

medicaid
and the uninsured

**State Perspectives on
Medicaid Long-Term Care:**
*Report from a July 2003
State Forum*

*Prepared by
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National Academy of State Health Policy*

January 2004

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The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

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This report summarizes discussions on Medicaid and long-term care held in July of 2003 with officials from seven states. The forum was convened by the National Academy for State Health Policy with support from the Kaiser Commission on Medicaid and the Uninsured. Forum participants – comprised of a cross-section of officials that included governors' policy staff, state budget officials, department directors, and program administrators – met to review Medicaid's long-term care program and to identify the program's goals, strengths, and weaknesses. We are grateful to the following individuals who participated in the forum and who have provided us with helpful feedback during the drafting of this report:

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It should be noted that this report summarizes the group's discussions as well as follow-up discussions with several other state officials who were unable to attend the meeting, and we are thankful to those individuals for their input and guidance.

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OVERVIEW

States, through the Medicaid program, are major purchasers of long-term care. Financed by the federal and state governments and administered by the states, Medicaid pays for over 40 percent of long-term care services nationwide. At the same time, long-term care for the elderly and persons with disabilities is the largest single component of Medicaid, averaging 35 percent (or \$76 billion) of the program's total budget. Soaring health costs combined with plunging state revenues have forced states to take a number of actions to control the growth of Medicaid. And as our nation ages and the demand for long-term care services continues to grow, long-term care programs are facing increasingly close scrutiny at both the federal and state levels.

In an effort to review Medicaid's long-term care program and identify its goals, strengths, and weaknesses, the National Academy for State Health Policy (NASHP), with support from the Kaiser Commission on Medicaid and the Uninsured, convened a forum of officials from seven states (Idaho, Maryland, Minnesota, New York, Ohio, Washington, and Wisconsin). The group met July 15, 2003, in Washington, D.C., and was comprised of a cross-section of state officials that included governors' policy staff, state budget officials, department directors, and program administrators. In addition, we have sought input from several other state officials who were unable to attend the meeting.

This report summarizes the group's discussions as well as follow-up deliberations. It first focuses on the current environment that states face, addressing such issues as Medicaid's role in long-term care, state fiscal crises and cost-containment strategies, and how state long-term care programs are evolving. It then details seven goals identified by the states participating in the forum. Those goals include 1) expanding access to home and community-based services; 2) reducing institutional bias; 3) allowing for greater consumer choice of services and settings; 4) expanding eligibility for long-term care; 5) improving coordination of care; 6) stabilizing financing; and 7) improving the capacity for strategic planning and tools development. Additional resources are included and referenced where useful.

THE CURRENT ENVIRONMENT

Medicaid is now the largest health insurance program in the nation, surpassing Medicare in both expenditures and number of clients. Medicaid pays for one-third of all childbirths, forty percent of states' mental health services, and forty percent of long-term care services nationally. In spite of the notable expansion of children's coverage in the last six years, Medicaid program expenditures remain heavily focused on other populations. In 2002, the elderly and persons with disabilities accounted for 70 percent of Medicaid expenditures and almost 25 percent of enrollment.¹

Medicaid is a means-tested entitlement program. State Medicaid expenditures are matched by the federal government. Although Medicaid is a federal/state partnership, Medicaid functions, in effect, as 54 separate programs under a federal umbrella. Federal guidelines mandate certain services for specified groups of beneficiaries, but they also allow considerable state flexibility and variation. As a result, each state (plus the U.S. territories and the District of Columbia) establishes its own eligibility standards, benefits packages, payment rates, and program administration.

Medicaid long-term care services were originally provided for the elderly and disabled in institutional care settings like nursing facilities and Intermediate Care Facilities for Mental Retardation (ICF-MR). The current trend, however, is towards provision of home and Community-Based Services (HCBS) to allow these individuals to remain in a non-institutional setting. In 1991, for example, 86 percent of Medicaid spending for long-term care was for institutional care and only 14 percent for HCBS. In 2001, 71 percent of spending was for institutional care and 29 percent for HCBS.²

The variation among states in Medicaid spending for long-term care is demonstrated by spending per state resident, which averages \$285, but ranged from \$86 in Nevada to \$754 in New York in 2002.³ The proportion of the Medicaid long-term care budget spent on ICF-MRs ranges from zero in Alaska and Arizona to 31 percent in the District of Columbia. The amount spent on HCBS programs varies from six percent in the District of Columbia to 55 percent in New Mexico and Vermont.⁴

