also designate a group of agencies, especially if private agencies are contracted for this purpose. Each agency may have a tradition of serving a specialized population. For example, one may have focused on the provision of personal care services to developmentally disabled adults. Another may have specialized in case management of home- and community-based services for the frail elderly. Still another may have adult day care as its core service. Yet, when and if they are designated as entry points under a standardized SEP process, that process uses a uniform approach to entry, screening, assessment, authorization of services, and case management. This allows entry point agencies to process clients more equitably and efficiently and with less inconsistency. Standardized procedures militate against bias by entry point staff who are used to serving only a certain population. Of course, this assumes that all entry point staff are continuously and adequately cross-trained.

Disadvantages of a Single Entry Point: Arguments against an SEP are often actually directed at the disadvantages of adopting a generic approach to long-term care. It is true that a generic approach benefits more from an SEP process than a categorical one. It makes little sense to coordinate service delivery and still retain the many categorical differences among the multiple populations processed through a single entry point. Much of the work of coordination would be wasted. Furthermore, as mentioned on numerous occasions previously, an SEP, even generically-based, does not necessarily require total system integration. Rather, processes can be coordinated without wasting the benefits. In other words, implementing an SEP is not the same as, and does not necessarily require, total system integration, even if based on a generic approach to care.

Even so, examining the difficulties of achieving total system integration in long-term care sheds light on how an SEP, which requires a lesser degree of coordination, may possibly incur disadvantages. Thus, the disadvantages of total system integration may apply in some cases, and to a lesser degree, to the implementation of an SEP. With this in mind, the following summarizes what have been identified as obstacles to true, total system integration:[5]

(1) No single federal or state program comprehensively finances the needed range of long-term care services so that multiple programs and funding sources have been used;

(2) Many public and private programs finance one or more services, adding to the fragmented patchwork system of care;

(3) Each provider and funding source has its own eligibility rules and types of eligible services, making it difficult to coordinate with other providers for different populations;

(4) Funding is directed to specific categorical long-term care populations causing gaps in coverage. In addition, various long-term care populations try to access financing and services not originally meant for them, adding to the confusion;

(5) Various funding streams have shaped the development of numerous agencies in the administration of different long-term care eligibility and service delivery components, for example, Medicaid must be administered by a single agency;

(6) Turf issues generate fights between providers and agencies over scarce resources to serve various long-term care populations served by different players;

(7) The existence and work of advocacy groups can obstruct integration because each group focuses on its own population's needs even though they may share needs with other populations;

(8) Technical issues relating to different populations are difficult to resolve, for example, different definitions of "disability" for each population and different eligibility criteria for services need to be resolved;

(9) A lack of information and communication among agencies and between government and the public hinder integration; and

(10) The lack of explicit state long-term care policies, goals, or commitment to implement that policy or goal can make integration hard.

Disadvantages may accrue to an SEP to the extent that it acknowledges the need to draw from a full continuum of services for multiple populations. In the current fragmented service environment, this implies the existence of many different service programs that operate with differing eligibility criteria, rules, and services. Programs are supported by different funding streams meant for differing, specific populations. They espouse their own philosophical and programatic goals dictated by dedicated funding or agency tradition or directives tailored to serve specific target populations. As a result, differing eligibility criteria and services often create both overlaps as well as gaps in coverage. ***Thus, to the extent that an SEP is intended to resolve or accommodate philosophical and programatic goals – and possibly to consolidate funding streams – for multiple populations, implementation will be difficult.*** This is not a disadvantage *stemming from* the operation of an SEP. Rather, the disadvantage lies in pre-existing conditions that make it difficult to achieve programatic coordination of any sort, including that achievable with an SEP.

A service population may also have unique needs and problems that are not easily or adequately addressed by programs tailored to address the needs of a different population. For example, some may feel that use of community-based supports may be inappropriate for profoundly disabled individuals for whom institutional care may be more appropriate. A common fear is that a system which is required to handle more than one population may dilute the strength of an individual program dedicated to serving only one specific population. The fear of a service system descending to the lowest common denominator is understandable. To the extent that the system recognizes that many long-term care populations share common needs, the operation of an SEP will be made easier. However, ***to the extent that certain long-term care populations have unique conditions and needs for services not shared by other populations, these differences make coordination in an SEP difficult.***

Some believe that an SEP does not assure quality of care. The coordination of screening, assessment, service authorization, and case management is conducive to creating uniform standards, including standards of quality care. However, it is true that monitoring of services and service delivery is not an inherent part of the SEP process. It is often necessary to add a quality of care component to an SEP. This need is magnified if an SEP, or any other coordinating system, makes liberal use of in-home personal care services and supports which, because they are performed "hidden away," are inherently difficult to monitor.

An SEP could possibly reduce system access for certain people residing in remote areas. This could happen if locally available traditional entry points such as rural physicians are not part of the designated regional or local entry point. The fear of restricting entry to

one, or a few, centrally located sites is less well-founded. Well-thought out SEP systems should not leave rural areas uncovered nor would they cause greater inconvenience in terms of additional time and travel to a smaller number of entry sites. To the extent that an SEP is poorly designed, this can be a disadvantage.

Concern is also expressed over the issue of ***possible conflicts of interest when case managers authorize services that they themselves directly provide***. This is a valid concern and a distinct disadvantage in an SEP system that allows it. However, many SEP systems explicitly prohibit case management agencies that authorize services from being direct service providers as well. In those states, agencies choose to either remain service providers or become part of the entry system that performs screening, assessment, service authorization, and case management.

A further disadvantage of implementing a successful SEP is the ***difficulty of actually translating coordination objectives and policies into actual working protocols and tools***. It is one thing to say all parties must be involved and consulted and to require that all differences be resolved. Compromises must be reached regarding both philosophical as well as operational approaches, generic vs. categorical beliefs, reconciliation of funding streams, differing categorical definitions and eligibility criteria, differing methods of evaluation and assessment, and different preferences for institutional vs. community-based services. It is quite another to actually work out the necessary compromises on these issues so that staff have usable concrete tools with which to work. On the one hand, they must be comprehensive enough to address the needs of multiple populations. On the other, they cannot be cumbersome to the point of being useless. The task is not impossible but it is not easy.

Related to this is the ***difficulty of cross-training entry staff***. It is very difficult to imagine a huge cadre of intensely and comprehensively cross-trained staff equally expert in the needs of multiple populations. Such staff would be extremely qualified, if not over-qualified for other work in the long-term care field. There may be several possible solutions. First, the work expected of highly cross-trained staff can be transferred to planners and expert practitioners who work out screening and assessment tools on the front end. That is, the necessary sophistication and knowledge can be built into the tools themselves so that entry staff need not be relied upon for the requisite expertise on the back end. Alternatively, the SEP system can be designed to be flexible enough so that a person or team with the appropriate expertise is always required and available to conduct assessments. For example, staff can be required to seek and defer to another if the assessing staff is not knowledgeable about the client being assessed. In addition, follow-up specialist assessments can also be required if necessary.

Operationally, ***an SEP can create a bottleneck in the entry process.*** For example, some states have generated waiting lists of people to be processed through a single entry point system up to two years long. Authorization and delivery of services must be delayed until all required screenings and assessments have been carried out. A state can either recommend or require either all or certain persons seeking long-term care services to use an SEP process to enter the system. If an SEP entry is *required* and not merely recommended or available, more people will go through the SEP. Similarly, if *all* populations are required to do so, the chances are that more people will be processed. If a goal is to increase the numbers of people accessing the system, an SEP should help achieve it. However, there is a possibility that the system can be overloaded, especially if there is insufficient funding to perform all required screenings and assessments.

An SEP is weak to the extent that states cannot mandate, but only persuade, physicians and hospital discharge planners to refer patients to non-medical community care programs. In the eyes of acute care facilities, pre-admission screening programs are often seen as:[6]

(1) Unnecessary bureaucracy;
(2) A challenge to physicians' authority; and
(3) Duplication of discharge planners' ongoing responsibilities which include some form of long-term care pre-admission screening.

