
The Changing Face of Long-Term Care

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In this article, we present population estimates of individuals with disabilities and discuss the manner in which the composition of this population is changing. We then highlight aspects of service delivery systems that are evolving in response to the changing long-term care (LTC) population. Following a summary of financing issues, we discuss several cross-cutting issues related to the organization of service delivery, quality assurance (QA), and financing. Current and future Health Care Financing Administration (HCFA) research and demonstrations emerging from these issues are then described.

INTRODUCTION

People with disabilities and chronic illnesses who require LTC encompass diverse populations, including persons with acquired immunodeficiency syndrome (AIDS), children who are technology dependent or otherwise disabled, persons with mental retardation and related conditions, and those experiencing serious mental illness or problems of substance abuse, in addition to the elderly disabled.

Subgroups of disabled persons may have specific service needs, and may differ from one another in many dimensions.

Yet individuals with disabilities and chronic illness may have similarities and face common service delivery and financing issues.

Research and demonstration work related to the disabled has been supported by disparate sources. To date, there has been limited effort to look across this body of work to identify the important similarities and differences between service delivery and financing issues we face in supporting LTC for various subgroups of the disabled as well as the general, shared solutions that may be available.

In this article, we hope to foster a more integrated approach that can inform our future research and demonstrations. We first define LTC and provide population estimates of those with disabilities. We then discuss in an illustrative (rather than comprehensive) manner the changing population of those with disabilities, highlighting aspects of service delivery systems that are evolving in response to these changes. Current LTC financing is summarized. We follow this introduction of LTC with a discussion of cross-cutting issues related to the organization of service delivery, QA, and financing. We conclude with a description of the current and future LTC research and demonstrations agenda.

The authors are with the Health Care Financing Administration. The opinions expressed are those of the authors and do not necessarily reflect HCFA's views or policy positions.

DEFINING CHARACTERISTICS

The literature suggests general agreement on the essential characteristics of LTC. The need for LTC arises from serious functional disability that tends to be of considerable duration. LTC involves the provision of a range of social and medical services and is provided in a variety of institutional, community, and home settings (Somers, 1987). As discussed later, both the service constellation and setting are heterogeneous across subgroups of the disabled.

Family and friends provide the majority of LTC on an informal basis. With respect to formal (paid) LTC, there has been a notable growth among a range of home and community-based services, although a clear bias remains towards institutional LTC. Residential options have likewise been expanding to include assisted living facilities, supported living arrangements, and board and care arrangements.

POPULATION ESTIMATES

Estimates of the number of individuals with disabilities vary, depending on the data source, definition of disability, method of measurement, and perspective of the individual creating the definition (i.e., researcher, advocate for the disabled, etc., and individual self-perception [LaPlante, 1991]). We provide estimates derived from the 1990 Survey of Income Program Participation (SIPP) conducted by the U.S. Bureau of the Census (1990) and supplement these with data from the University of Minnesota (for individuals with developmental disabilities), the National Institute of Mental Health (for individuals with serious mental illness), and the Centers for Disease Control (for

persons with AIDS). We believe these are the most current estimates available.

Approximately 42.6 million people, or 16 percent of the U.S. population, have a physical or mental disability. A subset of these individuals, 12.6 million, require LTC, when LTC is defined as needing assistance in either activities of daily living (ADLs) or instrumental activities of daily living (IADLs). These individuals represent about 25 percent of the total population of individuals with disabilities and about 5 percent of the U.S. population.

Of those individuals in need of LTC, approximately 42.1 percent are under 65 years of age—.5 million of the 12.6 million individuals in need of LTC are children, 4.8 million are non-elderly disabled adults, and 7.3 million are elderly individuals. Most individuals who need LTC live in the community, as opposed to an institution—10.3 million and 2.3 million individuals, respectively.

Those 65 years of age or over numbered 31.2 million in the 1990 census, or 12.5 percent of the population; this segment of the population is expected to grow to 52 million, or 17.7 percent of the population, by 2020. Those 85 years of age or over are expected to increase from 3.1 million in 1990 to 6.5 million in 2020. The prevalence of disability increases with age—data from the 1990 SIPP reveal that 10.5 percent of persons 65 to 74 years of age required assistance with ADLs, increasing to 51.2 percent for those individuals 85 years of age or over, with a total of 7.3 million in need of assistance for functional limitations.

Estimates are that 2.5 million individuals 18 years of age or over have mental retardation or related conditions; of these, about 930,000 have limitations in ADLs

or IADLs due to mental retardation. About 147,000 individuals reside in intermediate care facilities for the mentally retarded (ICFs/MR) and another 50,000 reside in nursing facilities (NFs). Use of community-based, non-institutional care for those with mental retardation continues to grow rapidly, with a projected 100,000 individuals receiving these services in 1993.

Approximately 2.7 million adults under 65 years of age have a physical disability and need assistance with either ADLs or IADLs. Another 182,000 individuals live in NFs and presumably need assistance in either ADLs or IADLs. About 475,000 persons under 65 years of age with disabilities need assistance with three or more ADLs.