Fiscal Crisis

States are facing their worst fiscal crises since the 1930s, with revenues plummeting across the nation. Medicaid, which is the second largest item in state budgets (after K-12 education), accounts for 15 percent of state spending, a total of \$218 billion in 2001.⁵ Medicaid spending continues to grow significantly, but the rate of growth declined from 12 percent in FY2002 to 9.3 percent in FY2003. According to a recent survey by the Kaiser Commission on Medicaid and the Uninsured, 50 states and the District of Columbia implemented Medicaid cost containment strategies in FY 2003, and each of these states planned additional spending constraints in FY 2004.⁶ State revenues are expected to grow much more slowly than the economy, and inflation in health care is not expected to abate.

Not surprisingly, forum participants expressed concern that a decline in state revenues is coinciding with an increase in demand due to medical and technological advances, an aging population, and changing social and family circumstances. A sluggish economy and rising unemployment have reduced incomes for millions of families, thereby increasing the number eligible for Medicaid. By the end of the decade, baby boomers will start entering the system, further exacerbating the problem. These factors, according to forum participants, have combined to create unprecedented pressure for cost containment in state Medicaid budgets.

Forum participants identified several strategies to contain costs:

- Rate freezes for community-based care (WI, OH);
- Partial funding of rate increases for nursing facilities (OH, WI);
- Nursing facility bed taxes imposed or increased (WA, MN);
- Downsizing ICF-MRs (WI, WA); and
- HCBS waivers as an alternative to nursing home care (OH, ID, WA, MD).

They also identified strategies to improve systems:

- HCBS (Assisted Living) waivers (MD);
- Single entry point/No wrong door access systems (MN, OH);
- Integrated acute and long-term care services and financing (MN) or capitated long-term care services (WI);
- Education initiatives to encourage the purchase of private long-term care insurance (MN);
- Consumer-directed care programs (OH); and
- Programs to identify and transition nursing facility residents to community living (OH).

As the above lists suggest, states are pursuing a range of strategies to contain costs, strategies that range from cutting provider rates and client services to reorganizing delivery systems. At the same time, they are working to ensure that important improvements to long-term care systems are not abandoned in the process. Forum participants are committed to initiatives that further the shift from institutional care to home and community-based care; that support the independence of elderly persons and people with disabilities; and that implement the requirements of the Americans with Disabilities Act.

State officials participating in the July forum noted strong support for community-based systems across the states. Although nursing facilities received greater rate increases than community based care, state FY04 budget deliberations generally maintained, and sometimes increased, funding for waiver programs. Some states initiated a shift from institutional services to community based care and began new waiver programs. Home and community based service providers, while sometimes having their provider rates frozen, were often granted additional resources to extend their services to other individuals choosing to obtain their long-term care services in the community.

THE EVOLUTION OF STATE PROGRAMS

All states administer long-term care programs and contract for these services; in fact, states are the primary purchasers of long-term care. Of total national spending on long-term care, Medicaid accounted for 42 percent of spending. Medicaid pays for a slightly higher share of nursing home care (47 percent), and Medicaid accounted for 21 percent of total spending on home health care services.⁷ As a result, states have built efficient systems at the state and local level to manage and deliver these services. As forum participants noted, states' comprehensive long-term care systems reduce fragmentation, coordinate multiple funding sources, promote awareness of long-term care services, facilitate access, develop provider capacity, and coordinate services.

Neither Medicare nor the private sector offers such an integrated delivery system. Medicare pays provider claims for acute care services, including short-term nursing facilities and home health services following an acute episode. The private long-term insurance industry pays claims filed by Medicare/Medicaid-certified nursing facilities, assisted living facilities, home health agencies, and sometimes other home-care providers.

Since Medicaid's creation in 1965, states have been responsible for providing long-term care services to low-income and persons with disabilities. For many years, this care was synonymous with institutional care. However, starting in 1970, home health services became a mandatory benefit for individuals entitled to nursing facility care and in the mid-1970's states were given the option of providing personal care services under a Medicaid state plan amendment. In 2001, 28 states covered personal care services. In 1981, states were given the option of providing home and community-based services to individuals who would otherwise qualify for institutional care. These efforts were accelerated with a 1999 Supreme Court ruling that required states to provide services in the most integrated setting appropriate to the wants and needs of qualified individuals. Today, in an effort to control costs and respond to consumer preferences, states continue to shift resources from institutional care to home and community settings.