A condition inherent in most public bureaucracies is that of interagency rivalry manifested in "turf wars." The empire-building, battles for leadership, and jurisdictional expansion engaged in by public agencies are to be expected in the normal give and take of government. At times, this dynamic serves to stimulate new ideas and approaches to solving problems through productive contention in otherwise moribund bureaucracies. However, they can also work against coordination. Thus, ***dysfunctional turf wars among public agencies serve to hinder coordination that may be a goal of an SEP.*** Turf wars may also be partly caused or exacerbated by a lack of communication among agencies which may generate misunderstanding and heighten unfounded suspicions.

This situation is mirrored in turf wars in the private sector. The activities and attitudes of various advocacy groups, each of which promotes the interests of a certain target population, work against coordination. Each contends for a piece of the funding pie for its own population. It is understandable for an advocacy group to cite its population's unique needs and problems in partial justification of their advocacy efforts. Commonalities shared by populations tend to be glossed over. ***Thus, an SEP that attempts to coordinate services, and possibly funding, for different populations may be seen as a threat that dilutes an advocate's "proprietary" program.***

The likelihood of successfully creating and operating an SEP is also weakened by a lack of clearly articulated public policy that sets priorities and goals for a unified statewide effort to coordinate the system. To the extent that an SEP is expected to coordinate entry and provision of services to multiple populations, it will be at a disadvantage in the absence of such an overarching policy. Discrete programs may have clearly stated policy goals. However, to the extent that their philosophies, objectives, and operational procedures may be categorically mutually exclusive, a coordinating SEP will suffer without clear governing policy.

It is, however, one thing to state policy and quite another to make an actual commitment to carrying out that policy. ***Lack of executive leadership and commitment to coordinate the system through an SEP*** would be a major disadvantage. Mandating a new policy of coordination would be greatly hindered operationally without the full support of the executive and the public agencies involved. Strong leadership must be brought to bear to facilitate cooperative efforts among the executive agencies responsible for long-term care. Without such leadership and cooperation, an SEP would be difficult to successfully implement.

Assuming that policy is articulated and commitment and executive leadership are forthcoming, a client's coordinated access through an SEP needs to be routed to adequate services. It would make no sense to invest the tremendous amount of effort required to overhaul the long-term care system in terms of coordinated access and service delivery if there are not enough services to deliver. This is a common caution that has surfaced in

various jurisdictions.[7] The lack of funding support for both institutional and home- and community-based long-term care services is not a disadvantage, *per se*, of an SEP. As mentioned earlier, program funding is independent of the type of access model. It is a disadvantage to the entire system that must be faced by any approach to long-term care reform. ***Thus, a general lack of funding for underlying long-term care services could be a disadvantage to the entire system in the sense that scarce funds that could otherwise have gone to bolster actual services may be used for an SEP.***

Cautions: There seems to be no disagreement that long-term care services can and should be better coordinated for at least the elderly population. However, there is doubt as to whether the provision of long-term care for the three designated populations may be successfully coordinated. There is also disagreement over the benefits of establishing an SEP for the three populations. In addition, it is the consensus that implementing an SEP, should it be decided to do so, will be a very difficult task.

Various cautions have also been raised, regardless of the decision to implement an SEP or not. The most critical of these is for adequate funding to be made available for both institutional and home- and community-based long-term care services. A second caution is that effective information and referral activities that include active outreach need to be added or incorporated into an SEP design or other coordination efforts. A third caution is that hospital discharge planning must be consistently available that conforms to any SEP process. A fourth is that the more pressing problem lies perhaps not in deciding whether or not to implement an SEP but in providing adequate funding for long-term care beds.

If it is decided to implement an SEP, several other cautions need to be heeded. The first is that experience in the six states studied by Justice, et al., points to incremental change. All added program components over several years. For example, pre-admission screening programs often were added after the supply of community care services was expanded so that community options offered by screeners made for viable choices.[8] Hand in hand with this go-slow approach is the need for prior broad-based, intensive and extensive planning involving all players. Their full working cooperation is necessary to make an SEP successful. For example, acceptable compromises must be fashioned on definitions, eligibility and assessment criteria, client needs, continuum of services availability, and possibly consolidation of funding streams. For the six states studied by Justice, et al.:[9]

> Each state utilized a broad planning program in its reform effort. Involving all state agencies with long-term care responsibilities, as well as advocacy and industry groups, helped generate commitment to reform and developed consensus on approaches taken. Each state implemented its community care system over a period of years through a phase-in process, helped by long range planning.

A third related caution is that turf wars may continue despite apparent coordination of services for multiple populations if factions are not creatively accommodated.[10] A further related caution is the desirability of operationally testing the SEP in some way. This could take the form of a pilot project in one geographical area. Alternatively, a pilot project can be run statewide but focusing on only one population. The mix of programs, services, and funding and how they are administered within each state's organizational structure is not always the same. Consequently, the feasibility of any model should be tested on a limited basis in each state before full program implementation. A final warning is the need to develop an effective audit and evaluation system because services and expenditure authorization in an SEP most probably will have been delegated to non-governmental agencies.

Support for System Coordination: Federal budget cuts and program re-structuring may force the State to better coordinate the delivery of long-term care services to multiple populations. It is possible that such federal pressure to conserve fiscal resources may not materialize. Even so, efforts to optimize the use of funds merit serious consideration due to depressed local fiscal conditions and the prospect of increased demand for long-term care in the future. Certain programatic benefits, although not unanimously agreed upon, may accrue from a more coordinated long-term care system. On the other hand, it is clear that the path to an SEP system will be liberally strewn with obstacles and difficulties requiring intensive and extensive good-faith cooperation and negotiation among multiple parties.

The thrust of an SEP is not for total system integration, but only for a degree of system coordination. There seems to be more consensus on use of the term "coordination" than "single entry point." The Executive Office on Aging (EOA), for example, recommended in 1988 "[t]he implementation of interdepartmental coordinating mechanisms . . . to ensure the coordination of services, systems, policies, and programs."[11] In support of this coordination effort *(and implicitly supporting a cabinet model)*, the EOA further recommended that:[12]

> A state interdepartmental coordinating council for the long-term care of older adults should be established by executive order. This interdepartmental council should include, at a minimum, the Executive Office on Aging, the Department of Budget and Finance, the Department of Commerce and Consumer Affairs, the Department of Health, and the Department of Human Services. [This coordinating council is to address, among other issues:]
>
> - Major interdepartmental programs, services, and funding strategies; and
> - Intergovernmental implementation policies, structures, and processes.

Although not envisioned for multiple populations, this coordinating council could serve precisely that role in a cabinet model where existing departments continue to provide services in a coordinated fashion. The EOA believes "that better coordination will result in easier access for all clients. . . . [and] improvements could include better coordination with agencies and providers, expanded use of technology for sharing information, standardized intake and/or referrals forms, etc. A movement towards some form of consolidation could be a cost saving measure [although the EOA is not sure this would work for combined groups]."[13]

The Department of Health (DOH) also recommended a form of coordination *(which may not be incompatible with an SEP)*:[14]

> **A coordinated management information system with the use of a uniform intake form and with immediate access information and referral capabilities.**
>
> In part, this would entail networking as many health and human services agencies by computer technology as possible and having them utilize standard forms with special supplements for differing populations, as needed.
>
> **A uniform, coordinated case management system.**
>
> This calls for a clearly articulated policy for case management and its utilization. . . . If service authorization is to be an integral part of case management, then the State must consider the conflict-of-interest implications of having private sector service or insurance entities involved in case management and in the determination of a client's service needs. The Department of Health is

currently in discussion on the centralization of case management capabilities for a number of programs which have a case management mandate.

The DOH also pointed out the need for consistently available, quality, hospital discharge planning. An SEP can conceivably incorporate this as it coordinates entry from all places, including from acute care hospitals.

RECOMMENDATION

Two-Phase Pilot Project: Despite the obvious difficulties, it is nevertheless worthwhile to pursue the concept of an SEP but, at least for the time being, only on a limited pilot project basis. This can be done in two phases.

Phase One: In the first phase, a coordinating committee should be created to perform the ponderous preliminary tasks required to create and implement a successful SEP process. Subject to broad guidelines *(see following section)*, the committee should have substantive power to design and develop the trial SEP system subject to a single proviso. This proviso would allow the committee, based on the results of actual negotiations among all relevant parties, to modify the SEP -- even to the extent of finding it not feasible under local conditions. After all, the objective of a pilot SEP project is to find out whether or not an SEP can generate the anticipated benefits in the manner envisioned. If, after good faith negotiations, the committee should find that workable compromises cannot be reached or if strong executive leadership and support is found lacking, it may recommend terminating or modifying the project. In the latter case, consistent with its mandate to design a system that works, the committee should be allowed to recommend some other form or level of coordination that may not be encompassed in a formal SEP system.

