

Medicaid Managed Care for People with Disabilities:

Policy and Implementation
Considerations for State and
Federal Policymakers



National Council on Disability
March 18, 2013

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

***Medicaid Managed Care for People with Disabilities:
Policy and Implementation Considerations for State and Federal Policymakers***

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March 18, 2013

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Letter of Transmittal

March 18, 2013

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit the enclosed report, “Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers.” The report is based on 22 principles developed by NCD to guide the design and implementation of managed care for people with disabilities. NCD recommends that the 22 principles be rigorously applied in designing and operating managed care services for people with disabilities, and that the *Centers for Medicare and Medicaid Services (CMS) should prepare and disseminate a written protocol outlining the criteria to be used in reviewing state demonstration waiver requests involving Medicaid managed long-term services and supports.*

In light of increasing concerns about state budget constraints and escalating health care costs, states are looking for ways to improve care and manage Medicaid spending more effectively. Many states are moving people with disabilities into managed care arrangements. In most states now, some children and/or adults with disabilities are subject to mandatory enrollment in managed care arrangements for at least some of their care, and more states are moving in this direction. Further, beginning in 2014, the Affordable Care Act will expand Medicaid to reach millions of low-income uninsured Americans, including many with disabilities, and states are widely expected to rely on managed care organizations to serve the newly eligible population.

With strong oversight and planning, managed care offers opportunities to improve the quality and cost-effectiveness of care for Medicaid beneficiaries in the setting of their choice. However, transitioning Medicaid beneficiaries with disabilities into managed care involves many challenges, and to be successful, must be tailored to meet the unique needs of people with disabilities. NCD’s report addresses these challenges and offers recommendations to assist policymakers and people with disabilities in the design and implementation of successful managed care programs.

NCD commends your Administration for its attention to the health care needs of people with disabilities and the many improvements in access to care afforded by provisions in the Affordable Care Act. We will also share this report with the Centers for Medicare and Medicaid Services, and would welcome the opportunity to work with the Administration on behalf of Medicaid beneficiaries with disabilities.

This report was approved by the Council prior to me becoming its Chair. I fully support the report and look forward to working with the Administration on the report's recommendations.

Sincerely,

A handwritten signature in black ink, appearing to read "Jeff Rosen", with a stylized flourish at the end.

Jeff Rosen
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the House of Representatives.)

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Preface

According to a recent state-by-state survey, more than half the states are planning to increase the number of Medicaid beneficiaries enrolled in managed care plans in an attempt to slow the growth rate of federal-state spending and improve the quality and accessibility of services.¹

States have steadily increased the number of individuals enrolled in Medicaid managed care plans over the past two decades. Today more than two-thirds of the 70 million Medicaid beneficiaries receive at least a portion of their services through a managed care plan. Until recently, the vast majority of these enrollees have been comparatively healthy children and working-age adults. But now more than half the states are enrolling senior citizens and people with disabilities, as well as children with specialized medical needs, in Medicaid managed care plans. A growing number of states also are offering dental care, behavioral health care, transportation, and pharmacy services through managed care plans.

Three factors are driving states to accelerate managed care enrollments: (1) severe budget constraints resulting from the deep, prolonged economic recession; (2) the impending expansion of Medicaid rolls in 2014 under the Patient Protection and Affordable Care Act, hereinafter referred to as the Affordable Care Act (ACA); and (3) the need to control outlays on behalf of the most expensive segment of the Medicaid population—seniors and people with chronic diseases and disabilities. Experts generally agree that well-designed managed care initiatives can lead to important efficiencies in the delivery and financing of health care services. But studies differ on the extent of cost savings achieved by shifting from a fee-for-service to a managed care format.

Observing these trends in Medicaid policy and recognizing the profound impact they could have on future services to people with disabilities, the National Council on Disability (NCD) commissioned a wide-ranging study of Medicaid managed care. In the fall of 2011, NCD contracted with the National Association of State Directors of

Developmental Disabilities Services to conduct the study and prepare a report summarizing its findings, conclusions, and recommendations. Specifically, the purpose of the study was to answer the following questions:

- What are the implications of managed care for Medicaid beneficiaries with disabilities, both within primary/acute health care settings and within long-term services and support settings?
- What benefits can states and people with disabilities expect to derive from a Medicaid managed care delivery system? And, conversely, what are the potential pitfalls of organizing and financing the delivery of services along managed care lines—from the perspectives of state policymakers and people with disabilities?
- What are the essential principles and precepts that state officials should follow in designing and operating a managed care system serving people with disabilities? And what criteria should responsible federal officials use in regulating state managed care plans and reviewing and approving related waiver requests?
- What are the similarities and differences in designing and operating a system of managed primary/acute care services vs. a system of managed long-term services and supports?
- How do the operational features of specialty managed care carve-outs for behavioral health and prescription medications differ from managed primary/acute care service systems?
- How can disability advocates play constructive, influential roles in shaping the contours of state managed care initiatives affecting people with disabilities?

This report is intended to address the implications of managed health care and long-term supports for all subpopulations of Medicaid-eligible people with disabilities, including those with physical, developmental, behavioral, and sensory disabilities. While in many

respects managed care has similar ramifications for older Medicaid recipients, the primary focus of the present analysis is on people ages 3 through 64 with chronic disabilities.

The report is divided into four chapters. Chapter 1 summarizes basic concepts underlying a managed care approach to delivering health care services, including the historical roots of those concepts. In addition, it reviews the origins and subsequent growth of managed care within the federal-state Medicaid program. The primary aim of the chapter is to provide readers with a firm grounding in the basic rationale for managed care and the principal techniques used in operating Medicaid managed care programs. Emphasis is on the growth of managed care arrangements within the overall Medicaid program and the reasons this trend is likely to continue and increasingly encompass health care and long-term supports for people with disabilities.

Chapter 2 reviews the Medicaid program's wide-ranging role in serving people with disabilities, including the number and composition of nonelderly people who qualify for Medicaid benefits on the basis of disability, the types of services they receive, and their recent utilization and expenditure trends in Medicaid-funded services. In addition, this chapter pinpoints the unique challenges associated with enrolling people with disabilities in Medicaid managed care arrangements and outlines the reasons that states, with an increasing sense of urgency, are choosing to confront these challenges.

Chapter 3 contains a set of principles to guide federal and state officials, as well as disability stakeholders, in designing and implementing managed care programs for Medicaid beneficiaries with disabilities. These principles articulate the broad societal outcomes that a managed care program should seek to achieve, and spell out the essential components of a well-designed, effectively administered service system for people with physical, sensory, developmental, and behavioral disabilities. Included with each of the 22 principles is a brief elaboration on the actions necessary to honor the principle, including in several instances state-specific illustrations.

Chapter 4 provides NCD's recommended action strategies to ensure the successful enrollment of people with disabilities in Medicaid managed health care and long-term support systems. These recommendations, addressed to federal and state officials, are aimed at improving the overall accessibility and quality of Medicaid-funded services and supports furnished to people with disabilities.

To assist readers who are not steeped in the nomenclature of Medicaid managed care policy, appendix A is a glossary of frequently used terms. Appendixes B through G present supplemental information on several topics related to Medicaid and managed care.

Our hope is that the report will help readers gain a better understanding of the intricacies of Medicaid managed care practices and the ways in which these practices can and should affect services for program beneficiaries with disabilities.