Forty-nine states now have HCBS programs under §1915c of the Social Security Act, the Home and Community-Based Services Waiver program. (Arizona offers its HCBS program under a §1115 Waiver.) These and other programs allow states to target specific population groups and limit the number of participants in order to control costs. Individuals with developmental disabilities or mental retardation constitute 38 percent of waiver program participants and 75 percent of expenditures. The elderly and persons with physical disabilities account for 62 percent of participants and 25 percent of program expenditures.⁸ (See Table 1.)

Population	Number of states
Elderly/people with disabilities	49
Mental retardation/developmental disabilities	46
Technology dependent children	17
HIV/AIDS	17
Brain injury	15
Mental illness	3

To complement Medicaid waiver programs, 46 states have developed state-funded long-term care services to meet the needs of their residents. Services such as personal care, supervision, and home modification can prevent physical deterioration and forestall the expensive and disruptive option of institutionalization. These expenditures range from one percent of HCBS spending in Nebraska and South Carolina to 43 percent in Pennsylvania and 53 percent in Illinois.¹⁰

Recent State Efforts to Promote Home and Community-Based Care

To promote alternatives to institutional care, states are also developing infrastructures that will allow informed decision-making by potential consumers and their families. Often times a decision to use institutional care is made following an acute care episode that results in hospitalization. Hospital discharge planners, operating under Medicare conditions of participation and Medicare Diagnostic Related Group payment incentives, often opt for the quickest and easiest discharge option: a nursing facility. Sometimes, when patients need post-hospital, short-term rehabilitation, this is the best choice. At other times, however, HCBS care is a cost-effective and preferable choice.

To promote this option, forum participants recommended replacing “any-physician authorization” for nursing home admission with pre-admission review procedures, to ensure that consumers qualify functionally as well as financially for Medicaid coverage and that they are aware of their long-term care choices.

As part of this process, states have developed client assessment instruments to assess a person’s ability to perform activities of daily living (eating, bathing, dressing, mobility, and toileting); cognitive and emotional status; social, housing, and environmental circumstances; nutrition and family/friend support networks. Several states also use this instrument to determine qualifications for (and to help a client choose from) a menu of program options, including Medicaid-waiver and state-plan services, state-funded services, and Social Services Block Grant programs.

States also reported efforts to make their delivery systems more efficient and user-friendly by establishing “single entry point” systems or “no wrong door” systems to help eliminate the confusion consumers have about choices for long-term care.

Thirty-one states and the District of Columbia have implemented “single entry point” systems, which combine information and referral, client assessment, eligibility determination, care plan development, authorization, and quality assurance in one entity at the local level. Some of these systems also coordinate with the client’s physician or hospital discharge planner to facilitate movement between services and settings. In Colorado and Washington, private long-term care insurers have also tapped into these systems.

“No wrong door” programs take a different approach, organizing the access system so that any agency or organization is prepared to provide information and connect the client or the client’s family to the next step in the process.

All of these changes reflect a welcome shift from a provider-centric to a consumer-centric long-term care system. One of the key elements of this shift has been the active participation of consumers, their families, and consumer advocates in the design and evolution of the long-term care system. This participation, which began with the introduction of HCBS in the early 1980s, recently accelerated with the requirement for consumer participation in the Centers for Medicare and Medicaid Services (CMS) System Change grants.

Another significant consumer-empowerment trend is consumer-directed care, which frees clients from the requirement of using a Medicaid-certified agency and allows them to hire and manage their own attendant-care providers. In 2002, CMS introduced an Independence Waiver format to facilitate Medicaid-funded, consumer-directed services. State-funded programs and the Robert Wood Johnson Foundation-funded Cash and Counseling programs have demonstrated increased consumer preference for and satisfaction with this delivery model.