The majority of the estimated 3.6 million non-elderly adults with serious mental illness (3.4 million) reside in the community, and only 200,000 reside in institutions at any one time. Estimates are that about 744,000 of these individuals require LTC, when requirement is measured by the need for assistance with ADLs or IADLs.

Among those under 18 years of age, about 4.1 million have chronic conditions, including between 10,000 and 30,000 who are technology-dependent. Estimates are that about 400,000 of these children with disabilities have three or more ADL limitations.

The cumulative number of AIDS cases in the United States (as of September 1993) is 339,250. A majority of these cases, 334,344, are adults over 13 years of age, and 4,906 cases are children. The cumulative number of deaths from AIDS is 204,390. Thus, there are 134,860 people

living with AIDS at this time (Centers for Disease Control, 1993).

Those who are disabled are more often poor than the non-disabled. Among the disabled, 38 percent of those under 65 years of age and 24 percent of those who are 65 years of age or over live below the poverty level. In contrast, 16 percent of those under 65 years of age and 10 percent of those 65 years of age or over without disabilities live under the poverty level. The need for LTC is heterogeneous across race and ethnicity, with the highest prevalence of LTC need found in black individuals—7.2 percent—compared with 5.5 percent across all other races (U.S. Bureau of the Census, 1990).

EMERGING TRENDS

Although longitudinal data across the diverse population of individuals with disabilities are limited, there are several apparent trends that suggest that the size and composition of the LTC population may be changing.

Some recent work suggests that the prevalence of chronic disability in the elderly may have declined in the period from 1984 to 1989 (Manton, Corder, and Stallard, 1993). Factors contributing to this decline may include biomedical innovations on the part of providers and increasing educational and economic status among the elderly. How changing demography, interacting with changing prevalence of disability, will affect the elderly's need for LTC is unclear, but the continuing growth in the absolute number of very old persons is likely to have a greater effect than reductions in age-specific disability rates.

Data suggest that the rate of growth in disabling conditions for the non-elderly is increasing rapidly. From 1959 to 1984, there was a 158-percent growth in the number of working-age persons experiencing severe disabilities, compared with a 38-percent growth in the number of working-age persons (DeJong, 1987). For the young working-age disabled (18 to 44 years of age), growth rates were even higher. This growth has been attributed, in part, to a decline in mortality rates for certain conditions, such as heart disease and hypertension, which increases the prevalence rates for these disabling conditions. Similarly, improvements in trauma care and emergency medicine have decreased mortality rates for individuals with major physical impairments such as spinal cord injury, again increasing their prevalence in the non-elderly population (DeJong, Batavia, and Griss, 1989).

Further changes in the composition of those in need of LTC are arising from recent developments in the epidemiology and treatment of persons infected with human immunodeficiency virus (HIV). First, survival time has increased, and may be further increased as treatment regimes are improved. Second, as the epidemiology of AIDS shifts from homosexual males to intravenous drug users and their sexual partners, prevalence is increasing among those who are poor and minorities, including women and children (Merzel et al., 1992). Thus, an increase in the number of persons with AIDS and an increase in their survival time may contribute to the greater prevalence of chronic disabling disorders in the

non-elderly, while changing epidemiology means that individuals with AIDS are increasingly poor and minorities.

EVOLVING SERVICE SYSTEMS

The LTC service system is evolving, driven in part by the varying needs of subpopulations, in part by technological advances, and in part as a response to preferences of those with disabilities and their families.

Much research and demonstration activity has focused on the LTC needs, service system, and financing for the elderly. The elderly disabled rely on both institutional and community-based care. Most LTC dollars, about 75 percent, support services for the elderly disabled. Support for community-based services for the elderly disabled is increasing, however, evidenced in the stated preferences of individuals and their families (Wiener, 1990) and in the continuing growth of community-based services for the elderly (Miller, 1992).

However, there is an extensive body of research suggesting that provision of non-institutional services has generally raised health care costs, as limited reductions in institutional use are more than offset by the increased demand for and use of community-based care (Hennessy and Hennessy, 1990; Weissert, Cready, and Pawelak, 1988; Wiener, 1990). Strategies suggested to make expansion of publicly financed home and community-based care less expensive in the aggregate include targeting services to those with the most severe disabilities, prioritizing hospital div-

ersion strategies, investigating the utility of technological advances, and improving utilization control (Morris, Sherwood, and Gutkin, 1988; Weissert and Cready, 1989; Wiener, 1990). Others suggest that criteria in addition to cost-effectiveness, such as the benefits associated with reinforcing existing informal support networks and meeting the preferences of the elderly and their caregivers, must be used to evaluate community-based care (Benjamin, 1988).

For individuals with mental retardation, service needs include income maintenance, habilitation (e.g., training in self-care), education, and vocational training—services distinct from the more maintenance-oriented needs of the elderly (Tompkins, Porter, and Harahan, 1988). There is a clear move toward keeping those with mental retardation out of institutions, bringing individuals currently in institutions into the community, reorienting the service system to support individuals of all severity levels in environments they choose themselves—i.e., apartments or homes—and supporting them in those chosen settings (Smith, 1990).