Executive Summary

The federal-state Medicaid program plays an integral role in financing health care services in the United States, accounting for 16 percent of total health spending and providing coverage for one out of every six Americans. Among the more than 60 million citizens who rely on Medicaid are about 9 million nonelderly people with disabilities, including 1.4 million children. The enactment of the 2010 health reform legislation (Affordable Care Act) promises to accentuate the importance of Medicaid financing of disability services, as well as the shift toward using managed care delivery systems.

The Medicaid program serves a diverse array of people with disabilities, ranging widely in age and type and severity of disability. Some enrollees with disabilities are difficult and costly to serve, primarily because of the complexity, intensity, and longevity of their health care and support needs. The service delivery challenges involved in serving low-income people with disabilities are magnified in the case of Medicaid enrollees who require a synchronized array of health care and long-term supports. In the United States, historically health care and long-term supports have been separately organized, financed, and delivered. Bridging the philosophical and practical barriers to integrating such services poses major service delivery and financing challenges.

Faced with growing caseloads, declining federal aid, and escalating health care costs, many states are electing to enroll high-cost people with chronic disabilities in Medicaid managed health care and long-term service plans. They are doing so in an attempt to place program expenditures on a more sustainable course, while simultaneously improving the quality and accessibility of services. The National Council on Disability (NCD) recognizes that managed care techniques can create a pathway toward higher-quality services and more predictable costs, but only if service delivery policies are well designed and effectively implemented. Cost savings should be achieved by eliminating inefficiencies, not by reducing the quality or availability of care available to people with disabilities.

Guiding Principles

Recognizing the many unique challenges involved, NCD recommends that the following guiding principles be rigorously applied in designing and operating Medicaid managed care systems serving children and adults with chronic disabilities:

1. The central organizing goal of system reform must be to help people with disabilities to live full, healthy, participatory lives in the community.
2. Managed care systems must be designed to support and implement person-centered practices, consumer choice, and self-direction.
3. Working-age enrollees with disabilities must receive the supports necessary to secure and retain competitive employment.
4. Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.
5. States must ensure that key disability stakeholders are fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of Medicaid managed care services.
6. Managed care delivery systems must be capable of addressing the diverse needs of all plan enrollees on an individualized basis.
7. States should complete a readiness assessment before determining the subgroups of people with disabilities to be enrolled in a managed care plan.
8. The provider network of each managed care organization should be sufficiently robust and diverse to meet the health care, behavioral health, and where applicable, long-term support needs of all enrollees with disabilities.

9. States planning to enroll Medicaid recipients in managed long-term services and supports plans should be required by the Centers for Medicare and Medicaid Services (CMS) to cover both institutional and home and community-based services and supports under their respective plans.
10. The existing reservoir of disability-specific expertise, both within and outside of state government, should be fully engaged in designing service delivery and financing strategies and in performing key roles within the restructured system.
11. Responsibility for day-to-day oversight of the managed care delivery system should be assigned to highly qualified state and Federal Government personnel, with the authority to proactively administer the plan in the public interest.
12. States should design, develop, and maintain state-of-the-art management information systems with the capabilities essential to operating an effective managed care delivery system.
13. States electing to compensate managed care contractors through a capitated payment system should adopt a fair, equitable, and transparent methodology for calculating and adjusting payment rates. Rates should be sufficient to allow a managed care contractor to (a) afford beneficiaries a choice among qualified providers and (b) address all of the service and support needs among plan enrollees with disabilities.
14. The Federal Government and the states should actively promote innovation in long-term services and supports for people with disabilities.
15. CMS should rigorously enforce the Affordable Care Act “maintenance of effort” provisions in granting health and long-term service reform waivers and mandate that any savings achieved through reduced reliance on institutional care be reinvested in home and community-based service expansions and improvements.

16. Primary and specialty health services must be effectively coordinated with any long-term services and supports that an individual might require.
17. Participants in managed care plans must have access to the durable medical equipment and assistive technology they need to function independently and live in the least restrictive setting.
18. The state must have in place a comprehensive quality management system that not only ensures the health and safety of vulnerable beneficiaries, but also measures the effectiveness of services in assisting individuals to achieve personal goals.
19. All health care services and supports must be furnished in Americans with Disability Act (ADA)-compliant physical facilities and programs.
20. Enrollees should be permitted to retain existing physicians, other health practitioners, personal care workers, and support agencies that are willing to adhere to plan rules and payment schedules.
21. Enrollees with disabilities should be fully informed of their rights and obligations under the plan, as well as the steps necessary to access needed services in accordance with the requirements of the Social Security Act.
22. Grievance and appeal procedures should be established that take into account physical, intellectual, behavioral, and sensory barriers to safeguarding individual rights.

Chapter 3 explains the rationale for each of the guiding principles outlined above.

Recommendations

Drawing upon the guiding principles, NCD recommends that federal and state policymakers initiate the following actions to ensure that people with disabilities gain access to the full array of health and long-term services and supports they need while enrolled in Medicaid managed care programs:

Recommendations to Federal Policymakers

Recommendation #1:

CMS should prepare and disseminate a written protocol outlining the criteria to be used in reviewing state demonstration/waiver requests involving Medicaid managed long-term services and supports (LTSS).

Recommendation #2:

In reviewing state waiver/demonstration requests involving the provision of LTSS, CMS should enlist the assistance of disability experts from other units within the U.S. Department of Health and Human Services (HHS).

Recommendation #3:

CMS should require states planning to deliver LTSS through managed care contracts to include in their LTSS coverage of both institutional and home and community-based (HCB) services.

Recommendation #4:

CMS should enforce the “maintenance of effort” requirement in the Affordable Care Act and require states to reinvest savings achieved by lowering institutional admissions and returning residents to the community in expanding access to, and the quality of, HCB supports.

Recommendation #5:

CMS should be allotted the personnel required to review, approve, and oversee implementation of state managed care waiver/demonstration programs and carry out its other related statutory responsibilities.

Recommendation #6:

Congress should restructure Medicaid laws governing LTSS to eliminate the bias toward institutional services and emphasize instead person-centered community supports designed to promote the inclusion of beneficiaries with disabilities in the mainstream of American society.

Recommendation #7:

The Federal Government should direct more time and resources to improving the information management capabilities of state and local LTSS systems for people with disabilities.

Recommendation #8:

HHS should designate LTSS as a priority area for comparative effectiveness research.

Recommendation #9:

Congress should eliminate inconsistencies between Medicare and Medicaid statutes governing durable medical equipment and assistive technology, possibly by assigning sole responsibility for purchasing such equipment to one program.

Recommendation #10:

CMS should encourage states that intend to enroll people with disabilities in Medicaid managed care plans to develop explicit strategies for eliminating existing disparities in access to health services between people with and without disabilities and promote wellness initiatives targeted to people with disabilities.

Recommendation #11:

The HHS Administration on Community Living, in collaboration with other departmental units and disability interest groups, should spearhead efforts to develop disability-specific outcomes standards to measure access to, and the quality of, health care and long-term supports for people with disabilities.

Recommendation to State Policymakers**Recommendation #12:**

Each state planning to enroll people with disabilities in Medicaid managed care plans should prepare a long-range strategic plan to guide the transformation of Medicaid-funded health care and LTSS for people with disabilities. A state's strategic plan should be built around a core set of disability values, and those values (see Principles #1–#4 above) should be reflected in the day-to-day service delivery policies and practices adopted by the state and all managed care contractors.

Recommendation #13:

States should actively enlist the assistance of nongovernment stakeholders in designing and operating a managed care system targeted to Medicaid-eligible people with disabilities.