GOALS FOR MEDICAID LONG-TERM CARE

Forum participants discussed a range of topics, including long-term care eligibility, benefits, cost-sharing, populations, reimbursement, service delivery, quality, financing governance, and administration. As part of this wide-ranging discussion, participants identified seven goals for Medicaid long-term care programs:

1. Expand access to home and community-based services;
2. Reduce institutional bias;
3. Allow for greater consumer choice of services and settings;
4. Expand eligibility for long-term care;
5. Improve coordination of care;
6. Stabilize financing; and
7. Improve the capacity for strategic planning and tools development.

Expand Access to Home and Community-Based Services

Forum participants agreed that greater access to home and community based services (HCBS) is critical to creating the kind of long-term care system that consumers and policy makers want. Over the past 20 years, waivers have proved to be a successful model for states to provide non-institutional services for the elderly and people with disabilities.

However, state officials would like to streamline the waiver process. Currently, nursing facility care is a mandatory Medicaid service whereas home and community-based services are offered through waivers. The federal waiver process includes budget neutrality requirements, annual reporting requirements, periodic reauthorization, and strict eligibility requirements. The process of obtaining a waiver to deliver home and community-based services can be cumbersome for states. A new waiver request and approval is required for each program design change, which can be a difficult process for states, particularly those with small program staffs.

The group favored making HCBS a state option rather than a waiver program. However, in contrast to other state-plan services, they want to retain the “waiver plan” options of being able to target certain populations and use enrollment caps.

In addition, officials noted several requirements of HCBS waivers that are outmoded. Budget neutrality requires that care provided under waivers be no more costly to the federal government than the care that would be provided to the target population in the absence of the waiver. Yet, for instance, in states where intermediate care facilities for mental retardation services (ICF/MR) have been discontinued, determining what the cost of care would be in an ICF/MR — if such a facility actually existed — in order to provide a budget comparison with home and community based services is a hypothetical exercise with little, if any, meaning. Meeting this requirement uses administrative time and talent

that could be better focused on developing and using client/program outcome quality measures.

Another outmoded requirement demands that participants who receive HCBS must meet the Medicaid criteria for admission to a nursing home. Several states have developed state-funded community based services that are designed to provide in-home services for clients not yet meeting the nursing facility level of care. These programs do not qualify for federal financial participation because the clients do not meet the nursing home level of care. While states have the flexibility to define nursing home level of care, once it is defined it applies uniformly, without regard to care setting. The state officials at this meeting wanted to be able to have a broader standard for community-based care and a narrower one for nursing home care. Officials feel that, with more flexible standards, HCBS would be a valuable tool to keep elderly or disabled individuals from deteriorating to the point where they meet Medicaid criteria for admission to a nursing facility. The forum participants also thought that states should have the Medicaid option of providing these services to people who qualify based on a comprehensive assessment of *risk* for functional decline, poor health outcomes or eventual admission to a nursing home, rather than *actual* decline.

Finally, HCBS waiver policies have not allowed community-based alternatives for adults with mental illness because Medicaid does not pay for adult care in Institutions for Mental Disease (IMD). However, due to new treatment protocols, many of these adults receive services in nursing homes rather than IMDs, and would therefore seem to qualify for HCBS services which are offered as an alternative to nursing homes. After a landmark lawsuit, Colorado was granted waivers to provide services to adults with mental illness. Kansas and Vermont have similar waiver programs for individuals with mental illness. Forum participants felt that states could build on these successes with other underserved populations.

Reduce Institutional Bias

All state officials who attended the meeting expressed a desire to reduce the bias in Medicaid towards institutional care over HCBS care. As noted above, nursing home services are mandatory Medicaid services, while HCBS programs require a waiver. In addition to having to comply with rigid budget neutrality and annual reporting requirements, HCBS waiver programs must be reauthorized every three or five years. Federal rules also require that eligibility for services under a home and community-based waiver be targeted to the population at risk for nursing home placement. States may not broaden the definition of disability under an HCBS waiver program to include a broader group of persons with disabilities, although they may use more restrictive criteria. In addition, Medicaid rules allow payment for room-and-board in nursing facilities but not in community settings such as assisted-living facilities or foster-care homes without a waiver.

Forum participants also noted that in cases when states want to provide clients with Medicaid community care options the eligibility determination process for community care takes too long. Because nursing facilities are often large enough to assume the financial risk that an individual may not be found to be financially and functionally eligible for Medicaid funded services, they can provide comprehensive services immediately and wait to collect payment retroactively. Due to their generally smaller size, community care providers cannot bear this risk and must wait until a final eligibility determination is made. The time consuming procedural barriers to community care eligibility can mean that home and community based services are not really an option for many individuals.