This movement is demonstrated in a decline in institutional placements and associated decline in expenditure growth, relative to the rapidly increasing use of home and community-based care services provided in non-institutional settings. Passage of the Community Supported Living Arrangements (CSLA) program in 1990 as a State optional plan service further demonstrates the movement of services into a person's home and community, placing more responsibility and authority on the consumer for care planning and service authorization.

The effectiveness of community-based care for individuals with developmental disabilities has received far less attention than similar programs for the elderly disabled. A review of 17 studies of the outcomes of deinstitutionalization for persons with mental retardation and related conditions generally showed greater achievement either in overall adaptive behavior or in the basic self-care and domestic skill domain, relative to persons who remain in an institution (Lakin et al., 1989). While average yearly costs of community-based services per recipient are lower than yearly costs for institutional care (Lakin et al., 1993), research regarding the impact of expanding non-institutional care on the use of institutional services and how expanding community-based services affect total costs of Medicaid services for those with developmental disabilities has not been conducted.

People experiencing serious mental illness suffer acute episodes of mental illness interspersed with periods of relative stability. Community care for these individuals leads to improved outcomes when psychiatric care is appropriately combined with an array of training and support services, including housing (Mechanic and Aiken, 1989). Costs of effective community-based care are no greater than institutional care (Taube, Goldman, and Salkever, 1990; Halvorson, 1992). However, unlike other subgroups of the disabled, investments in community systems of care for the chronically mentally ill have been limited, particularly with respect to public dollars. For example, use of 1915(c) waivers by State Medicaid agencies to build community-

based systems for those with serious mental illness has been quite constrained. Since the waiver program's inception in 1982, only four States have used the waiver program for this population, and in 1992 only one State, Vermont, continues to do so.

As a final example, the shifting of AIDS from an acute to more chronically oriented disease has resulted in the need to develop responsive LTC systems. Younger persons with AIDS often need child care, treatment for substance abuse, and other support services not required by the elderly. Their LTC service needs may be discontinuous, due to a more episodic functional limitation. Relative to other individuals with disabilities, persons with AIDS may often be more medically complex and may require more intensive home care, as well as institutional, services (Merzel et al., 1992). As with other groups of the disabled, one response to persons with AIDS' increasing need for LTC services has been a rapid growth in home and community-based care services through 1915(c) waivers. In 1987, two States began serving people with AIDS through 1915(c) waivers. By 1992, 14 States were providing waiver services to persons with AIDS, while an additional two States served children with AIDS through a waiver program for children (Miller, 1992). A range of services is provided under these waivers, including specialized medical day care, substance abuse treatment, supplemental foster care for children with AIDS, counseling, and transportation. The services most frequently provided are case management, personal care, and adult day care (Lindsey, Jacobson, and Pascal, 1990).

The effectiveness of community-based care for persons with AIDS has received limited attention. However, there are reasons to believe that home and community-based care may have a more noticeable impact on the level of institutional use and associated costs for persons with AIDS than for the elderly. Benjamin (1988) suggests that the goal of community care for persons with AIDS is to reduce hospital, rather than nursing home, use. Both the greater probability of hospital use by persons with AIDS and the greater costs of care for hospitalization differ from the experience of the elderly with nursing home care. It seems reasonable to expect that community care and short-term skilled nursing facility (SNF) care may substitute for hospital days at certain points in the disease course and be associated with reduced institutional use and costs. Yet data at present are limited (Benjamin, 1988; Lindsay, Jacobson, and Pascal, 1990; Merzel et al., 1992).

Clearly, the most common trend across service systems for the disabled is the movement to build community-based systems of care. Evaluation of the effectiveness of such care has been far less systematic, and it seems likely that the strategies to improve effectiveness vary, depending on the particular subgroup of the disabled. Also disparate are the specific service needs—both the type of services and their intensity, and the duration and pattern of LTC needs. An increasing role for consumer control is reflected in the service system for those with mental retardation and related conditions, and has been raised as an important concern in service provision for other individuals, particularly the elderly disabled.

FINANCING

Estimates are that approximately \$108 billion, or 12 percent of the projected \$903.3 billion in national health expenditures, will be spent on LTC in 1993 (Burner, Waldo, and McKusick, 1992). Of this, about 36 percent comes from personal resources, 41 percent from Medicaid, and 23 percent from other, primarily public, sources. LTC is overwhelmingly funded by public dollars. Private LTC insurance represents only about 1 to 2 percent of total LTC dollars.¹

In 1993, more than twice as much will be spent on institutional care than on home and community-based care. Current projections suggest that \$74.9 billion will be spent on institutional care, with close to 40 percent of this amount representing direct, out-of-pocket expenditures. Medicaid will cover close to 50 percent of institutional expenditures, Medicare will pay for 6 percent of these expenditures, and the remaining 4 percent of non-private dollars will come from other sources.