Recommendation #14:

Disability policy experts—both within and outside of state government—should be involved in designing and implementing Medicaid managed care plans involving beneficiaries with disabilities, especially when LTSS are covered under the plan.

Recommendation #15:

State policymakers should grant the state Medicaid agency the authority and resources necessary to hire and retain an adequate number of qualified personnel

to effectively administer managed care contracts in collaboration with relevant disability-specific state agencies.

Recommendation #16:

Any state planning to enroll beneficiaries with disabilities in a Medicaid managed care program should complete a readiness assessment to determine the barriers to enrolling various subpopulations of people with disabilities and use the results of this assessment to establish a population-specific phase-in plan.

Recommendation #17:

States intending to enroll people with substantial disabilities in a risk-based Medicaid managed LTSS program should develop capitated payment methodologies that include incentives for providing such services in HCB settings.

Recommendation #18:

States planning to enroll Medicaid beneficiaries in managed long-term services should carefully analyze the diverse support needs among people targeted for enrollment and require managed care organizations (MCOs) to include skilled providers of such services and supports within their respective provider networks.

Recommendation #19:

States should institute a comprehensive management information system (MIS) to support effective, real-time administration of managed health and LTSS at both the state and MCO levels.

Recommendation #20:

States should establish a comprehensive quality management (QM) system to ensure the integrity of services to, and safeguard the health and welfare of, enrollees in managed health and LTSS plans that serve people with disabilities.

Recommendation #21:

Enrollees in Medicaid managed health care and long-term support plans should have access to conflict-free service coordination (case management) to assist them in navigating their way through the intake, assessment, service planning, provider selection, and service-monitoring processes.

Recommendation #22:

States should conduct or commission independent surveys of facility and program sites used by managed care network contractors and subcontractors to ensure that they comply fully with the provisions of the ADA and implementing regulations.

Recommendation #23:

State officials and MCO personnel should allow managed care enrollees with disabilities to maintain their relationships with physicians and other health practitioners, as well as personal support agencies and workers, wherever possible.

Recommendation #24:

States should develop and implement an aggressive education and outreach strategy to ensure that all plan enrollees (and potential enrollees) have accessible information concerning the services and supports available to them under the plan and how such services may be obtained.

Chapter 4 provides additional information and justifications related to these recommendations.

CHAPTER 1. **An Overview of Medicaid Managed Care**

Medicaid plays an integral role in financing health care services in the United States, accounting for 16 percent of total health spending and providing coverage for one out of every six Americans. Among the more than 60 million citizens who rely on Medicaid are about 9 million nonelderly people with disabilities, including 1.4 million children. While people with disabilities constituted 16.5 percent of Medicaid enrollees in fiscal year (FY) 2008, expenditures on their behalf represented 44 percent of total Medicaid outlays.²

The Medicaid program serves a diverse array of people with disabilities, ranging widely in age and type and severity of disability, and has an extraordinary impact on the health and quality of life of beneficiaries with disabilities. The program rolls include children with physical, sensory, intellectual, and developmental disabilities; working-age adults with spinal cord and traumatic brain injuries; children and adults with severe and persistent mental illnesses; and low-income adults with other serious, chronic illnesses and disorders such as diabetes and cardiac and pulmonary diseases.

Medicaid enrollees with disabilities have extraordinarily varied needs for both acute health care and long-term services and supports (LTSS). As Rowland noted, “people with intellectual disabilities have specialized needs that would not be met in a long-term service system developed to meet the needs of people with physical disabilities.”³ Of course, the converse is true, and applies equally to various other subgroups within the population of people with disabilities. The health and long-term support needs of this population are wide ranging and subject to rapid changes.

In 2010, President Obama signed the Affordable Care Act (ACA),⁴ a measure calling for sweeping changes in the U.S. health care system. Clearly, people with disabilities have a major stake in efforts to restructure the health care and long-term service delivery system in the United States. And today, in many states, managed care is viewed as the

chief vehicle for transforming the delivery of Medicaid services to beneficiaries with chronic disabilities and illnesses.

The two opening chapters of this report explore recent and emerging trends in financing and delivering Medicaid-funded services and supports to people with disabilities, with particular emphasis on the opportunities and risks associated with the growing shift toward managed care delivery systems. In this examination, we will review the number and composition of nonelderly people who qualify for Medicaid benefits on the basis of disability, the types of services they receive, and recent utilization and expenditure trends in Medicaid-funded services for such beneficiaries. In addition, we will pinpoint the unique challenges associated with enrolling people with disabilities in Medicaid managed care programs and outline the reasons that states, with an increasing sense of urgency, are choosing to confront these challenges.

The Meaning and Origins of Managed Care

The term “managed care” has different meanings depending on the context in which it is used. These multiple meanings can be confusing, especially to those who are not well versed in the terminology of health care delivery systems. Reduced to its fundamentals, however, managed care involves efforts to coordinate, organize, and rationalize the delivery of health care services and supports in a manner designed to improve service access and quality while avoiding unnecessary expenditures.

Managed health care emerged in the 1930s in response to the growing cost of medical services in the United States. Physicians and hospitals banded together in local or area-wide cooperatives to provide primary and acute care services to individual subscribers in exchange for the payment of a fixed monthly fee, or premium. As employer-based health insurance became the norm in the United States, commercial insurers and large employers came to recognize the advantages of a managed care approach to controlling the costs and quality of health services. By the early 1990s, a majority of American workers were enrolled in some type of managed care arrangement.

Although managed care began in the private sector, it eventually spread to publicly financed health programs. From the onset of the Medicaid program, a few states enrolled selected program beneficiaries in managed health care plans, typically health maintenance organizations operated by nonprofit corporations. The Federal Government, however, did not begin regulating Medicaid managed care arrangements until the early 1970s. The introduction of managed care as a formal Medicare option came more than two decades later, with the introduction of the Medicare Advantage program. By the late 1990s, a few states began applying the principles of managed health care to the provision of LTSS to Medicaid recipients with severe, chronic disabilities (see appendix B for a brief history of managed care in the United States and appendix C for a concise summary of the evolution of managed care within federal Medicaid policy).

Common Cost-Containment Strategies

Historically, Americans have paid for health care and long-term supports on a fee-for-service (FFS) basis. Under this approach, a hospital, a physician, or another qualified health care practitioner bills and receives payment for each episode of service rendered to a patient. In contrast, like big-box stores and other discount retailers, managed health care plans use their buying power to negotiate lower costs. At discount stores, shoppers are willing to trade amenities, such as knowledgeable sales staff, a more comfortable ambiance, and attractive displays, for lower prices than they find at traditional retail stores. Similarly, in exchange for a comprehensive array of health care services at a fixed monthly premium, enrollees in managed health care plans typically face the choice of using participating health care professionals and facilities or incurring higher out-of-pocket costs for treatment.

Among the methods commonly used by managed health care plans to control costs and thus remain financially viable are the following:

- Contracting exclusively with providers willing to offer their services at discounted rates.

- Monitoring the use of basic and ancillary services furnished by network providers and using incentives to reward below-average use and disincentives to discourage excess (above-average) use. These techniques are generally referred to as utilization review.
- Discouraging the excessive use of tests and prescription medications.
- Requiring plan participants to obtain a referral (prior authorization) from their primary care physician to gain access to specialty services reimbursable under the plan.
- Requiring providers to assume part of the financial risk of cost overruns for services they control, directly or indirectly.