Broad Guidelines: During its preliminary work, the committee should be subject to certain broad guidelines. The first is that it must consider a system to accommodate all three designated populations. The committee must also adopt, on an experimental basis, a flexible generic approach to determine eligibility and assess clients based on functional limitations. Third, the committee must design a system that makes the most efficient use of resources. Fourth, the system must attempt to benefit the greatest number while reasonably accommodating individuals with extreme needs. Lastly, the pilot project should be geographically limited to an area in which all three populations are likely to reside or receive services. Within these general guidelines, the committee should have broad latitude in shaping the form of the actual SEP, if one is ultimately found feasible.

At a minimum, during actual negotiations, the committee should specifically attempt to determine whether:

(1) Differing financial eligibility criteria can be reconciled, including whether differing funding streams can be usefully consolidated and made available to support services for all three populations;

(2) Sufficient common ground exists for the use of standardized functional assessments for the three populations and if provisions for supplementary specialist assessments are necessary, feasible, and can be made available;

(3) Cross-training for entry staff is feasible or can be made adequate to handle the needs of all three populations or, alternatively, whether sufficient "expert" knowledge and sophistication can be built in to whatever standardized tools that will be used;

(4) Case management can be consolidated for the three populations;

(5) If the power to authorize services is given to case management agencies, whether case managers will be allowed to provide direct services; and

(6) Existing services can be placed in and accessed from a continuum of services available to all three populations through the SEP or coordinated system;

The committee should include representatives of all public agencies involved in the provision of long-term care to the three designated populations, including at least:

(1) The Executive Office on Aging;
(2) The Department of Budget and Finance;
(3) The Department of Commerce and Consumer Affairs;
(4) The Department of Education;
(5) The Department of Health;
(6) The Department of Human Services;
(7) The Department of Labor and Industrial Relations;
(8) The Department of Transportation;
(9) The University of Hawaii;
(10) County agencies in the pilot project county providing relevant care to the three populations;
(11) Acute care hospitals, long-term care institutions, adult day health centers, adult day care centers, and adult residential care homes;
(12) Other relevant profit and nonprofit providers of care; and
(13) Advocacy groups including consumers from each of the three designated populations.

Flexibility Must Be Maintained: Although based on an experimental generic approach, the pilot project should remain flexible enough to adapt to real needs and conditions as encountered by the committee during actual negotiations. A rigid posture negates the purpose of the project -- to find out what elements will work and how. The underlying goals to be kept in mind should be those previously enumerated as advantages. Thus, the committee should be flexible in designing and developing the project to best achieve those goals. For example, the committee should be able to expand its membership to include other participants if it feels necessary. It should identify the relevant issues to be negotiated and decided upon; set up its own substantive working sub-groups to achieve consensus; set project milestones and deadlines; schedule timely meetings; and make interim reports.

Phase Two: The coordinating committee should be allowed sufficient time to work out the numerous difficult issues previously enumerated. Accordingly, the committee should be given one year until June 30, 1997 to accomplish this. If the committee wishes to proceed with either the originally envisioned SEP or an alternative, it should prepare proposed legislation to implement actual field operation of the pilot project in phase two. Because proposed legislation must be prepared by late December, 1996, the committee will actually have only about six months in which to resolve the major issues. However, the committee

should have the flexibility to request an extension of time. The committee can either hold off requesting an appropriation to fund implementation of the pilot project or proceed to make such an appropriation request in the proposed legislation, pending the completion of its preliminary work by June 30, 1997. This proposed legislation should be prepared by the convening of the regular session of 1997 so that field operation can begin by July 1, 1997, or earlier. Generally, the pilot project should be in operation for at least two full years.

Funding for Phase One: The work of the coordinating committee should not require an appropriation of general funds. Most members of the committee will be from the public sector carrying out duties on the committee as part of their jobs. Participation is voluntary for private sector representatives. However, incidental expenses for necessary intra-island travel should be reimbursed. This should not amount to much, especially if the pilot project focuses on only one island, say, Oahu. The committee can be temporarily attached to either the Department of Health, the Department of Human Services, or the Executive Office of Aging for administrative purposes only. Alternatively, it can be attached to the Governor's office. Wherever it is located, necessary travel expenses can be reimbursed from the sponsoring agency's budget.

Funding for Phase Two: In phase two, assuming that the committee recommends moving forward to implement an actual SEP or other coordinating measures, funding will most likely be needed. The magnitude of this funding cannot be known until the committee has conducted its preliminary work of broad-based planning and negotiations in phase one. The committee should include a request for funding in the proposed legislation to carry the project out to fruition. Assuming that funding is necessary and forthcoming, the committee can then move on to actual implementation including final project evaluation and recommendations for project termination or expansion.

Funding, of course, for both nursing home beds and home- and community-based supports must not be neglected even as plans to coordinate the long-term care system proceed with a pilot SEP project. On a more general level, it would make less than no sense to more effectively route more people through the system to a dead end with inadequate nursing home beds and community supports. On a more specific level, it would similarly make no sense to legislate this pilot project if there is no broad-based support and strong executive leadership and commitment to carry it through.

Endnotes

1. Theodore H. Koff, New Approaches to Health Care for an Aging Population: Developing a Continuum of Chronic Care Services, Jossey-Bass Inc., Publishers, 350 Sansome Street, San Francisco, California 94104, 1988, pp. 166-167.

2. Barbara Wright and Martha P. King, Americans With Developmental Disabilities: Policy Directions for the States, NCSL Task Force on Developmental Disabilities (National Conference of State Legislatures: Denver) 1991, pp. 15-16.

3. Diane Justice et al., State Long Term Care Reform: Development of Community Care Systems in Six States, National Governors' Association Center for Policy Research, Health Policy Studies, Washington, D.C., April 1988, p. vii.

4. Justice, et al., p. 113.

5. Maryland, Report of the Governor's Commission on Health Care Policy and Financing: Joint Recommendations of the Governor's Commission and the Committee on Long-Term Care, Governor's Commission on Health Care Policy and Financing, vol. V, December 20, 1991, p. 54.

6. Justice, et al., p. 93.

7. According to Teresa Tritch, "Best Ways to Beat the Cuts in Medicare and Medicaid," in Money Magazine, December, 1995, p. 95: "In Oregon, for example, since 1981 the number of Medicaid-sponsored seniors in nursing homes has declined to 7,300 from 8,400, as the growing demand for elder care has shifted to home- and community-based options. Unfortunately, the Oregon experience also exposes the danger in state experimentation. Last year [1994], the Oregonian newspaper reported conditions of filth, neglect and cruelty in dozens of adult foster-care homes. In a rush to accommodate growing numbers of needy elderly, the state licensed many more homes than it could effectively monitor."

8. Justice, et al., p. viii.

9. Indiana, Long-Term Care and the Elderly, Evaluation Audit, Indiana Legislative Services Agency, May 1990, p. 43.

10. For example, it has been recounted that various advocacy groups were initially united in Wisconsin's efforts at coordination because they could not be played off against each other. However, after the Community Options Program began to operate, the groups again began to fight over the amount of funding to be made available to each's traditional target population. Wisconsin attempted to solve this by mandating the program to serve persons from the major target groups in proportions which approximate the percentages served in nursing homes prior to the program's inception. Telephone interview of October 3, 1995 with John Lorimer, Director, Bureau of Long Term Support, Wisconsin Department of Health and Social Services.

11. Hawaii, Long Term Care Plan For Hawaii's Older Adults, Executive Office on Aging, Office of the Governor, July, 1988, pp. x & 25.

12. Ibid., p. 28.

13. Memorandum from Marilyn R. Seely, Director, Executive Office on Aging, to Wendell Kimura, Director, Legislative Reference Bureau, September 14, 1995, p. 2.

14. Memorandum from Jeanette C. Takamura, Ph.D., Deputy Director of Health, to Wendell Kimura, Director, Legislative Reference Bureau, November 17, 1995, p. 2.