It is estimated that, in 1993, \$33 billion will be spent on home and community-based LTC.² Of that \$33 billion, approximately 46 percent will come from private

sources, including out-of-pocket expenditures of \$9 billion, 32 percent will come from Medicare, and the remaining 22 percent will come from Medicaid. Although Medicare funds acute care services, the growth in the Medicare home health benefit and its perceived expansion to providing more home health to chronically disabled elderly make Medicare the largest payment source for home and community-based services.

Medicaid is a significant source of funding for the chronic care needs of those with disabilities. The 1993 projected aggregate Medicaid LTC expenditures of \$44.3 billion represent a 13.9-percent increase over 1992. Although institutional dollars continue to dominate Medicaid LTC expenditures (4 of every 5 Medicaid LTC dollars supported institutional care in 1992), Medicaid expenditures for home and community-based services are increasing at a noticeably higher rate than institutional services. From 1991 to 1992, non-institutional LTC expenditures increased 21.7 percent, to \$5.8 billion, while institutional services increased 14 percent, to just over \$33 billion. Within institutional services, NF expenditures continued to grow, increasing 17 percent from 1991 to 1992, while the rate of growth for ICFs/MR has drastically slowed, growing only 6.6 percent from 1991 to 1992 (Burwell, 1993).

There is great variability in the per capita expenditures and striking differences in the provision of institutional services relative to community-based services for subgroups of the disabled both within and across State Medicaid programs. For example, in 1991, the percent of Medicaid LTC dollars for non-institutional services, including home health,

¹Lewin-VHI estimates based on data from the Bureau of Data Management and Strategy, HCFA, for Medicare and Medicaid expenditures, the 1987 National Medical Expenditures Survey for out-of-pocket expenditures, and the Brookings-ICF LTC Financing Model for expenditures of the elderly.

²This estimate is larger than the estimate given in HCFA's national health account (NHA) estimates. The estimated expenditures for home health care in this article are \$12.3 billion in 1993. Home health care in the NHA includes only services and supplies provided by non-facility-based home health agencies (HHAs). Therefore, services provided by hospital-based HHAs are not included. The NHA also does not include any services delivered by non-Medicare certified providers. Some services which Lewin-VHI has counted as home and community-based are included in the NHAs as "other personal care," but the HCFA-projected national health expenditures probably include only \$20 billion of the \$33 billion cited in this article.

personal care, and 1915(c) waiver services, ranged from a low of 1.3 percent in Ohio to a high of 43.4 percent in Wyoming (Miller, 1992). Changes in the disabled population affect both the Medicaid and Medicare programs. Although the most recent growth in the number of Medicaid recipients has been primarily among low-income families with dependent children, acute and LTC expenditures associated with the disabled population contributed substantially more to the growth in Medicaid program expenditures. From 1988 to 1991, more than 50 percent of enrollment growth was related to increases in the numbers of pregnant women and children, yet their costs accounted for only 11 percent of the growth in Medicaid spending. In contrast, the elderly and disabled accounted for 16.6 percent of increased enrollment in Medicaid, yet their costs accounted for 19 percent of total expenditure growth (Feder et al., 1993).

The number of disabled entering the Medicare program is also growing rapidly. From 1983 to 1992, the number of Medicare disabled increased 18 percent, to 3.2 million, and is projected to almost double from 1983 to 2000, to 5.3 million (Board of Trustees, 1993). This growth is expected to have a significant impact on the Medicare program. In 1990, average Medicare payments for the disabled were 26.3-percent higher than payments for the aged (Helbing, 1993). Although the cost patterns of the non-elderly disabled are not projected to change, the size of their costs relative to aged Medicare enrollees can be expected to make a significant impact on Medicare program expenditures as their enrollment increases over the next several years.

An important source of LTC is informal care provided by family and friends. Among persons with functional disabilities who live in the community, roughly 90 percent receive some informal help, while 67 percent depend solely on help from family and friends. It has been estimated that more than 27 million unpaid days of informal care are provided each week (Liu, Manton, and Liu, 1986).

ORGANIZATION OF SERVICE DELIVERY

As the characteristics of the disabled population change, services and supports necessary to maintain or improve functional independence change as well. While there are characteristics common across individuals with disabilities, service needs are distinct to particular disabled individuals. For example, needs for substance abuse treatment and child care that a younger person with AIDS or an individual with serious mental illness might require are not shared by the elderly disabled, although all may share the need for publicly supported housing. The habilitation training needed by a person with mental retardation is not shared by other individuals with disabilities. The challenge for providers is to develop service delivery systems and arrangements that are flexible and adaptable to the individual preferences and changing circumstances of those with disabilities.

Clearly, the transition to community-based systems of care continues. Use of community-based care relies in large part on the availability of both informal and formal caregivers and a home or community residence. Yet the incidence of disabling conditions such as AIDS is

increasing among individuals who lack a stable home and informal caregiver support (Mechanic and Aiken, 1989). Others, such as the elderly disabled, prefer to remain in their home or in community settings but may lack informal systems to support them in these settings. These circumstances highlight the increasing need for housing to be integrated with supportive services, so as to enable the disabled to remain in the community.