State participants also noted that there is an over-supply of beds in nursing homes, and that, at the same time, many states have waiting lists for home and community based services.¹¹ States have tried a number of strategies to reduce the supply of nursing home beds and seek additional tools to more fully accomplish that goal. At the same time, states need tools to control the demand for nursing facility services. State officials would like the option to use selective contracting with nursing facilities rather than being required to contract with all certified facilities. They believe selective contracting could be used to increase the quality of nursing homes and control the growth of nursing home expenditures.

Housing is another critical component of long-term care. However, Medicaid does not pay for housing services except as part of institutional care. New models to integrate housing and long-term care services are important. A 2001 joint HUD-CMS demonstration project, which allocates fifty Section 8 housing slots to each of ten states for individuals being discharged from nursing facilities, is a good example of unprecedented programmatic coordination that should be expanded.

In the private-pay market, consumers are voicing their long-term care preferences by choosing assisted living facilities over nursing homes. Forum participants expressed concern that many of these consumers are unaware that Medicaid typically does not pay for the housing component of assisted living and that they will not be allowed to continue this arrangement if they spend down and become Medicaid eligible. To address this issue and provide for a continuum of care, some states are developing HCBS waiver programs to more smoothly move individuals out of nursing homes and into assisted living.

Allow for Greater Consumer Choice of Services and Settings

As mentioned above, consumer-directed care is a growing service delivery model for personal-care services. Instead of being required to use agency-provided services, participants are allowed to select, train, supervise, and fire the personal-care attendant workers of their choice.

Although some demonstrations and waiver programs are underway, these efforts should be expanded and strengthened. Forum participants felt that more research is needed to

ensure that adequate consumer safeguards are being incorporated into this process. HBCS waiver programs serve vulnerable populations, so care must be taken to balance the value of autonomy with the risks that can come with consumer choice. In addition, individual budgets to pay the salaries of personal-care workers must be in line with the local marketplace.

To assist individuals and their families with long-term care needs, Forum participants noted the need for states to develop and demonstrate best practices in consumer-directed care. Approaches that would allow Medicaid programs to *support* rather than *supplant* the use of informal caregivers, including family members, need to be explored. This approach could involve increased federal, state, and local coordination with the Administration on Aging Caregiver Support program. State officials also noted that more program development work is needed to remove barriers to returning to work for individuals with disabilities, and new approaches are needed to encourage and expand the purchasing of long-term care insurance.

Expand Eligibility for Long-term Care

For the low-income elderly and persons with disabilities, Medicaid is the only source of long-term care assistance. Because the program is targeted to help low-income people, it only reaches those who are poor to begin with or those who impoverish themselves to become eligible for Medicaid. States commented that current rules should allow more flexibility for incremental expansions in eligibility.

Currently, individuals qualify for Medicaid through the following pathways:

- Supplemental Security Income (SSI) program (income \$552/month and assets \$2,000/month in 2003). Eleven 209(b) states can use more restrictive eligibility standards that were in place before SSI was enacted;
- Special Income Rule, under which states can expand eligibility to 300 percent of SSI (\$1,656/month in 2003);
- Medically Needy program, states can expand coverage to individuals whose income exceeds the SSI income standards, but who have expensive recurring medical or long-term care expenses. Such individuals spend down on a continuing basis. In the 14 states that do not permit spend-down, individuals in institutions can be covered under the special income rule.

Regardless of which pathway is used to establish eligibility, an individual who is institutionalized must put all of his or her monthly income toward the cost of nursing facility care, except for a small personal needs allowance. Medicaid pays the difference between this income and the nursing home payment level. When a spouse remains in the community, some additional protections are provided to protect that spouse from impoverishment.

Some state officials are concerned that middle and higher income elderly individuals, prompted by elder law attorneys, seek to divest their assets in order to qualify for Medicaid. Federal Medicaid law attempts to discourage individuals from transferring savings and other countable resources to adult children, siblings, or others in order to satisfy the Medicaid resource test and qualify for nursing facility coverage. It does so by imposing, for a specified period of time, an exclusion of nursing facility coverage upon those individuals who engage in such transfers.¹² Despite these penalties, some believe that techniques to shelter and dispose of assets create inequities in healthcare coverage policy, allowing higher income individuals to receive Medicaid coverage.