THE SENATE
EIGHTEENTH LEGISLATURE, 1995
STATE OF HAWAII

S.C.R. NO. 33

SENATE CONCURRENT RESOLUTION

URGING A STUDY ON THE MERITS OF ESTABLISHING A SINGLE ENTRY POINT FOR LONG TERM CARE SERVICES.

WHEREAS, long term care is one of the most pressing health care issues in Hawaii today; and

WHEREAS, to meet the growing demand and complexities in the area of long term care, the State must look towards methods or systems which will allow the State to effectively manage its long term care needs; and

WHEREAS, a "single point of entry" for long term care services is a method which may simplify access to long term care services because it provides a local or regional access point where consumers receive information and assistance, assessment of needs, care planning, and authorization of services; and

WHEREAS, a single point of entry is only one component of a comprehensive long term care system which also involves working with state resources to help individuals become aware of the services available; and

WHEREAS, a number of states have already established single points of entry to long term care services, but the systems have differed from state to state due to demographics, geography, and government structure; now, therefore,

BE IT RESOLVED by the Senate of the Eighteenth Legislature of the State of Hawaii, Regular Session of 1995, the House of Representatives concurring, that the Governor is requested to explore the merits of establishing a single entry point for long term care services in Hawaii; and

BE IT FURTHER RESOLVED that the Governor may use models of systems from other states in exploring a system appropriate for Hawaii's environment and population; and

BE IT FURTHER RESOLVED that the Governor report his findings and recommendations to the Legislature twenty days prior to the convening of the Regular Session of 1996; and

BE IT FURTHER RESOLVED that a certified copy of this Concurrent Resolution be transmitted to the Governor.

OFFERED BY: _____

Model Long Term Care Assessment Tool

Division of Community Services
Wisconsin Department of Health and Social Services

May 1995

Supported in part, by a grant (90AMO714) from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201

THE MODEL ASSESSMENT TOOL

The Assessment: Assessment is a structured process of interviews which is used to identify the participant's abilities, needs, preferences and supports; determine eligibility for programs and services; and provide a sound basis for developing the care plan. A secondary purpose of the assessment is to provide the participant with a good understanding of the program and the services that can be provided and of what is expected of him/her. Assessments are conducted in partnership with the participant and his/her family, guardian, or other supports as appropriate.

Purpose of the Assessment Tool: This assessment tool is designed to be a comprehensive examination of an individual's life situation which includes their deficits and their strengths. This tool is part of the assessment process that is on-going throughout the period of time that an individual receives long term care services. The assessment process includes constant re-evaluation of the person's situation in order to change services provided to meet changing needs.

This assessment tool was developed to enable care managers to perform a thorough assessment that will result in a comprehensive care plan that is individualized and considers the participant's preferences. The objective of this tool is to learn enough about the individual to create with the participant a comprehensive plan, meeting his/her needs and enhancing his/her life.

Part of the assessment process is the inclusion of addendum tools which have more in depth questions to determine additional services or to prompt the referral to professionals outside of the care management team. These addenda are used on an individual basis and will provide a greater amount of information.

Completing the Assessment: It is recommended that a social worker and a nurse complete the assessment as a team. Due to the length of this inquiry, it may be advisable to conduct the assessment in two separate sessions. If a county has limited staff time and cannot perform this assessment in two separate sessions, it is suggested that the nurse and social worker divide the survey and conduct their sessions separately. If the tool is used in this manner, it is recommended that a meeting take place in order for the two assessors to discuss the findings and any follow-up that is necessary.

Please note that specific instructions for each page are printed on the back of the page.

ASSESSMENT FACE SHEET

Name: (Last, First, M.I.) _____ Birthdate / /

Address: _____ Zip _____ Telephone _____ County _____

Marital Status:
☐ married ☐ widowed
☐ divorced ☐ single
☐ separated

Sex: ☐ female ☐ male

Veteran: ☐ yes ☐ no

Ethnic Origin:
☐ American Indian ☐ Hispanic
☐ Asian ☐ White
☐ Black ☐ Other_____

Primary language (if other than English) _____

Emergency Contact Person:

Name/Relationship _____ Address _____ Telephone _____

Guardian/Durable POA/Protective Payee/POA for Health Care/Primary Caregiver:

Name _____ Address _____ Telephone _____

Name _____ Address _____ Telephone _____

Chapter 55: ☐ yes ☐ no Chapter 51: ☐ yes ☐ no 1.67 Referral ☐ yes ☐ no
If yes, name of Court _____ Court ordered care ☐ yes ☐ no

Social Security Number: _____ Medicare Number: _____

Medicaid Number/Start Date: _____ Other Insurance: _____

Person's Disability(ies):
☐ frail elderly
☐ chronic alcohol or drug abuse
☐ developmentally disabled
☐ serious or persistent mental illness
☐ physically disabled
☐ alzheimer's/dementia

Program(s):
☐ SHC ☐ CIP II
☐ CIP 1A ☐ CSP
☐ COP ☐ COP W
☐ CIP 1B ☐ CSLA
☐ MA Case Management ☐ Other _____

Living Arrangement:
☐ own home/apartment
☐ relative's home/apartment
☐ friend's home/apartment
☐ CBRF/AFH #beds _____
☐ Supervised/semi-super. apartment
☐ Other _____

Household Composition:
☐ lives alone
☐ w/spouse
☐ lives with others: _____

Formal Supports	NAME	ADDRESS	TELEPHONE	FREQ.OF CONTACT	OTHER INFO.
primary physician					
dentist					
specialist					
pharmacy(ies)					
agency					
agency					
other					

DATE COMPLETED _____

ASSESSMENT FACE SHEET

The assessment face sheet is designed to gather pertinent information and keep it within easy reach of the care manager for quick reference. It is also designed to provide a short review of information about the participant if it is needed and the care manager is not available.

Much of the information on the face sheet could/should have been obtained in the initial intake procedure.

Participant Information

Record the participant information as completely as possible. If information is unknown, write unknown. Do not leave any spaces blank. The emergency contact person and the guardian... may be the same person. Write "same" in the second line.

Person's Disability(ies)

Check all that apply.

Program(s)

Check all that apply. If the person is not currently on a program but will be applying to one or more programs, check those that are anticipated to be providing services to the participant.

Formal Supports

Complete as accurately as possible with complete addresses and phone numbers. Complete addresses and phone numbers do not need to be obtained at the time of the assessment but do need to be filled in later. If the individual has no dentist, etc. write "none" and note that this may be an area to pursue.

LONG TERM SUPPORT ASSESSMENT

Date of Assessment: _____ ☐ Initial Assessment ☐ Assessment Update

Referral Source: Date of Referral: _____

_____

Name/Agency/Relationship to participant Address Telephone

Situation Precipitating Referral: _____

_____

_____

_____

Assessment Completed By: _____

Others present at assessment (relationship): _____

_____

Additional information obtained from: _____

_____

Level of care on Functional Screen: _____ COP Rights given: ☐ yes ☐ no

ADVANCE DIRECTIVE: Have you been advised about Advance Directives? ☐ yes ☐ no

If yes, have you completed one and where is it kept? _____

If no, has the Advance Directive pamphlet been given to you? ☐ yes ☐ no

What family, friends or reliable resources can and/or do provide help to you? Please list the activity provided.

NAME		RELATIONSHIP	
ADDRESS		TELEPHONE	
SERVICE PROVIDED			
NAME		RELATIONSHIP	
ADDRESS		TELEPHONE	
SERVICE PROVIDED			
NAME		RELATIONSHIP	
ADDRESS		TELEPHONE	
SERVICE PROVIDED			

LONG TERM SUPPORT ASSESSMENT

Complete the first section with an explanation of the reason for the referral. If others are present at the assessment please indicate who they are and their relationship to the participant. When asking the assessment questions, direct them to the participant. If someone other than the participant answers the question, re-direct the question to the participant (unless they are physically incapable) and politely request that the individual answer the question.

Note where you receive conflicting information or if the participant is unable to answer a question.

Advance Directives: Be sure the participant understands what an advance directive is and understands the difference between living wills, power of attorneys, and durable power of attorney for health care.

PHYSICAL HEALTH

It is recommended that a nurse complete this section along with the section on ADLs and IADLS. If completed by the care manager, no need to duplicate top section.