Research has focused on the relationship between informal and formal care, but has been driven by the concern, largely unsubstantiated, that formal, paid care would replace the informal care of family and friends who currently provide the majority of LTC services (Wiener, 1990). We have not focused on the issue of how to better integrate informal and formal care systems. While informal caregivers are essential to the understanding of the needs and preferences of many disabled individuals, some believe that health care professionals do not know how to use this expertise to more effectively link informal and formal care. It is argued that our payment systems, by supporting only formal care, exacerbate the problem. States are beginning to focus on this issue, primarily in the context of person-driven care in supported living for those with mental retardation.

There is increasing interest in the development of service delivery models that integrate acute and LTC services. Persons with disabilities tend to have higher acute care costs than persons without disabilities and are much higher users of institutional services to meet basic acute and LTC needs. As currently structured, there are no incentives under either Medicare or Medicaid to fully inte-

grate and coordinate these services. Chronic care services are not covered under Medicare, producing no incentive for integration. Effective integration of acute and chronic care services should result in substitution of non-skilled for skilled services, likely producing Medicare savings while increasing Medicaid expenditures; thus, there is no incentive under Medicaid to foster integrated systems. The creation of new structures that provide greater flexibility to providers to manage all the health and chronic care needs of persons with disabilities under one service delivery and financing system may provide greater potential to tailor benefits to individualized needs and lower aggregate health care costs.

With the exception of a few HCFA-sponsored demonstration projects, there are limited operational programs that fully or partially integrate acute and LTC services. Traditional managed care systems such as health maintenance organizations (HMOs) that are designed to provide flexibility in health services delivery under risk-based payment systems have not developed programs oriented toward persons with disabilities. Of concern is whether the development of integrated care models, financed under capitation or other fixed budget methods, is programmaticaly feasible, financially viable, and more effective than the current fee-for-service (FFS) system in tailoring services to the specialized needs and preferences of persons with disabilities.

Another area of interest is the development of case management systems for client assessment, care planning, and service coordination. Almost all legislative proposals to reform the LTC system include some case management compo-

ment. In the acute care system, case management functions are almost always performed directly by physicians, either as independent practitioners or as part of more organized systems such as HMOs. However, in LTC, there is much less consensus over issues such as whether the case management function should be provider-based or be located in an agency independent of the provision of service, whether case managers should operate as advocates for the client or whether they should also take into consideration the resources available to payers in developing service plans, and what role case managers should have in monitoring quality of care. There is little information available on the value added of case management in the LTC system or on what forms of case management are most cost-effective in assisting persons with disabilities to obtain the services they need and prefer.

QUALITY OF CHRONIC CARE SERVICES

Several studies have documented the often poor quality of care historically available in nursing homes, ICFs/MR, and other institutions serving disabled persons (Institute of Medicine, 1986). In the past few years, several programmatic initiatives have been undertaken to correct these deficiencies. The Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203) mandated the development of new programs for improving resident assessment, care planning, and staff training in nursing homes. However, the relationships between these new requirements and the clinical and functional outcomes of nurs-

ing home residents are not yet fully understood. The implementation of the minimum data set (MDS) for nursing homes provides a unique opportunity to evaluate quality of care and understand the resource requirements of caring for different types of residents. How much the quality of nursing home care has improved as a result of the OBRA 1987 reforms, and whether the new information available in the MDS can be used more systematically by nursing homes and State health agencies to monitor the quality of care of nursing home residents, are central issues for the provision of NF services under Medicare and Medicaid.

Emerging residential alternatives in the private sector present new challenges for QA in LTC programs. There has been considerable growth in recent years in board and care homes and assisted living facilities. Whether these facilities are simply alternative housing for persons with disabilities or serve as substitutes for institutional care is unclear. We have very limited information on the quality of care provided in alternative residential settings. As the use and intensity of home care and other community-based services financed under Medicare and Medicaid continue to increase in alternative residential settings, a significant challenge will be to organize QA programs in housing arrangements that serve multiple purposes for people with disabilities.

Home care use and expenditures continue to rise under Medicare and Medicaid, increasing concern over the quality of home care services. External monitoring of home care quality is complex because home care services are typically provided only a few hours a day

and a few days a week in home environments that vary greatly in their security, cleanliness, informal supports, and structural condition. There is considerable controversy on how to define quality of semiskilled personal care services, how to measure differences in quality, and the appropriate mechanisms of QA. As home care services and costs continue to increase, assuring payers and consumers of high-quality skilled and custodial home care is of utmost importance.

LTC systems are under increasing pressure to tailor service programs to the preferences of persons with disability. QA programs will need to create new balances between traditional QA concerns of client health and safety with the need to promote and foster autonomy, risk-taking, and empowerment over their lives. How far public programs will evolve in allowing home and community-based service authorization and QA to be driven by consumer preferences and satisfaction (as opposed to professional judgment) is a significant issue if programs like the previously cited CSLA program are developed for other special populations with disabilities.