About 44 percent of Americans received their health care through managed care plans during 2010. Most of them were served through health maintenance organizations (HMOs; 48.9%) or preferred provider organizations (PPOs; 39.3%), with the balance (11.9%) receiving service through either a point-of-service (POS) plan or a high-deductible health plan. The managed care penetration rate in commercial health plans (54%) was somewhat lower than among Medicaid recipients (71%).⁵

Types of Managed Care Arrangements

The principal difference between managed care and conventional health insurance payment methods is that the responsible entity (i.e., the managed care organization (MCO)) usually pays for and provides services, either directly or through contracts with third party providers, whereas conventional health insurers underwrite the cost of coverage but are not involved in the delivery of services.

The private sector uses several types of network-based health programs, some but not all of which are generally considered to be “managed care” approaches. The principal types of network-based programs are discussed in appendix D. Given the purpose of this

report, however, the discussion here is limited to applications of managed care techniques within the federal-state Medicaid program and the similarities and differences between managed care in the public and private sectors.

Differences Between Private and Public Sector Managed Care Arrangements

Managed care arrangements within the Medicaid program differ from managed care in the private sector, as well as from Medicare managed care plans, in the following ways:

- **The role of provider networks.** The majority of enrollees (55%) in employer-sponsored health insurance plans in 2011 were participating in PPOs. Considerably fewer were enrolled in employer-sponsored HMOs (19%), high-deductible health plans with a savings option (13%), or POS plans (8%).⁶ PPOs also are the most popular choice among Medicare beneficiaries who elect to enroll in a Medicare Advantage managed care plan, with 64 percent opting for a PPO.

In contrast, most Medicaid beneficiaries, including those dually eligible for Medicare and Medicaid benefits, who participate in at-risk managed care plans, are enrolled in HMOs. Because of limited financial resources, Medicaid recipients, including dual eligibles, are unable to afford the out-of-pocket deductibles and coinsurance payments associated with a PPO, a POS, or a high-deductible plan.⁷ Furthermore, because Medicaid payment rates are generally lower than commercial rates, provider networks and access to out-of-plan services typically are more tightly controlled under Medicaid managed care plans than they are under employer-sponsored and Medicare Advantage plans.

- **Limited cost sharing.** Cost sharing is frequently used in commercial managed care plans to discourage overutilization of services; but because the Medicaid program serves a low-income population, Medicaid managed care plans use cost sharing sparingly. Under federal law, states are allowed to impose only nominal

cost-sharing requirements, and deductibles are rarely used. Since such cost-sharing requirements are unlikely to serve as an effective deterrent to using expensive out-of-network providers, states usually elect to establish defined provider networks and hold MCOs responsible for ensuring that beneficiaries gain access to needed services within the network and at negotiated payment rates.

- **Choice of plans and enrollment processes.** States are required under federal law to offer Medicaid beneficiaries a choice of at least two health plans if enrollment in managed care is mandatory (with the exception of certain rural areas). In contrast, private employers are not required to offer employees a choice among alternative health plans, and only a little over half (52%) do so.⁸ Typically, where a plan choice exists, employees exercise their option at the time they become eligible for coverage and are given an opportunity to change plans during an annual open enrollment period. Similarly, Medicare recipients who elect to enroll in a Medicare Advantage plan may do so at initial enrollment or during a subsequent annual open enrollment period. Medicaid beneficiaries, unlike participants in private and Medicare managed care plans, often move in and out of managed care plans because of changes in income that affect their eligibility for Medicaid benefits.⁹

Types of Medicaid Managed Care Plans

Three different types of arrangements are commonly referred to as managed care within the Medicaid policy arena: comprehensive risk-based health plans, primary care case management programs, and limited-benefit plans.

- ***Comprehensive risk-based plans*** are the most commonly used type of Medicaid managed care arrangement. Typically, states employ an HMO model in which qualified health plans receive fixed per member per month (PMPM) payments from the state for furnishing a defined range of health services to plan enrollees. Enrollees receive services through a network of participating providers. If aggregate expenditures exceed total income, the health plan is responsible for

absorbing the losses, although sometimes the health plan passes on a portion of the financial risk to participating providers. In addition, states sometimes agree to share financial risk with the health plan by assuming losses in excess of a specified level (e.g., above 107% of aggregate PMPM payments). Such arrangements are often referred to as “risk corridors.”

Twenty-three million Medicaid beneficiaries (47% of all recipients) were enrolled in comprehensive at-risk managed care plans in 2009.¹⁰ Of this number, 56 percent were enrolled in Medicaid-only MCOs, while the balance (44%) were participating in plans operated by private health insurers that enroll both private and Medicaid-eligible individuals.¹¹

- Participants in **primary care case management** (PCCM) programs are assigned a primary care provider who receives a small, monthly per capita payment for coordinating each enrollee’s care. With the exception of this care coordination and case management function, all other health services—including those furnished by the individual’s primary care provider—are reimbursed on a FFS basis. In 2009, 7.3 million Medicaid beneficiaries were enrolled in PCCM programs.¹²
- Various types of Medicaid services are provided through **limited-benefit plans**. These plans typically cover only a single type of benefit. With payment generally made on a capitated basis, these plans are used in conjunction with other Medicaid managed care or FFS arrangements. Limited benefit plans frequently are used to deliver mental health and/or substance use services (7.4 million enrollees in 2009), transportation services (6.1 million), and dental services (1.2 million). Of the 15.9 million beneficiaries enrolled in limited benefit plans as of June 30, 2009, 54 percent were enrolled in prepaid inpatient health plans (PIHPs) and 46 percent in prepaid ambulatory health plans (PAHPs).¹³ As the names imply, the primary difference between a PIHP and a PAHP is that the former plan includes inpatient services (e.g., inpatient psychiatric care), while the latter plan does not (e.g., outpatient mental health services only).

The managed care penetration rate varies significantly from state to state. During 2009, four states had more than 75 percent of Medicaid beneficiaries enrolled in comprehensive, at-risk managed care plans, while in 17 other states, between 51 percent and 75 percent of Medicaid beneficiaries were enrolled in such plans. Meanwhile, nine states had no Medicaid beneficiaries enrolled in comprehensive, at-risk managed care plans, and an additional 11 states had participation rates of between 1 percent and 25 percent.¹⁴

State-to-state variations in PCCM enrollment followed a similar pattern, with four states having 75 percent or more of their Medicaid beneficiaries enrolled in PCCMs and 17 other states with PCCM penetration rates of between 51 percent and 75 percent of all enrollees. Conversely, nine states had no beneficiaries enrolled in PCCMs, and 11 other states had enrollment rates of between 1 percent and 25 percent of total Medicaid enrollees.¹⁵ As a general rule, states with highly urbanized populations tended to have a higher percentage of beneficiaries enrolled in comprehensive, at-risk plans, whereas sparsely populated states tended to rely more heavily on PCCM programs.