Name: (Last, First, M.I.) _____ Birthdate / /

Address: _____ Zip _____ Telephone _____ County _____

Physicians name:_____ Clinic:_____ Hospital:_____

List previous, present or potential health problems	Under Treatment		Comments:
	Yes	No	

When did you last see your doctor? _____ What was this for? _____

How often do you see your physician? _____

Are you happy with your medical care? ☐ yes ☐ no If no, explain _____

_____

_____

Have you been hospitalized in the last year? ☐ yes ☐ no If yes, how many times? _____

What was this for?_____

_____

What hospital do you go to? _____

Have you ever been admitted to a nursing home, CBRF, AFH, other? ☐ yes ☐ no When? _____

Where? _____ Why were you there? _____

PHYSICAL HEALTH

It is important to obtain as complete a physical assessment as possible. This will help you to involve medical professionals in the care plan if it is indicated. You will also become knowledgeable about areas to focus prevention efforts. It is recommended that this section be completed by a nurse. If the individual is in the hospital or has had a recent examination by a physician, medical records may be used in addition to the information obtained in this section. Do not use any medical information in lieu of asking the participant the questions directly.

Part of a good health assessment is determining if the individual is happy with their health care provider and what preferences they may have. If a participant is unhappy with his/her provider or feel she/he doesn't have choices in his/her health care, it may lead to non-compliance with health care recommendations.

MEDICATIONS (including over-the-counter)/TREATMENTS/SERVICES/SUPPLIES

For each medication ask the person: What is the medication for? What are the side effects of this medication? How and when do you take this medication?

Name	Dosage/Frequency	Client's Understanding/Compliance

Nurse: If medications indicate the need for blood levels, are blood levels being done as needed? ☐ yes ☐ no

Are you allergic to any medications? ☐ yes ☐ no What? _____

How do you obtain your medications? _____

Do you use a pill box or other reminder? ☐ yes ☐ no What? _____

Do you use tobacco? ☐ yes ☐ no Do you drink caffeine? ☐ yes ☐ no

Do you currently drink or have you ever drank alcohol? currently: ☐ yes ☐ no in the past: ☐ yes ☐ no
How much do you drink each day_____ week_____

Do you use or have you ever used street drugs? ☐ yes ☐ no

Which ones and how much? _____

Assessor: If this information or other info indicates a need for more complete AODA data, see addendum tool

Are you currently receiving any services? (HHA, PT, OT, ST, etc.) ☐ yes ☐ no If yes, describe what those are and who provides these services: _____

_____

_____

Do you routinely purchase any medical supplies? ☐ yes ☐ no What?_____

_____

Medications/Treatments/Services/Supplies

When listing the medications, it is helpful to ask to see the medications and where they are kept. Take each medication individually and ask the participant the accompanying questions. Be sure to include over-the-counter medications. Note any indications that the person does not understand or is not taking the medication properly. If the individual does not administer their own medications, be sure to ask these questions of the provider.

If you are able to look at the medication bottles, check the expiration dates. Follow-up with the physician and/or home health providers to double check the accuracy of the medications being taken.

In general, how would you say your health is? _____

What is your height? _____ What is your weight? _____

Has your weight gone up or down in the past year? ☐ yes ☐ no

Assessor: if yes, please complete nutritional assessment and/or depression screen

Vision - How is your eyesight?

- ☐ Client has no problem
- ☐ Client is blind: (circle) one eye both eyes
- ☐ Client wears corrective lens: glasses: ☐yes ☐no contacts: ☐yes ☐no
- ☐ Date of last exam: _____
- ☐ Impairment is not corrected
- Can you see to read? ☐yes ☐no
- ☐ Client needs exam

Comments: _____

_____

Hearing - How is your hearing?

- ☐ Client has no problem
- ☐ Impairment is not corrected
- ☐ Client is deaf: (circle) one ear both ears
- ☐ Date of last exam: _____
- ☐ Client wears hearing aid: ☐yes ☐no
- ☐ Client experiences ringing in the ears
- ☐ Client needs exam

Comments: _____

_____

Dental - Do you have any dental concerns?

- ☐ Client has own teeth
- ☐ Client needs dentures
- ☐ Client has a dental disease: describe _____
- ☐ Date of last exam: _____
- ☐ Client wears dentures
- ☐ Client needs exam

Comments: _____

_____

Respiratory - Do you have any difficulty breathing?

- ☐ Client has no difficulty
- ☐ Client reports experiencing shortness of breath (SOB)
- ☐ Client is currently on oxygen
  - Usage/number of liters per minute _____
  - Where is it obtained? _____
- ☐ Client experiences sinus problems
- ☐ Client has frequent cough
- ☐ Client is observed experiencing SOB

Comments: _____

_____

Question: In general, how would you say your health is?

Record the participant's response to this question. This question provides a good insight into the participant's own view of their health and is a key to how the person views their current ability to manage their health. If the participant is currently in the hospital, record how she/he would have responded before admission and how she/he responds now.

Physical Systems Breakdown

Ask the participant each of the accompanying questions, i.e. "How is your eyesight?" Allow the participant to answer the question and use the prompts that follow if the answer is not complete enough to provide you with the information requested. Question and note any instances in which your observation differs from the participant's response. For example, The participant responds that their eyesight is fine and you observe the participant wearing glasses. If the participant is blind in one eye - note which eye. Do the same with ears.

If the participant (particularly an elderly person) has not had a vision, hearing or dental exam in the past two years it is an indication that they may need to be examined. (A younger person may not need a vision or hearing exam.)

Cardiovascular - Have you experienced any heart problems?

☐ Client has no difficulty ☐ Client experiences edema (swelling)

☐ Client experiences chest pain ☐ Client experiences leg pain (intermittent claudication)

Pulse _____ Blood Pressure _____

Comments: _____

_____

Skin - Do you have any open sores or skin problems?

☐ Client has no difficulty

☐ Client has ulcers, open wounds or bruises. Where: _____

☐ Client has a rash or skin disease(s). Describe: _____

Comments: _____

_____

Nutrition - Are there certain foods that your doctor says you should or should not eat? (ie. no salt, diabetic) **What?** _____

☐ Client has no difficulty ☐ Client requires nutritional supplements

☐ Client is unwilling or unable to follow diet ☐ Client's food or fluid intake must be monitored

How would you describe your appetite: ☐ excellent ☐ good ☐ fair ☐ poor

Comments: _____

_____

Assessor: additional nutrition assessment is found in addendum section

Elimination - Do you have any problems with your bowels or bladder?

☐ Client has no difficulty

☐ Client experiences bladder incontinence. When? _____ How often? _____

☐ Client experiences bowel incontinence. When? _____ How often? _____

☐ Client has colostomy or ileostomy ☐ Client wears protective pads

☐ Client has recently experienced a change in elimination; Describe: _____

Are any of the following a problem to you?

☐ constipation ☐ diarrhea ☐ frequent urination at night

Do you need or use any of the following?

☐ commode ☐ urinal ☐ toilet railings ☐ bed pan ☐ catheter ☐ elevated toilet seat ☐ other: _____

Comments: _____

_____

Musculo Skeletal - Do you have any problems with the following:

☐ muscle weakness ☐ swelling ☐ joint stiffness ☐ pain ☐ muscle cramps

Comments: _____

_____

What is your activity/exercise level? Assessor: please record participant's perception

☐ bed bound ☐ inactive or sits most of the time ☐ moderately active ☐ very active

Comments: _____

_____

Central Nervous System - Do you experience any of the following:

☐ tremors ☐ headaches ☐ seizures ☐ trouble speaking ☐ abnormal muscle movements ☐ loss of sensation/feeling
☐ other: _____

Comments: _____

_____

Miscellaneous	yes	no	Explain:
Do you have any problems with your feet?			
Do you experience weakness, fatique or dizziness?			
Have you experienced a fall within the last year?			
Do you have a history of stroke?			

If the client has identified either visual or auditory impairments, please describe how they communicate:
(i.e., gestures, sign language, interpreter, communications board, etc.)_____

_____

What does the individual require in the area of health teaching about their illness, disability, medications or treatments? Describe what is needed and follow-up required:

_____

_____

_____

_____

Physical Health (con't)

Note any difficulty in communicating needs and what services, supports, etc. may help the person become more independent.

The last question in this section about follow-up required, is designed to prompt the assessor to think about ways to improve the health and independence of the person being assessed. Anything noted in this section should be included on the care plan.