The development of integrated systems of acute care and LTC also presents challenges for QA systems. Integrated care systems, like any HMO-type system, must assure that medical care is accessible, of high quality, and provided at a reasonable cost. However, when chronic care services are included as part of the benefit package, defining quality of care becomes more complex. Not only do these programs need to expand the definition of QA from a focus on clinical issues to include functional outcomes, but they also will be under

increasing pressure to develop standards and measures of quality of life (levels of independence or dependence). Whether integrated programs will expand measures of program performance beyond traditional clinical concerns to include dimensions of personal autonomy, dignity, and self-determination will be a major focus of future research regarding these systems.

ISSUES IN FINANCING AND REIMBURSEMENT

As described earlier in this article, public financing programs, principally Medicaid, currently target coverage and financing at the extreme ends of the service delivery continuum; more than 70 percent of public financing goes to cover institutional care in nursing homes and ICFs/MR, and the remaining funds are almost exclusively targeted toward services delivered on a part-time or intermittent basis (a few hours a day, a few days a week) directly in the client's home. Other residential care options for individuals requiring 24-hour supervised care, such as assisted living facilities, supported living arrangements, shared housing, and foster care are generally not widely available under Medicaid. Similarly, other community-based services often needed by younger people with disabilities, such as employment assistance and vocational training, are not permissible under Medicaid. One challenge is to develop program financing structures suited to tailoring services and financial support to people with disabilities, so that services are reflective of their diverse needs.

At the same time, both the Federal and State governments are concerned about the rapidly rising costs of LTC. Much of this attention has focused on nursing homes, ICFs/MR, and efforts to reform payment systems to improve efficiency in the delivery of LTC in institutions. The central issue is determining the forms of payment that provide the best incentives for efficient delivery of institutional care without compromising access to and quality of those services.

Alternatively, many have looked to the development of community-based systems to provide a lower-cost substitute to institutional care. As previously discussed, the evidence that community-based care can substitute for institutional care varies across the disabled population. For the elderly, it is clearly a complement, tending to increase institutional use, when paid for on an FFS basis. Here, work needs to attend to ways of improving efficiency, because home is the preferred setting for many elderly. Closer linkages to supported housing, greater targeting, and improved utilization controls may facilitate cost-effectiveness. For others with disabilities, work must focus on determining when and through what methods community-based care effectively substitutes for institutional care.

Another challenge of the current LTC system is the lack of opportunity for people to insure themselves against the risk of catastrophic LTC costs. Public assistance through Medicaid is only available to the poor who cannot afford to pay for LTC benefits. Social insurance that provides LTC without regard to income is unavailable for persons with disabilities. At the same time, the private LTC insur-

ance market, while growing, plays a very small role in providing people financial protection against the catastrophic costs of LTC. There are a number of problems with the current LTC insurance marketplace, and substantial disagreement exists over the potential of private insurance to finance LTC costs in the future. A key research issue is determining what types of public and private financing mechanisms are best suited to providing financial protection to persons with disability (especially those individuals with low or moderate levels of income and assets) without forcing them either to overburden existing informal support systems or to deplete life savings on the private costs of LTC.

The current LTC financing structure has been criticized as providing perverse incentives for the non-poor disabled to shelter and divest financial assets in order to "look poor" and meet the financial eligibility requirements necessary to receive LTC services under Medicaid. The extent to which estate planning is used for the purpose of establishing Medicaid eligibility for LTC is unclear. One concern centers on the extent to which elderly persons engage in estate planning activities to protect themselves against the catastrophic loss of needing LTC in nursing homes, and, if so, the implications of such activities for Medicaid LTC expenditures.

RESEARCH AND DEMONSTRATION AGENDA

This review of the current LTC system reveals that Medicare and Medicaid are not structured to effectively respond to diverse acute and chronic care needs of

persons with disability. Priority must be placed on designing and testing new models and methods that provide States and providers more flexibility in tailoring acute and chronic care service packages to the preferences and individualized needs of this diverse population. In particular, activities should foster continued development of community-based systems that are clearly the chosen setting of persons with disabilities. Both QA strategies and financing methodologies need to support these developments. Drawing from the previous discussion, it continues to be essential to identify important similarities and differences in service delivery and financing for various subgroups of the disabled and to explore potential shared solutions to these problems.

A multitiered research and demonstration strategy that is reflective of these complexities targets the following priority areas: integrating acute and LTC delivery systems; enhancing community-based LTC access and quality; developing and evaluating new financing mechanisms; and examining demographic and service delivery trends.

Integrating Acute and LTC Delivery Systems

We have discussed increased interest in the development of service delivery models that integrate acute care and LTC. Such integration is expected to provide greater flexibility to providers to manage all health and chronic care needs of persons with disabilities under one service delivery and financing system, providing greater potential to tailor benefits to individualized needs of those

with disabilities while lowering aggregate health care costs. Yet the lack of operational experience with such programs suggests the need to experiment with a wide variety of models that tailor specific benefit packages to different subsets or needs of persons with disability.