The current health care system does not encourage individuals to obtain preventive care and early treatment. For vulnerable populations, such as the elderly and persons with disabilities, this could have the effect of worsening their health status. Often, when they qualify for Medicaid, they have greater health care needs and, are thus, more expensive to cover. States would like to reach these people earlier, at a time when intervention can improve outcomes. They would like to be able to set eligibility as a percentage of poverty and establish cost-sharing arrangements that vary by income. Another option is to set a higher asset limit for specific eligibility groups, so that they can enter the long-term care system sooner, but before they need to be institutionalized.

State officials are also concerned about inequities in Medicaid that result in upper and middle-class families receiving help with long-term care needs, while lower-income individuals remain excluded from the program. For example, under the family-income deeming provisions of the (Katie Beckett) Model Waivers, only a child's income is counted, rather than family income, allowing children from higher-income families to be covered. If states were allowed to deem some but not all of the family income and/or require some level of cost-sharing for upper- or middle-income families, state resources could be used to cover more individuals at lower income levels.

Currently, states can use waivers to cover individuals who are "at risk of institutionalization." However, states would like more flexibility in the eligibility rules to target individuals who, in addition to meeting income and resource standards, have specific chronic conditions or diagnoses, such as HIV/AIDS or children with severe mental illness, but are not necessarily at risk of institutionalization. States would like to be able to target these individuals before their conditions worsen and put them at risk of institutionalization. States cannot now generally expand eligibility for HCBS to certain members of a broad eligibility group (SSI, Special Income Rule, Medically Needy) based on condition or diagnosis. Recently, CMS rejected a State of Washington waiver request that included differential eligibility to encourage HBCS services.

States representatives also indicated that they would like to target specific benefits to specific populations. For example, states would like to be able to tailor a benefits package for individuals with specific health care needs, such as an individual who receives an organ transplant and needs anti-rejection medications. Medicaid administrators would like the option of providing benefits, such as prescription drugs, rather than full Medicaid benefits, through a targeted program; however, under current

law, states must provide the same set of benefits to all Medicaid eligibles in their state and cannot target specific benefits to specific populations (except for the medically needy).

Among forum participants, there was recognition that filling the gaps in the long-term care system, gaps that result in Medicaid being the only source of assistance, will require a broad societal discussion of who is, and should be, responsible for long-term care in this country.

Improve Coordination of Care

State officials report a need for better coordination between Medicare acute care services and Medicaid long-term care services in order to provide dual enrollees with effective care management, cost control, quality assurance, prevention, and client-tracking across the continuum of services.

About 17 percent of Medicare beneficiaries are also Medicaid-eligible, and about 60 percent of Medicaid long-term care clients are also Medicare-eligible. These dual enrollees rely on Medicaid to pay Medicare premiums and cost-sharing, and to cover benefits that Medicare does not, such as prescription drugs and long-term care. As these two programs struggle to maintain payment boundaries for dual-eligible clients, many state officials feel that they get stuck with the “failures” of the Medicare program, and they need to provide services to fill the large gaps in Medicare’s coverage.

Many dual-eligible clients start as Medicare beneficiaries facing an acute episode that results in hospitalization. From the hospital, they are often discharged to a nursing home where they begin to spend down or shelter assets to become Medicaid-eligible. The Medicaid program then inherits the client, incurring substantial financial liability without having had the opportunity to intervene and offer alternatives to the original nursing facility admission.

The incentives built into the Medicare hospital reimbursement system encourage speedy, rather than preferred (or least costly), discharge. Forum participants felt that the hospital discharge planning process needs to be realigned to facilitate returning home with services (as needed). Hospital discharge planners should be required to have responsibility and accountability to the other public payer in the system (Medicaid). Medicare conditions of participation for hospitals could be used to elicit improved coordination.

Federal waivers require states to assure the health and welfare of waiver program recipients, and states have been given flexibility to design systems that meet their program needs. However, forum participants noted that these quality assurance efforts are made difficult by a fragmented health care system, and states’ effort to look at client outcomes across the continuum of services are complicated by an individual’s dual

eligibility status. For persons covered by both Medicare (acute) and Medicaid (long-term care), tracking their service utilization is very difficult.