ACTIVITIES OF DAILY LIVING

CODE: A = NO DIFFICULTY
B1 = ADAPTIVE AID NEEDED
B2 = ADAPTIVE AID USED
C1 = ASSISTANCE NEEDED
C2 = ASSISTANCE USED

ACTIVITIES	CODE	COMMENTS (please describe code)
Do you use utensils and eat without help?		
How do you get in and out of bed and/or a chair?		
How do you dress and undress yourself?		
How do you get in and out of the bath or shower?		
How do you prepare your bath, wash and dry yourself?		
How do you complete toilet activities?		
Do you have difficulty walking up and down a flight of stairs?		
How far are you able to walk without becoming tired or requiring assistance?		

Would this person benefit from any teaching or therapy to become more independent? Describe:

_____

_____

_____

What assistive devices could this person use to be more independent? Describe:_____

_____

_____

_____

Nurse's Signature:_____ Date:_____

ACTIVITIES OF DAILY LIVING

Completing this section will help the care manager get a good picture of what the participant is able to do for themselves and what assistance is needed or provided. Follow the code guide as to what the participant either needs or has and define the code in the comment section. The comment section is designed to specifically state what the participant needs and/or has in the way of services. Any line that has a code other than A should have a comment. Note any areas that the assistance is not enough to maintain the participant in the environment they choose to be in. This should then be a part of the care planning process.

The questions in this section are designed to elicit a narrative response by the participant. The assessor may need to prompt with additional questions to obtain the information required. It is also helpful if this information can be corroborated by either a care provider or individual knowledgeable about the participants abilities.

Again, be thinking about ways in which this individual may become more independent by receiving teaching, therapy or assistive devices. You need not complete this section immediately but may wish to make notes so as not to forget to provide any follow-up that is required.

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

CODE: A = NO DIFFICULTY
B1 = ADAPTIVE AID NEEDED C1 = ASSISTANCE NEEDED
B2 = ADAPTIVE AID USED C2 = ASSISTANCE USED

ACTIVITIES	CODE	COMMENTS (please describe code)
How are your meals prepared? (complete nutritional addendum if warranted)		
How do you complete the housekeeping and outside chores?		
How do you do your grocery shopping?		
How do you travel in a van, taxi, bus, or car?		
How do you answer the telephone or call the telephone operator?		
How do you clean your teeth, comb your hair and (shave) yourself?		
How do you handle your bill paying, banking, etc.?		
How do you do your laundry?		

FOR PEOPLE USING WHEELCHAIRS:

Describe your ability to independently propel your own wheelchair, both inside and outside your home: _____

_____

Describe how you transfer (i.e., from bed to chair, chair to toilet): _____

_____

Describe your chair: age ___ ☐ prescribed by physician ☐ fitted ☐ cushion
☐ special attachments ☐ needs evaluation

Would this person benefit from any teaching or therapy to become more independent? Describe:

_____

_____

What assistive devices or services could this person use to be more independent? Describe: _____

_____

_____

_____

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

This section will also provide you with a picture of the participant's abilities. Be thinking of adaptive aids the individual could benefit from and/or consultation with physical therapists, occupational therapists, etc.

If a participant answers a question by stating that they are unable to do that particular activity any longer, be sure to ask if they would like to be involved in that activity and make a note to discuss that particular area when determining the services the participant will receive. For example, if the participant responds that they can no longer participate in grocery shopping because they can't see the labels well enough, but would like to continue with this activity, you may want to pursue a vision exam or providing a support worker to go shopping with the individual.

DECLARATION OF INCOME & ASSETS Name:_____

MONTHLY EARNED INCOME	CLIENT	SPOUSE
1. Before tax wages or salary	_____	_____
2. Before tax income from self-employment	_____	_____
ALL OTHER INCOME		
1. Social Security	_____	_____
2. SSI/SSI-E	_____	_____
3. Veteran's Pension	_____	_____
4. Pensions/Annuities	_____	_____
5. Interest/Dividend Income	_____	_____
6. Other: (i.e. estates/trusts, net rental income, workman's compensation, unemployment compensation, alimony, etc.	_____	_____

COMBINED ASSETS OF CLIENT AND SPOUSE - Consider assets over the protected limits. Do not count your home, furnishings, or car.

1. Cash on hand _____ 2. Savings _____
3. Checking _____ 4. IRA _____
5. Certificates of deposit _____ 6. Money Market _____
7. Other: (i.e. stocks, bonds, trusts-excluding funeral trusts under $2,000, money owed to you and any property not used for any of the following: the person's homestead, a business, farming operation or rental income, a vehicle to go to work, to medical providers or for normal participation in community living.)

_____

_____

_____

8. Life ins. cash value if face value is more than $1500 _____

TOTAL ALL OTHER INCOME _____ TOTAL ASSETS _____

Income received for children in the home (i.e., child support, soc.security, SSI, etc.) _____

EXPENSES

Child support or family support ordered to be paid monthly: Yours _____ Spouse's _____

Maintenance or alimony court ordered to be paid monthly: Yours _____ Spouse's _____

List **average monthly** out-of-pocket expenses which could be considered medically related to the person's condition. Medically related expenses should be interpreted broadly. The following are examples of what should be counted, but the list is not complete: medications, medical supplies, equipment, payments on outstanding medical bills, caregivers, excess energy costs related to a medical condition, health insurance premiums, doctor/dentist/hospital bills (not covered by a third party), MA co-payments, hearing aids, wheel chair expenses, diapers, bed pads, etc.

Do you have an irrevocable funeral trust fund? _____

Have you or your spouse sold or given away property (such as land, stocks, bonds, cash, etc.,) within the last thirty months including transfers of property to children, relatives or other persons? ☐ YES ☐ NO

I have tried to give true and accurate information. I understand that the agency may request more detailed and documented information later.

Date:_____ Signature:_____

Relationship to participant

DECLARATION OF INCOME AND ASSETS

This form is the same as the form which may have been completed to determine initial eligibility for services. If a form has been completed, you may need to update it only and/or complete any missing information. If a form has previously been completed and signed, this form does not need to be signed.

If the individual is applying for the Medicaid-Waiver, it is important to obtain complete information on the monthly medical expenses to put on the medical/remedial expenses part of the cost sharing form. Also, your county may allow some or all of these expenses to apply to an individual's cost share for Community Options Program services.

If the participant does not have an irrevocable funeral trust fund and needs to spend down to qualify for services, this area should be pursued.

SOCIAL HISTORY/RESOURCES

Please tell me about your personal history. (i.e., birthplace, youth, maiden name, education, work, veteran, marriage(s), etc.) _____

Please describe your family of origin. (i.e., parents, brothers, sisters, etc.)

Living	Deceased	Name/Relationship	City/State	Phone	Has contact how often?

Do you have any children? If so, please list:

Living	Deceased	Name/Relationship	City/State	Phone	Has contact how often?

Please describe what a typical day is like for you now: _____

How is this different from what it used to be? _____

SOCIAL HISTORY/RESOURCES

It is very important to obtain complete information about the informal supports available to the participant as it is the goal of community programs to support and enhance services to individuals, not supplant what is currently being provided. It is also important to learn if informal supports will continue and/or need to be increased. Be aware of indications of caregiver stress and burden. You may wish to complete the addendum "Family Screen" or additional caregiver burden screen.

When asking the participant to tell you about their personal history, allow them to freely share what they choose. You may wish to prompt them with the examples provided. Help the individual to focus on positive life experiences. Help them to see where they have struggled and coped with difficult situations in the past.

What do you enjoy doing around your home? (i.e., gardening, pets, crafts, cooking, t.v., reading, etc.) _____

_____

What activities do you enjoy outside of your home? (i.e., church, sporting events, concerts, dining, movies, etc.) _____

_____

Are you currently employed either paid or volunteer? ☐ yes ☐ no If no, would you like to be? ☐ yes ☐ no

What activities have you always wanted to try but have not been able to? _____

_____

Do you now or have you in the past, belonged to any groups? ☐ yes ☐ no If yes, what?_____

_____

What do you usually do for holidays? _____

_____

Do you regularly visit anyone? ☐ yes ☐ no If no, is there a transportation problem? ☐ yes ☐ no

_____

Assessor: please determine the transportation problem

Do other people regularly visit you? ☐ yes ☐ no If yes, who? _____

_____

Assessor: determine connection and importance of visitor(s)

Is there anyone who routinely checks on you to be sure you are okay? ☐ yes ☐ no If no, is there someone you would like to check on you routinely? ☐ yes ☐ no Who? _____

Do you regularly talk to anyone over the phone? ☐ yes ☐ no If yes, who? _____

How would you describe your social activity level?