HCFA is experimenting with two different approaches to integration. First, we are sponsoring research and demonstrations to develop fully integrated models, designed to provide a continuum of acute and LTC benefits. The Program of All-inclusive Care for the Elderly (PACE) demonstration is the only fully integrated model that incorporates all acute and LTC services available through Medicare and Medicaid under full provider financial risk. Enrollment is limited to the frail elderly who are either dually entitled to Medicare and Medicaid benefits or who have the financial resources to pay a premium equal to the Medicaid capitation rate. The PACE model includes as core services the provision of adult day health care and multidisciplinary team case management through which access to and allocation of all health and LTC services are arranged. Approximately 1,500 individuals are enrolled across the nine operational PACE sites and the PACE prototype, On Lok Senior Health Services in San Francisco. Several additional sites are under development.

Reflective of an interest in identifying broad, common solutions to service delivery and financing across the disability spectrum, several PACE sites are currently receiving funds through the Robert Wood Johnson Foundation (RWJF) to determine whether a PACE-like model can be tailored to meet the service and financing needs of various non-elderly

disabled groups. Efforts are focused toward persons with AIDS (East Boston, Massachusetts), children with severe disabilities (Columbia, South Carolina), and the non-elderly, primarily physically disabled (Bronx, New York).

The Social Health Maintenance Organization (S/HMO) demonstration supplements the existing Medicare benefit package available through Tax Equity and Fiscal Responsibility Act (TEFRA)-risk HMOs with expanded benefits such as drug coverage and chronic care benefits such as homemaker, transportation, and home health services. S/HMOs enroll a cross-section of the elderly, including both the functionally unimpaired and impaired elderly. Financing is accomplished through prepaid capitation, pooling funds from Medicare, member premiums for the chronic care benefit, and Medicaid (for eligible enrollees). Over 21,000 individuals are enrolled in one of four sites, which have been in operation since 1985.

OBRA 1990 (Public Law 101-508) authorized HCFA to develop up to four new S/HMO sites, for purposes of refining the S/HMO model of care. We are completing a solicitation that will emphasize primary care and prevention activities; integrate acute, post-acute, and chronic care services throughout the delivery system, including management in the nursing home; and highlight the role of geriatric care in the model. Refinements in targeting eligibility criteria, the chronic care benefit, premium structures, and reimbursement methodology will be undertaken in support of this model.

HCFA is also supporting, with the PEW Charitable Trust Foundation, RWJF,

and the Medicaid Working Group, a demonstration initiative to develop integrated care models primarily for non-elderly persons with disabilities, all of whom are eligible for Medicaid, and about 40 percent of whom are dually entitled. Initiatives are in various stages of development in the States of Wisconsin, Florida, and Ohio, and the foundations are considering expansion to two additional States.

The most fully developed of these initiatives is the Wisconsin Special Care Initiative. Focusing on the Supplemental Security Income (SSI) population, this demonstration is designed to provide Medicaid-covered medical services and additional social services such as respite, family training, long-term planning, referral, and mediation services to up to 3,000 Medicaid-eligible SSI recipients in Milwaukee County. About 75 percent of projected enrollees are between 21 and 64 years of age, most have never been employed, and many receive some form of day programming either through the Milwaukee Public Schools (if school-age) or through a community-based organization. Capitation payments will be made to HMO providers for these services. Central to the model are a physician panel of experienced providers, case management services through a multidisciplinary team, and specialized clinics. Enrollment in the 3-year demonstration is projected to begin in early 1994.

HCFA is also sponsoring a number of studies and demonstrations of partially integrated systems that provide a limited set of acute and LTC services to those with disabilities. For example, the Medicare EverCare demonstration targets coordinated care techniques to

improve the management of the specialized acute care needs of the institutionalized frail elderly. Through better coordination of all acute care services (primary care, specialized care, and hospitalization), EverCare provides the institutionalized elderly better continuity of care of higher quality, at a lower cost to the Medicare program. Nine sites are currently under development.

The Community Nursing Organization demonstration tests the impact of nurse-directed home health care and nurse case management on enrollees' use of home health and ambulatory services. Sites receive a capitation payment for these services. Four sites have completed development and have just begun the operational phase of the demonstration. Approximately 6,000 Medicare beneficiaries are expected to participate in the demonstration, representing a mix of both well and frail individuals.

Enhancing Community-Based LTC Access and Quality

Current HCFA payment systems for Medicare post-acute care providers create problems in the accessibility of SNF care—the retrospective, cost-based method of paying for Medicare SNF services discourages nursing homes from admitting “heavy care” Medicare patients. Availability of community-based services differs widely by State and within State by disability group.

HCFA is sponsoring several initiatives to reform the payment of Medicare post-acute care; these reforms are intended to increase access to services on the part of beneficiaries, yet encourage cost-effectiveness on the part of providers. For

example, the Multi-State Nursing Home Case-Mix Payment and Quality demonstration is designed to pay SNFs for Medicare-covered services on a prospective basis that is adjusted to the case mix of the patients. The demonstration is intended to increase access for heavy-care Medicare patients by adjusting payments to reflect the resource requirements of caring for different types of Medicare residents. This is a joint Medicare and Medicaid initiative as both HCFA and the States are designing payment systems based on the same case-mix classification system so that incentives for care will be consistent across programs.