Managed Care Utilization and Expenditures

The federal-state Medicaid program provided health care coverage for approximately 67 million Americans in 2010. Almost three-quarters of Medicaid enrollees were children and adults without disabilities (33 million children and 17 million adults). The remaining enrollees included 10 million children and adults with disabilities (16%) and 6 million low-income people age 65 or older (9%).¹⁶

Participation in Medicaid managed care plans varies widely by eligibility group. Eighty-five percent of children without disabilities receiving Medicaid were enrolled in some type of managed care arrangement as of June 30, 2009. They also represented the majority (60%) of all Medicaid beneficiaries enrolled in managed care plans. The managed care participation level among adults without disabilities (57%) also was high. They made up 22 percent of the Medicaid managed care population in 2009.¹⁷

The managed care participation rate of nonelderly beneficiaries with disabilities and people 65 years of age or older, in contrast, was considerably lower (14% and 4%, respectively). In particular, people with disabilities and older people were less likely to be enrolled in comprehensive risk-based managed care plans (see table 1-A for details) and more likely to participate in limited benefit plans.¹⁸

Table 1-A. Percentage of Medicaid Beneficiaries Enrolled in Managed Care by Type of Arrangement and Eligibility Category: FY 2008

Type of Plan	Children (\$)	Adults (%)	Disability (%)	Aged (%)
Any type of managed care	84.6	57.1	58.4	32.9
Comprehensive risk-based plans	60.0	43.8	27.9	10.9
Primary care case management	19.0	8.9	12.6	2.1
Limited benefit plans	36.6	23.6	37.0	25.2

Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress: The Evolution of Managed Care in Medicaid* (Washington, DC: Medicaid and CHIP Payment and Access Commission, June 2011).

Although more than 70 percent of Medicaid beneficiaries receive at least a portion of their services through a Medicaid managed care plan, only about one out of every five Medicaid dollars (21%) were expended on managed care services in FY 2008 (see table 1-B).¹⁹ Most Medicaid managed care expenditures (18%) were channeled through comprehensive at-risk health plans, with the balance going to limited benefit plans (3%) and PCCM programs (1%).

Table 1-B. Percentage of Medicaid Spending on Managed Care by Eligibility Group

Basis of Eligibility	Total Medicaid Payments (\$)	Any Managed Care (%)	Comp. Risk-based Plans (%)	Primary Care Case Management (%)	Limited Benefit Plans (%)
Total	338.6	21.1	18.2	0.3	2.6
Aged	70.4	7.4	6.4	0.01	1.1
Disabled	150.5	13.5	10.9	0.1	2.4
Children	68.1	39.6	34.5	0.8	4.2
Adults	49.5	38.6	34.8	0.7	3.0

Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress: The Evolution of Managed Care in Medicaid* (Washington, DC: Medicaid and CHIP Payment and Access Commission, June 2011).

Managed care expenditures remain a minority share of overall Medicaid outlays because FFS arrangements continue to dominate services to older beneficiaries and people with disabilities—especially in the long-term services arena. With the average per capita cost of aged and disability services running five and six times, respectively, the per capita cost of services to children and adults without disabilities, overall Medicaid spending is still heavily weighted toward an FFS approach.²⁰ This pattern is likely to change over the next few years as a growing number of states enroll seniors and people with disabilities in comprehensive, risked-based managed care plans.

Managed Care Enrollment

States have used several approaches to enrolling Medicaid beneficiaries in managed care plans. These approaches include voluntary enrollment, mandatory enrollment, and a hybrid model that combines elements of both approaches.²¹

- **Voluntary enrollment.** In plans with voluntary enrollment, the beneficiary may elect to participate in the managed care program or receive services on an FFS basis. Consumers and consumer advocates usually favor voluntary enrollment because it imposes no restrictions on individual choice should existing FFS arrangements be deemed preferable. However, states using a voluntary enrollment model have found that it is difficult to attract high-quality MCOs. In the absence of a critical mass of enrollees from the onset, MCOs are unable to achieve financial viability and build the infrastructure necessary to serve populations with complex service and support needs. Voluntary enrollment also can work at cross-purposes with a state's managed care goals, including the goals of balancing medical home enrollments, holding MCOs accountable for delivering improved health outcomes, and placing expenditures on a predictable and sustainable course.
- **Mandatory enrollment.** Under a mandatory enrollment model, all members of the target population are enrolled in a managed care program. This approach appeals

to MCOs because it ensures that enough Medicaid beneficiaries will be enrolled to achieve financial viability. With confidence that a sufficient number of beneficiaries will be enrolled, an MCO can create the infrastructure to deliver services efficiently (e.g., hire specialized staff, develop data management capabilities, build a robust provider network). State Medicaid officials usually prefer mandatory enrollment as well because it links consumers to a primary care provider, allows the state to hold MCOs accountable for improving health outcomes, and offers better prospects of budget predictability. Consumers and consumer advocates, in contrast, often oppose mandatory enrollment because it restricts individual choice and may disrupt long-standing provider-patient relationships.

- **Hybrid enrollment models.** Mandatory enrollment with an opt-out requires targeted beneficiaries to enroll in the managed care program for a specified period of time (usually 60 to 90 days), after which they may either remain in the program or opt out and receive services on an FFS basis. Consumers and consumer advocates prefer this approach to strict mandatory enrollment because it gives the individual a chance to opt out of managed care if they are dissatisfied with their service arrangements. MCOs are generally supportive because they get a chance to prove the value of their services with a critical mass of enrollees. This approach also meets the key state objectives outlined above.

As states gain experience with enrolling people with complex health and support needs in managed care plans, they are beginning to introduce additional features to their hybrid enrollment models. For example, Massachusetts plans to allow participants in its integrated services demonstration program for nonelderly dual eligibles (ages 18–64) to retain existing community service providers for the first 90 days of the enrollment period and require all managed care entities (referred to as integrated care organizations in Massachusetts) to include in their provider networks essential community provider agencies (see additional discussion of the Massachusetts dual-eligible proposal in chapter 3).

Federal Statutory Authorities

States interested in enrolling Medicaid recipients in a managed care program must adhere to a set of federal requirements governing provider payment rates, provider availability within the plan network, the provision of covered health services, grievance and appeal procedures, and the quality of care furnished to enrollees. States can use one of several statutory authorities as the basis for a managed care initiative:²²

- **Offering managed care as a state plan option under the authority of Section 1932(a) of the Social Security Act.** States can implement a voluntary managed care program by obtaining Centers for Medicare and Medicaid Services (CMS) approval of a Medicaid state plan amendment. Once its state plan amendment is approved, a state can operate its managed care program(s) indefinitely without obtaining further CMS approvals. States, however, may not enroll dual eligibles, American Indians, or children with special health care needs in a managed care program under this authority. As of the summer of 2012, 21 states were operating a total of 24 managed care programs under the Section 1915(a) authority.
- **Offering managed care services under the authority of Section 1915(a) of the Social Security Act.** States also may initiate a voluntary managed care delivery system by executing contracts with MCOs selected through a competitive procurement process. CMS, however, must approve a state's plans before it can make payments under the program.
- **Requesting waivers under the provisions of Section 1915(b) of the Social Security Act.** These waivers permit a state to implement a managed care program that (a) restricts the types of providers that program enrollees may use (Sec. 1915(b)(1)); (b) allows a county or local government agency to provide choice counseling or enrollment brokerage services to plan enrollees (Sec. 1915(b)(2)); (c) permits the use of any savings resulting from cost efficiencies to be used to provide additional services to plan enrollees

(Sec. 1915(b)(3)); and/or (d) allows a state to restrict the types and number of providers that furnish particular elements of Medicaid services (e.g., disease management or transportation) to plan enrollees (Sec. 1915(b)(4)).

- **Requesting a combination of waivers under Sections 1915(b) and 1915(c).** Since the late 1990s, a number of states have operated Medicaid managed long-term services and supports under such “combo” waiver programs. The Section 1915(c) waiver authority permits a state to provide home and community-based (HCB) services that otherwise would not qualify for federal financial participation (FFP), while the Section 1915(b) waivers allow a state to use managed care techniques in operating its program.
- **Requesting secretarial approval of statutory waivers under Section 1115 of the Social Security Act to operate a managed care program.** The secretary of the U.S. Department of Health and Human Services (HHS) has broad authority under Section 1115 to grant waivers that allow a state to operate a research and demonstration program aimed at improving the effectiveness of services provided under the various titles of the Social Security Act. Over the past 30 years, a number of states have used this authority to make sweeping, structural changes in the financing and delivery of Medicaid services, including the introduction and expansion of managed care services.