Forum participants felt that Medicare and Medicaid should not behave as completely separate programs, rather the healthcare system should be a service delivery system responsible for the health and functioning of the whole person. Having one program pay for acute care and another for long-term care without coordination leads to both unnecessary expense and poor client outcomes. An integrated service-delivery system should be responsible for a continuum of care and the overall health of the individual.

State officials want more tools for coordinating care, focusing on the management of chronic care rather than episodes of service. Several CMS demonstration programs — such as Programs for All-Inclusive Care for the Elderly (PACE) and Minnesota Senior Health Options (MSHO)— have shown the value of coordinating acute and long-term care.

There is room for improved coordination within the Medicaid program as well. Long-term care is currently fragmented into a variety of programs presenting a confusing array of services with differing federal authority, varying funding streams, and different eligibility rules. Services for the aging, for example, have few eligibility criteria and their own “agency door.” Persons with developmental disabilities face narrow eligibility criteria and a segregated system. Persons with mental illness face highly restrictive eligibility requirements. Long-term care programs have income and asset criteria and entitlements to services. HCBS programs have level-of-care criteria and waiting lists.

Stabilize Financing

As mentioned above, the demand for long-term care is expected to grow as the aging and disabled populations increase. Although long-term care costs have been growing more slowly than acute-care costs, state revenues are tightly constrained, and officials are looking for innovative cost-containment strategies.

The state forum participants felt there needs to be a national discussion on long-term care that includes a careful assessment of federal and state roles in program development as well as financial support. Currently, states are left with financial responsibility for the growing elderly and disabled populations.

The National Governors’ Association recommends that the federal government assume fiscal responsibility for long-term care for dual enrollees. This would shift the revenue base for the majority of Medicaid expenditures to the national level. However, this change would raise significant issues since program administration currently resides with the states, and the federal government lacks the necessary administrative structure to operate a long-term care system. Alternatively, the federal match rate for HCBS could be increased, thereby increasing the capacity of states to expand community care to meet the growing demand for services.

Improve the Capacity for Strategic Planning and Tool Development

State officials reported the need for assistance in developing tools to speed up the eligibility process, to standardize the client-assessment process, to replace the level-of-care criteria with more flexible standards, to establish beneficiary-tracking systems, to improve quality assurance systems, and to improve care coordination. These tools must be able to function in both the Medicare and Medicaid environments and must be attached to measures of client outcomes.

In addition, as states continue to increase the use of HCBS waiver options, better measurement and quality-monitoring systems will need to be developed for these programs. As required by federal law and regulations, all states have implemented systems to assure the health and welfare of HCBS waiver program participants. As these programs grow, more research is needed to obtain evidence on which innovations actually improve quality of care and quality of life for HCBS program clients. States need solid research on what works, best practices, and comparative analyses of different program features. Many structure and process measures have been implemented, but program performance indicators and client-function indicators need more attention. Based on research findings, client-satisfaction measures need greater standardization across states.

CONCLUSION

Forum participants pointed to a strong Medicaid long-term care service delivery system operated by states. Even during the current fiscal crisis, states are moving forward with implementing and enhancing long-term care systems designed to provide consumers with greater choice of community-based care and to reduce the costs of care. While the existing programs are strong, room exists for improvement in the areas of program flexibility, financing mechanisms, and Medicare/Medicaid coordination.

Endnotes

- ¹ Kaiser Commission on Medicaid and the Uninsured estimates based on Congressional Budget Office and Office of Management and Budget data, 2003.
- ² Laura Summer, *Medicaid and Long-Term Care* (Washington, D.C.: Georgetown University Long-Term Care Financing Project, May 2003, fact sheet).
- ³ Ellen O'Brien, *Medicaid and Long-Term Care* (Washington, D.C.: Kaiser Commission on Medicaid and the Uninsured, Forthcoming).
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- ⁹ HCFA 64 data, Center for Medicaid and State Operations, Division of Financial Management, HHS website, June 22, 2003.
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- ¹¹ Steven Gregory and Mary Jo Gibson, *Across the States: Profiles of Long-Term Care: 2002*, Fifth Edition (Washington, D.C.: AARP Public Policy Institute, 2003), p.4.
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