Efforts related to quality of care continue to be directed, in part, toward the definition of and adequacy of post-acute and chronic care services in NF and home settings. As part of the multi-State case-mix payment system, HCFA is developing quality-of-care indicators that will enable States participating in the demonstration to conduct continuous monitoring of the quality of care in nursing homes, based on information submitted on the MDS and claims data. States will receive this information on a monthly basis and anticipate using the information to schedule surveys, and select survey samples prior to visiting the nursing home, as well as to work with providers to assist them in efforts to improve the overall quality of care for NF residents.

The Medicare Home Health Agency (HHA) Quality Outcome Study is developing quality indicators for Medicare HHAs and protocols for assessing the quality of care based on a review of HHA medical records. The indicators cover all aspects of home health quality, but focus

on the clinical and functional outcomes of patients served by HHAs. We are exploring the feasibility of a demonstration to test this outcome-oriented quality indicator approach as part of the survey and certification process.

As previously discussed, there is also interest in determining the nature of quality of care in new settings, such as supported living for those with disabilities, and in integrated service settings, such as PACE. A central focus of the CSLA evaluation is to assess approaches States are taking to QA in this service model that emphasizes consumer autonomy and choice, fostered by consumer service authorization. How States are balancing traditional concerns of client health and safety with efforts to foster autonomy and risk-taking is being assessed through studies of community monitoring boards, provision of training and technical assistance, identification and dissemination of "best practices," and similar activities. The QA program developed for PACE (see the article by Kane and Blewett in this issue) is currently being refined and will be tested in PACE sites during the next 2 years. Of particular interest is the extent to which similar approaches can be applied to other integrated systems for the elderly disabled, as well as modified for use in integrated settings providing acute and chronic care services for non-elderly disabled populations.

Developing and Evaluating New Financing Mechanisms

Medicaid reforms must facilitate the flow of dollars to the settings and services preferred by the disabled. If LTC is

financed in the future through new program structures, additional policy research will include how to develop and administer new eligibility criteria (if the program is not means-tested), new financing mechanisms (if the program is not an open-ended entitlement), and new funding allocation formulae and indexing methodologies (to assure that Federal funds are equitably allocated across States and that resources are adequate over time).

HCFA anticipates sponsoring research in a number of areas, including public LTC insurance options, development and assessment of new eligibility criteria (e.g., disability-based eligibility systems), Statewide global budgeting methodologies for institutional and community-based services, and simulations of new funding allocation methodologies.

With regard to private financing, the marketplace for private LTC insurance is changing. Most reform proposals assume more aggressive Federal regulation of private LTC insurance, which could increase the cost of insurance products. At the same time, private LTC insurance is expected to be one of the fastest growing sectors in the supplemental insurance market. States may increasingly want to experiment with innovative ventures with private or public insurance schemes to encourage the elderly to purchase insurance as a supplement to benefits under public LTC programs.

Several research studies of trends in LTC insurance are currently under way, including simulations of the affordability of LTC insurance products and State regulation and enforcement of consumer protection standards for LTC insurance

products. We are also sponsoring studies and demonstrations of estate planning mechanisms and asset transfers across States and the extent to which these activities are primarily undertaken to obtain Medicaid eligibility.

Examining Demographic and Service Delivery Trends

Previously reviewed changes in demography of those with disabilities require ongoing study, so as to assess their impact on current and future LTC service needs. To assist in such ongoing analysis of the LTC population, HCFA is supporting several national surveys of those with disabilities and is sponsoring research utilizing these databases. For example, HCFA is providing funds for the Disability Supplement to the National Health Interview Survey. This survey is the most extensive ever conducted on a number of disabled populations, including children with disabilities, individuals with mental retardation and related conditions, and persons with serious mental illness, in addition to SSI and Social Security disability income populations. We plan to use data from this survey to better understand the demographics, financial resources, and service utilization of these individuals, so as to assess the impact of any changes in the demography of these populations on current and future programs.

We continue to support the National Long-Term Care Survey and use survey data to examine characteristics of the disabled and their LTC service use. Further, we expect to sponsor studies linking such surveys as the SIPP, the Medicare Current Beneficiary Survey,

and the National Medical Expenditure Survey with HCFA administrative data to examine, using both cross-sectional and longitudinal analyses, characteristics of those with disabilities and their LTC service use. For example, we are using data from the Medicare Current Beneficiary Survey to study characteristics of the non-elderly Medicare population and those enrollees who are dually entitled to Medicare and Medicaid and to relate these characteristics to their service use.

SUMMARY

Clearly, the projected growth in the number of persons with disabilities, coupled with the changing composition of the population, presents significant challenges. While this growth will test the capacity of our LTC system, the heterogeneity of disabled individuals and their LTC needs call forth our creativity to develop service delivery and financing systems that reflect preferences of individuals with disabilities and their families, respond to both common and diverse service needs, and effectively link informal caregivers to formal care providers. To do so in a manner that assures access to and quality of services in the current fiscally constrained environment will require considerable effort, creativity, and patience. Yet efforts currently under development by providers in collaboration with foundations and public sponsors offer the prospect of new approaches to meeting these challenges effectively.

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