All of the statutory authorities discussed above permit states to circumvent the following requirements of Medicaid law:

- **Statewideness:** The waiver allows states to operate managed care programs in only selected geographic area(s).
- **Comparability of services:** The waiver allows states to provide differential benefits to designated groups of managed care program beneficiaries.

- **Freedom of choice:** The waiver allows states to restrict beneficiaries to receiving services through a managed care plan or a primary care provider.

Given a state's objectives, there are advantages and disadvantages to using each of the above-listed alternatives to enrolling Medicaid beneficiaries in managed care programs. An analysis of key features of each alternative can be found in appendix E.

According to CMS' Medicaid Web site, 13 states and Puerto Rico were using Section 1915(a) contracts to administer 24 managed care programs as of the summer of 2012. In 2010, 20 states and the District of Columbia were operating at least selected managed care programs under a Section 1932(a) state plan option—up from ten states in 2002.²³ At the same time, 17 states were operating managed care programs under Section 1115 research and demonstration waivers, 25 states had Section 1915(b) managed care/freedom of choice waiver programs, and eight states were administering managed care programs under a combination of Section 1915(b) and 1915(c) waivers.²⁴

Federal and State Oversight of Medicaid Managed Care Services

While Congress has afforded states flexibility in designing and operating managed care programs, states still must adhere to basic statutory provisions governing the administration of their Medicaid programs. Moreover, statutory requirements have been added under Section 1903(m) of the Social Security Act to ensure that states are held accountable for services delivered to participants in Medicaid managed care plans.

These requirements are as follows:

- Plans must grant federal and state auditors access to their financial accounts and program records.
- In delivering and financing services, plans are prohibited from discriminating on the basis of an enrollee's health status.

- Plan enrollees must be afforded the right to disenroll within the first 90 days without cause and every 12 months thereafter.
- Plans must maintain encounter data and provide this data at a level of detail and frequency specified by HHS.

In addition to any state-imposed stipulations governing noncompliance, federal law specifies that, if a managed health plan fails to provide medically necessary services as called for in its contractual agreement with the state, charges premiums in excess of permissible limits, or violates other contractual requirements, the secretary of HHS may impose certain penalties in addition to those specified in law, including monetary penalties and denial of Medicaid payments to the state for amounts paid under the contract (Sec. 1903(m)(5)(B)).

The success or failure of Medicaid managed care plans often hinges on the contractual obligations placed on the entity administering the plan. The contract is a legal agreement between the state and the managed care plan and functions as a mechanism for enforcing requirements established by the Federal Government and the state. States can shift to an MCO the financial risk associated with caring for plan enrollees, but the state retains ultimate responsibility for plan performance.

A managed care plan's contractual responsibilities generally include the following key requirements:

- **Network development and maintenance.** In risk-based managed care plans, states delegate responsibility to the MCO for creating and maintaining a comprehensive provider network. To ensure that managed care plans contract with adequate numbers and types of providers, including providers of specialty services, states often include network requirements in their MCO contracts. MCOs also are contractually responsible for ensuring that providers are properly credentialed or licensed.

- **Care management and coordination.** MCOs often are required to assign each plan enrollee a primary service provider who is responsible for coordinating the enrollee's care across all providers and all services. Plans also may be obligated to assign certain enrollees (i.e., enrollees with complex health and support needs) a care or service manager who is responsible for providing additional assistance in coordinating services as well as providing enrollees services such as health education and disease management counseling.
- **Customer service and member education.** Plans are contractually responsible for ensuring that enrollees receive information on accessing services and have their questions and concerns addressed. Toll-free phone lines and ombudsman programs are commonly used in performing this function.
- **Quality standards and reporting.** In addition to federal requirements governing external quality reviews and reporting, states may impose other quality management requirements.
- **Data gathering and reporting.** The Federal Government and the states impose various data collection and reporting requirements on managed care plans. These requirements usually include enrollment data, encounter data, and data related to various quality measures.
- **Monitoring and evaluation.** States are required to determine whether managed care plans are complying with contractual requirements. Some states instruct health plans to file frequent, highly structured performance reports, while others impose fewer monitoring requirements, relying to a greater extent on ad hoc monitoring and reporting.
- **Payments.** Contract language often specifies the capitated payments a managed care plan is entitled to receive. Frequently, the contract language also spells out standards governing payment processing timelines.

- **Corrective actions.** MCO contracts usually specify how corrective action plans are to be developed and implemented when deficiencies in a plan's performance are identified.

Each state develops its own managed care contracts, with the level of detail in such contracts varying greatly from state to state. The managed care contracting process, however, is subject to CMS oversight, including plan review and approval by agency staff.

Under federal policy, states must require each managed care plan to conduct an ongoing quality and performance improvement program. In addition, each state must retain an external quality review organization (EQRO) to conduct an annual quality review of each contracted plan. States are required to report to CMS on the EQRO's validation of certain measures, but are not obligated to report the results of the measures themselves. A recent analysis conducted by CMS found that because EQROs used a variety of measures, nationally standardized information on the quality of Medicaid managed care services is currently unavailable.²⁵

Managed Care and People with Disabilities

Managed care has been introduced to state Medicaid programs on an incremental basis, beginning in most states with the enrollment of low-income children and parents and proceeding in stages to nonelderly people with disabilities and senior citizens. With some notable exceptions, states have elected to carve out dual eligible beneficiaries and continue paying for long-term services on an FFS basis when they have enrolled seniors and Medicaid beneficiaries with disabilities in managed health care plans. In 2008, just 28 percent of people with disabilities and 11 percent of older beneficiaries were enrolled in comprehensive, risk-based managed care plans. Faced with expanding caseloads and declining revenues, however, states are in the process of sharply expanding managed care enrollments among seniors and people with disabilities.

A 2011 50-state survey of Medicaid managed care programs found that states expect to substantially increase their reliance on managed care delivery systems in the years ahead. Of the 45 states responding to the survey, 27 reported plans to expand the use of managed care. Of these 27 states, six indicated that they plan to extend mandatory managed care enrollment to additional Medicaid populations (California, Kentucky, Louisiana, Michigan, New Jersey, and South Carolina), and four states reported plans to expand managed care to additional geographic areas of the state (Florida, Texas, Kentucky, and Virginia).²⁶ The following are additional key findings of the survey:

- All but three states operate comprehensive, risk-based managed care programs, covering approximately 66 percent of all Medicaid beneficiaries.
- Half the states with risk-based MCOs and PCCM programs also contract with noncomprehensive prepaid health plans (PHPs) to provide specific categories of services.
- States increasingly are mandating managed care for previously exempt or excluded Medicaid beneficiaries, including Supplemental Security Income (SSI)-eligible children with disabilities, children with special health care needs, and seniors and people with disabilities who²⁷ are not dually eligible for Medicare and Medicaid benefits.²⁸

In a separate, state-by-state survey, the authors found that 17 states in 2011 and 24 states in 2012 intended to expand the geographic areas and populations served by managed care programs. States also reported that they are expanding disease and care management programs as well as patient-centered medical home initiatives to improve coordination of care and increase the focus on high-need, high-cost Medicaid recipients.²⁹

Efforts to enroll dual eligible beneficiaries also are moving forward swiftly, spurred by statutory provisions of the ACA aimed at improving the quality and cost-effectiveness of services to this high-cost target population. In the spring of 2011, the secretary of HHS

announced the award of \$1 million grants to 15 states to assist them in designing new approaches to integrating and coordinating health care and long-term supports for dual eligible beneficiaries.³⁰ Since then, CMS' Medicare and Medicaid Coordination Office, a unit established under the provisions of Section 2602 of the ACA: —

- Issued a State Medicaid Directors letter outlining two models for integrating Medicare and Medicaid financing of services and supports for dual eligibles and invited all states to submit expressions of interest in participating in a three-year demonstration program.³¹ By October 2011, 37 states had expressed interest in testing one of the proposed financial integration models.
- Established an Integrated Care Resource Center to provide technical assistance to all states interested in coordinating and integrating Medicare and Medicaid services to dual eligibles.