☐ isolated ☐ socially active ☐ uninvolved by choice

Would you like to increase the amount of your social activity? ☐ yes ☐ no

If yes, a) what would you like to do? _____

b) what is stopping you from doing this? _____

When you have a decision to make, do you make it yourself or do you often have someone help you?____

_____

Social History/Resources (con't)

When asking questions about social activities be sure to identify barriers to participation and address those issues in the care plan.

What aspect of your life are you most proud of? _____

_____

_____

_____

_____

What other information would you like to share with me that will help me to know you better? _____

_____

_____

_____

_____

PHYSICAL ENVIRONMENT

How long have you lived in your current residence? _____ Are you happy here? _____ If not, why not? _____

Do you own or rent? _____ Landlord (if applicable) _____

Do you feel safe living here? _____

Check which items are currently a problem for you		Describe the Problem/Repair Plan
Upkeep of building		
Hot water		
Comfortable temperature		
Stove/Refrigerator		
Telephone		
TV/Radio		
Washer/Dryer		
Trouble with neighbors/roommate		
Isolated location		
Access barriers inside home		
Access barriers outside home		
Substantial repairs needed		
Lack of space		
Housing too expensive		
Client must move		
Tub/Shower		
Difficulty with landlord		
Plumbing		
Other		

Additional Comments: _____

_____

PHYSICAL ENVIRONMENT

When completing this section of the assessment it is helpful to compare your observations with what the participant says. It may help to look around the home with the participant's permission or even have the participant show you around. This will give you an opportunity to observe the participant's mobility as well as how they have adapted to their environment.

Be aware of your own personal biases. If the house looks run down and you may not want to live in it, it doesn't mean the participant does not want to live there.

EMOTIONAL FUNCTIONING

Have you had any major changes or losses in your life in the past year? (i.e., death of a loved one, loss of job, divorce, illness, moving, retirement, change in financial status) ☐ yes ☐ no

Comments: _____

_____

Do you ever have trouble getting to sleep or staying asleep? ☐ yes ☐ no

Assessor: If yes, determine how often and what might be the cause, i.e., sleeping during the day

Have you had a change in appetite? ☐ yes ☐ no Comments: _____

Do you get upset easily? ☐ yes ☐ no

If yes, a) What kind of things upset you? _____

b) How often does that happen? _____

c) What do you usually do when you get upset? _____

Are you happy most of the time? ☐ yes ☐ no What kinds of things make you happy? _____

_____

Do you sometimes find yourself feeling unhappy or depressed? ☐ yes ☐ no

If yes, a) What kinds of things depress you? _____

b) How often does that happen? _____

c) Is there a pattern to this depression (i.e., weather, increased isolation, finances, special dates, etc.)?

_____

d) What do you usually do when you get depressed? _____

How often do you feel lonely? _____ What do you do when you feel lonely? _____

_____

Do you suddenly change moods for no apparent reason? ☐ yes ☐ no Comments: _____

Are you very worried or afraid about some things? ☐ yes ☐ no

If yes, a) What things worry you? _____

b) What things are you afraid of? _____

Do you ever feel that life isn't worth living? ☐ yes ☐ no

If yes, a) Do you ever feel that you want to die? _____

b) Do you ever think about suicide? _____

c) When does that happen? _____

d) How often? _____

EMOTIONAL FUNCTIONING

This section is often difficult to talk about with a participant because of the emotion involved. Participants may not be completely honest with you about their feelings. Be sure to note differences between what the participant states he/she feels and the affect they show. It is important for the assessor to feel comfortable with questions in this section. If you don't feel comfortable, the participant won't feel comfortable. You may wish to try them out on a co-worker before actually going through the interview. If the participant does become emotional, give him/her time to compose himself/herself and let them know it is all right to express emotions. Don't rush through the questions or ignore the emotion or the participant may feel they have done something wrong.

Do you sometimes have trouble getting along with people you are close to? ☐ yes ☐ no

If yes, a) What kinds of things cause the trouble? _____

b) What do you usually do about it? _____

How would you rate your mental or emotional health at the present time?

☐ excellent ☐ good ☐ fair ☐ poor

Are you receiving any mental health treatment or services now? ☐ yes ☐ no If yes, what?

_____

_____

ADDITIONAL COMMENTS: (Is further mental health assessment needed?)_____

_____

_____

_____

_____

SHORT MENTAL STATUS QUESTIONNAIRE (SPMSQ)
E. Pfeiffer (1975)

Instructions: Ask questions 1-10 in this list and record all answers. Ask questions 4a only if patient does not have a telephone. Record total number of errors based on ten questions.

1. What is the date today? _____
2. What day of the week is it? _____
3. What is the name of this place? _____
4. What is your telephone number? _____
4a. What is your street address? _____
(ask only if patient doesn't have a telephone)
5. How old are you? _____
6. When were you born? _____
7. Who is the President of the U.S. now? _____
8. Who was President just before him? _____
9. What was your mother's maiden name? _____
10. Subtract 3 from 20 and keep subtracting from each new number, all the way down.

TOTAL NUMBER OF ERRORS

0 - 2 Errors =	Intact Intellectual Functioning
3 - 4 Errors =	Mild Intellectual Impairment
5 - 7 Errors =	Moderate Intellectual Impairment
8 -10 Errors =	Severe Intellectual Impairment

COGNITIVE FUNCTIONING

This section is also difficult for assessors to conduct. It is important to ask the questions in a straight forward manner so as to not bias the results. It is helpful to tell the person the test is given to all people going through the assessment process. It may also be helpful to simply ask the participant for permission to ask them questions about their memory. In most cases they will agree. If the participant should refuse to answer the questions, note their refusal and move to the next section. It is also helpful to practice this test before actually giving it to a participant.

Nurses are often trained in completing the cognitive assessment. If you have a nurse complete the physical assessment, you may also wish to have them complete this section.

INSTRUCTIONS FOR THE USE OF ADDENDUM ASSESSMENTS

The attached addendum assessments are to gather additional information about specific topics related to cues that are presented by the person being assessed. For instance, you may want to use the Family Screen tool when a family member is present at the assessment and gives indications that they would answer some of the questions differently from the consumer; if either the person being assessed or family members indicate stress in their caregiving situation; or if family will continue with caregiving responsibilities and you would like to gather baseline information for the future.

Indications for using the Alcohol and Drug Assessment tool might be when the person being assessed reports drinking alcohol in addition to taking medications that are contraindicated with alcohol, the referral source indicates there may be an alcohol or drug problem, or family and/or friends indicate there may be an alcohol or drug problem. The use of this tool would help the assessor to gather additional information and determine if a more complete assessment by an alcohol or drug counselor might be an appropriate referral.

These tools are not necessarily done at the initial interview. In fact, due to the more personal nature of some of the questions it is recommended that they be done after a relationship has been established with the client.