The CMS Office of Innovation has announced that it will fund up to 15 projects under the State Demonstration to Integrate Care to Dual Eligible Individuals program. The deadline for submitting applications was May 30, 2012. The initial awards to states were to be announced in early October, with a projected start date of January 1, 2013, for some of the participating states and later start dates for others.

CHAPTER 2. **Medicaid, Managed Care, and People with Disabilities**

Many Medicaid enrollees with disabilities are difficult and costly to serve, primarily because of the wide-ranging needs within the target population; hence the importance of coordinating and synchronizing services and supports across multiple service delivery systems. The fact that Medicaid recipients with disabilities frequently require both health care services and long-term supports adds to the complexity of the service delivery equation, since the latter services, historically, have been provided through networks that operate outside the health care delivery system.

Disability-Based Medicaid Eligibility

For eligibility and spending purposes, enrollees are classified as “disabled” when they are under 65 years of age and qualify for Medicaid benefits on the basis of a disability. Of the 58.8 million Medicaid enrollees in FY 2008, 9.1 million, or 15.5 percent, were classified as disabled, including approximately 1.4 million children under age 19. Approximately 3.5 million of these people were also eligible for Medicare benefits.³²

Categorical Eligibility

Most enrollees with disabilities qualify for Medicaid benefits based on their SSI eligibility. SSI recipients are automatically eligible for such benefits in 39 states and the District of Columbia. The remaining 11 states use modified, pre-1972 definitions of disability.³³ To qualify for SSI benefits, an adult must have a medically determinable physical or mental impairment (or multiple impairments) that prevent him/her from engaging in substantial gainful activity (Sec. 1614(a)(3)(A) of the Social Security Act). The impairment must be expected to last at least 12 months. A person earning more than a specified amount (minus impairment-related work expenses) is considered to be engaging in substantial

gainful activity (SGA) and is therefore subject to the loss of SSI benefits unless certain benefit retention provisions apply (see discussion in appendix G).

Children under age 18 meet SSI's definition of disability if they have a medically determinable physical or mental impairment which results in "marked and severe limitations" (Sec. 1614(a)(3)(C)(i) of the Social Security Act). As in the case of adult beneficiaries, a child's impairment must be expected to last 12 months or longer. A child may be found eligible at birth or later. When a childhood recipient reaches age 18, his/her continued eligibility for SSI benefits is reevaluated using adult disability criteria.

Optional Eligibility

States may elect to extend Medicaid benefits to people with incomes above standard financial eligibility levels if they are medically needy. Under this option, people can become eligible for Medicaid once a certain level of medical expenses is incurred (referred to as a "spend-down"). In 2010, 33 states offered services to at least some medically needy recipients. The income cutoff level under state medically needy programs ranges widely, from 11 percent of the federal poverty level (FPL) in Louisiana to 110 percent the FPL in Vermont.³⁴

For people with disabilities residing in a Medicaid-certified long-term care institution³⁵ or at risk of placement in such an institution, states may establish special income eligibility levels not exceeding 300 percent of the SSI payment standard. People qualifying for benefits under a special income standard must have resources that do not exceed the state's Medicaid eligibility limits and must pay a portion of the cost of services in accordance with state-established rules. Originally established to allow nursing home residents with higher incomes to qualify for Medicaid benefits, the special income option was extended to community-based services when the HCB waiver authority was authorized in 1981.³⁶ In 2010, 43 states and the District of Columbia had established special income eligibility levels for recipients of institutional and home and community-based services (HCBS) under their Medicaid state plans. Income eligibility was set at the

maximum level (300% of the SSI payment standard) in the vast majority of states (39 plus the District of Columbia out of 43).³⁷

States also may elect to disregard family income and resources in determining the eligibility of children under 19 years of age who have a severe, chronic disability. Under this so-called Katie Beckett option, a child must meet SSI disability standards, be in need of institutional care, and be capable of benefiting from alternative home-based care and services.

In recent years, Congress also has extended Medicaid eligibility to several categories of low-income workers with disabilities. Appendix G summarizes these employment-related Medicaid coverage options.

Despite the expansion of Medicaid eligibility to additional subpopulations of people with disabilities over the past 30 years, it is important to point out that millions of Americans with disabilities do not qualify for benefits furnished through the Medicaid program, because of either a nonqualifying disability or excess income and/or resources. Of the 36 million Americans with functional disabilities in 2010, approximately one-fourth were Medicaid eligible.³⁸

Covered Services

The Medicaid program serves beneficiaries with diverse health and social support needs, including children and adults with severe, chronic disabilities. Consequently, the program provides a comprehensive range of acute and long-term care benefits that reach considerably beyond typical commercial health insurance plans. These services include support services designed to complement medical care and help people with disabilities to achieve and maintain their independence.

States are required to offer certain “mandatory services” to Medicaid-eligible people. Mandatory services include physician and hospital services, laboratory and diagnostic tests, and nursing facility (NF) services. In addition, states may elect to provide an extensive list of “optional services” under their Medicaid state plans, such as prescription

medications, personal care services, and HCBS. The availability of optional services varies significantly from state to state, and the choices that state policymakers make are particularly important to Medicaid enrollees with disabilities. Access to proper prescription drugs, for example, is vitally important in people with acute and chronic physical and mental illnesses. And access to personal/attendant care services is critical for people who require assistance in performing activities of daily living.

Population Characteristics

During FY 2008, 9.1 million people under 65 years of age were enrolled in the Medicaid program on the basis of disability. The eligibility of approximately two-thirds of these people was linked to the receipt of SSI benefits, with the eligibility of the remaining enrollees based on a variety of non-SSI criteria (see table 2-A).