FAMILY SCREEN

To what extent has this illness/disability affected family and personal relationships? _____

_____

_____

What do you hope to see happen for your family member as a result of this assessment? _____

_____

_____

What role do you see for yourself and other family members involved with this person? _____

_____

_____

What support services do you see as most necessary to help your family member? _____

_____

_____

Do you have any reason to believe your family member has a problem with alcohol or drugs? _____ Please describe: _____

_____

_____

Does your family member exhibit any memory problems or fail to recognize people he/she should know? Please describe: (ie. when did it start, how often does this happen, etc.) _____

_____

_____

Are you concerned about your family member having hallucinations or delusions? _____

_____

_____

Does your family member wander away from home and/or appear lost in familiar surroundings? _____

_____

_____

Has your family member been physically aggressive towards themselves or others? _____

_____

_____

How would you describe your family member's judgement and ability to make decisions? _____

_____

_____

Do you believe your family member is sad or depressed a great deal of the time? _____

_____

_____

ADDITIONAL COMMENTS: (Is further assessment of the family/caregiver needed?) _____

_____

_____

_____

_____

ALCOHOL AND DRUG ASSESSMENT TOOL

ALCOHOL

1. Do you drink alcohol? Yes_____ No_____
   If yes: a. What? _____
   b. How much?_____
   c. How often?_____
   d. Have you ever had DTs?_____
   e. Have you ever had blackouts?_____

2. Has your use of alcohol ever caused you a problem?
   If yes: a. What?_____
   b. When?_____

3. Have you ever felt you should cut down on your drinking? Yes_____ No_____

4. Has a family member or friend ever expressed concern that you drink too much?
   If yes: a. Who?_____
   b. Concern? _____

5. Have you ever been to treatment for alcohol?
   If yes: a. Where?_____
   b. When?_____
   c. Outcome_____

6. Have you had any health problems related to alcohol?
   If yes: a. What?_____
   b. When?_____

PRESCRIPTION AND STREET DRUGS

1. Do you use prescription or over the counter medication to help you sleep?
   If yes: a. What?_____
   b. How often?_____

2. Do you use prescription or over the counter medication to calm you down?
   If yes: a. What?_____
   b. How often?_____

3. Do you use prescription or over the counter medication to pep you up or to feel better about yourself?
   If yes: a. What?_____
   b. How often?_____

4. Have you used more prescription medication than was prescribed for you?
   If yes: a. What?_____
   b. How much?_____

5. Do you or have you ever used street drugs or drugs which are illegal?
   If yes: a. What?_____
   b. When?_____

6. Do you use caffeine?
   If yes: a. What?_____
   b. How much?_____

7. Do you use tobacco?
   If yes: a. What?_____
   b. How much?_____

If the assessor thinks there may be an alcohol or drug problem, please refer to supervisor for the possibility of an in-depth substance abuse evaluation.

NUTRITIONAL ADDENDUM

1) Do you find it difficult to follow your diet? If so, why? _____

_____

2) Please describe a typical daily intake for yourself.

BREAKFAST	LUNCH	SUPPER

3) Do you experience any difficulties with chewing and/or swallowing? _____
If so, please describe. _____

_____

4) Have you had a recent gain or loss of 10 pounds over the last 6 months without intending to? _____

Does your weight fluctuate by more than 3 pounds from month to month?

_____

Please explain above answers. _____

_____

5) Approximately how many servings do you get from each of the four food groups per day?

Fruit/vegetables (4 servings/day)	
Proteins (2 servings/day)	
Milk/dairy (2-3 servings/day)	
Breads/cereals/grains (4 servings/day)	

Assessor: Try to get an idea of the average intake per meal on a usual day. If the participant is ill that day or not feeling well, be certain that you obtain intake for an average day.

6) Do you take vitamins daily? _____ If so, what and how many? _____

_____

Assessor: Please do a quick look at the outlay of the kitchen and dining area and note any unsafe or questionable items. (i.e. presence of all appliances and proper working order.)

GERIATRIC DEPRESSION SCALE

1. Are you basically satisfied with your life? . . . . . N
2. Have you dropped many of your activities and interests? . . . . . Y
3. Do you feel that your life is empty? . . . . . Y
4. Do you often get bored? . . . . . Y
5. Are you hopeful about the future? . . . . . N
6. Are you bothered by thoughts that you just cannot get out of your head? . . . . . Y
7. Are you in good spirits most of the time? . . . . . N
8. Are you afraid that something bad is going to happen to you? . . . . . Y
9. Do you feel happy most of the time? . . . . . N
10. Do you often feel helpless? . . . . . Y
11. Do you often get restless and fidgety? . . . . . Y
12. Do you prefer to stay home at night, rather than go out and do new things? . . . . . Y
13. Do you frequently worry about the future? . . . . . Y
14. Do you feel that you have more problems with memory than most? . . . . . Y
15. Do you think it is wonderful to be alive now? . . . . . N
16. Do you often feel downhearted and blue? . . . . . Y
17. Do you feel pretty worthless the way you are now? . . . . . Y
18. Do you worry a lot about the past? . . . . . Y
19. Do you find life very exciting? . . . . . N
20. Is it hard for you to get started on new projects? . . . . . Y
21. Do you feel full of energy? . . . . . N
22. Do you feel that your situation is hopeless? . . . . . Y
23. Do you think that most people are better off than you are? . . . . . Y
24. Do you frequently get upset over little things? . . . . . Y
25. Do you frequently feel like crying? . . . . . Y
26. Do you have trouble concentrating? . . . . . Y
27. Do you enjoy getting up in the morning? . . . . . N
28. Do you prefer to avoid social gatherings? . . . . . Y
29. Is it easy for you to make decisions? . . . . . N
30. Is your mind as clear as it used to be? . . . . . N

Scoring:

0 - 10 answers the same as listed = normal

11 - 20 answers the same as listed = mild depression

21 - 30 answers the same as listed = moderate or severe depression

HOME SAFETY CHECK-UP

ENTRANCE

( ) Are SIDEWALKS and STEPS in good repair?
( ) Are HANDRAILS present and securely fastened?
( ) Do DOORWAYS and DOORSWINGS allow safe passage?
( ) Can VISITORS BE SCREENED to control their access?
( ) Is there a household EMERGENCY EXIT PLAN?
( ) Is the PATHWAY to each exit clear and uncluttered?

LIVING AREAS

Floors, doors and living space:

( ) Are carpets and throw rugs slip-resistant with edges secured?
( ) Are walkways clear of clutter and extension cords?
( ) Are doorways adequately wide with low/flat thresholds?
( ) Are chairs sufficiently tall for ease sitting down and getting up?
( ) Is temperature during all seasons within a safe and comfortable range?
( ) Is there evidence of adequate pet maintenance?

Illumination and electrical equipment:

( ) Is lighting adequate in all rooms and stairwells?
( ) Are outlets grounded and of sufficient number?
( ) Are there nightlights to improve nightime visibility?
( ) Is there a flashlight handy for nighttime use?
( ) Are light switches easily accessed near room entries?

Fire and overall safety:

( ) Is there a phone or personal alarm system to call for help?
( ) Is there adequate access to escape doors or windows?
( ) Are smoke detectors installed and working?
( ) Is there a fire extinguisher in working order?
( ) Are solvents, detergents and toxins properly stored?
( ) Is smoking restricted to certain rooms or not allowed in the home?

KITCHEN

( ) Is the floor slippery?
( ) Are cords away from the sink?
( ) Are stove dials large, easy to read and reach?
( ) Are potholders nearby?
( ) Are flammables kept from heat sources?
( ) Is storage convenient?

BATHROOM

( ) Are handrails present in bath and by commode?
( ) Is there a non-skid mat or skidproof stripping in shower or bath?
( ) Are rugs skid-proof?
( ) Is water temperature regulated at 120 degress F or lower to prevent scalding?
( ) Is illumination good both day and night?
( ) Are medicines stored properly?

STAIRWAYS

( ) Are handrails present & sturdy?
( ) Is lighting adequate?
( ) Are switches at both top & bottom?
( ) Are non-skid treads on each step?
( ) Are top & bottom steps marked?
( ) Are stairs free of stored items?

BEDROOMS

( ) Is the path to the bathroom direct and clear?
( ) Are bedside rugs skid-free?
( ) Is the bed relatively high and firm?
( ) Is there a light within easy reach of the bed?
( ) Is a smoke detector near the bedroom entrance?
( ) Is smoking in bedrooms prohibited in the home?

UTILITY/BASEMENT

( ) Are laundry appliances in safe working order?
( ) Is the hot water heater kept at its LOW setting?
( ) Does the furnance receive maintenance on a regular basis?
( ) Is chimney/wood stove cleaned on a regular basis?

Jane H. Williams, OTR HBHC
March 1989

INSTRUCTIONS FOR HOME SAFETY CHECK-UP

The Home Safety Check-up is a tool that can be used at any time in the assessment process or it can be used in the on-going monitoring process. If an individual's home appears dilapidated you may wish to do the tool early on in the "getting to know you" process.

The Care Manager who uses the Home Safety Check-up may score the tool as they wish, either checking boxes "yes" or "no" whichever they prefer. It is recommended that a county decide how they prefer to use the tool and be consistent within their county. The importance of completing this tool is that any areas of concern need to be addressed with the participant and should be included in the care plan.