Table 2-A. Medicaid Enrollees on the Basis of Disability by Eligibility and Age Group, FY 2008

	No. Eligible (in millions)	Medicaid Eligibility		Age Group	
		SSI (%)	Non-SSI (%)	Under 19 (%)	19–64 (%)
Total number of eligibles	9.1	65.8	34.2	15.7	84.3
Medicaid-only eligibles	5.6	79.9	20.1	25.4	74.6
Dual	3.5	43.2	56.8	0.1	99.9

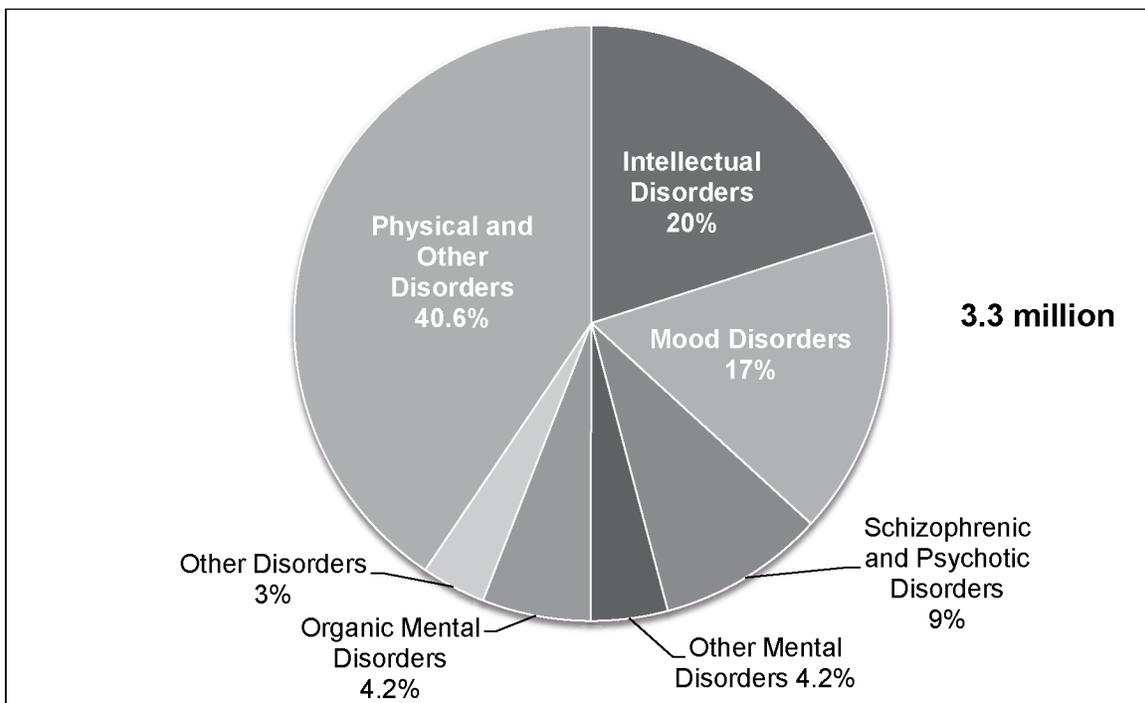
Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress on Medicaid and CHIP* (Washington, DC: Medicaid and CHIP Payment and Access Commission, March 2012), <http://www.macpac.gov/reports>.

Approximately 38 percent of nonelderly people who qualify for Medicaid on the basis of disability, or 3.5 million beneficiaries, are also eligible to receive Medicare benefits. These so-called dual eligibles³⁹ are enrolled in both programs. Most dual eligibles under 65 years of age qualify for income maintenance payments through the Social Security Disability Insurance (SSDI) program. Medicaid eligibility is not linked to SSDI eligibility. Although SSDI beneficiaries have to meet the same disability test as SSI recipients, they also must meet SSI financial eligibility criteria or qualify for Medicaid benefits through an alternative pathway.⁴⁰

State Medicaid agencies are not required to collect and report diagnostic information on recipients who qualify for benefits on the basis of disability. Nonetheless, because disability-related Medicaid eligibility is based on SSI eligibility for about two-thirds of Medicaid-only recipients, it is possible to gain a sense of the diversity of the population from diagnostic data gathered and reported by the Social Security Administration.

As shown in chart 2-A, 59 percent of the 3.3 million nonelderly adults receiving SSI benefits in 2010 had as their qualifying disability either a mental disorder (35.9%) or an intellectual disability (20.1%). The remaining 41 percent qualified on the basis of a physical or other nonmental disorder, such as spinal cord injuries, birth defects, or diseases of the organs system.⁴¹

Chart 2-A. SSI Adults not Receiving SSDI



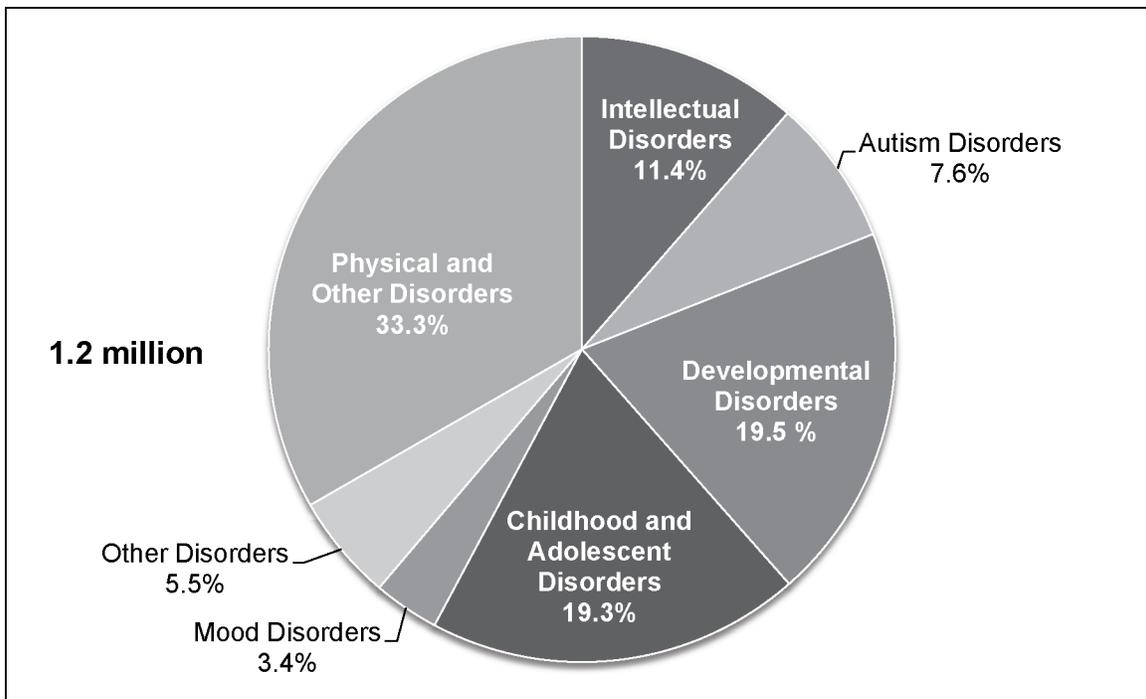
Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress on Medicaid and CHIP* (Washington, DC: Medicaid and CHIP Payment and Access Commission, March 2012), <http://www.macpac.gov/reports>.

As shown in chart 2-B, compared to nonelderly adult beneficiaries with disabilities, a significantly larger proportion of SSI-eligible children qualify on the basis of a mental or

intellectual disability. Among the 1.2 million children receiving SSI benefits because of a qualifying disability during 2010, two-thirds (67%) qualified on the basis of a mental or intellectual disability. Twenty percent of the qualifying children had developmental disorders, and eight percent had autistic disorders. Another 19 percent qualified on the basis of a childhood or adolescent disorder, including attention deficit hyperactivity disorder.

Only 33 percent of children receiving SSI benefits qualified on the basis of a physical or other nonmental disability.⁴²

Chart 2-B. SSI Children



Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress on Medicaid and CHIP* (Washington, DC: Medicaid and CHIP Payment and Access Commission, March 2012), <http://www.macpac.gov/reports>.

Comorbidity

Many people eligible for Medicaid services on the basis of disability have multiple disabling conditions, including co-occurring behavioral disorders and physical health

conditions. In examining the rate of comorbidity among Medicaid enrollees with disabilities, Kronick and colleagues⁴³ discovered the following:

- There was a high prevalence of mental illness (47%), cardiovascular disease (38%), and central nervous system diseases (28%) among Medicaid-only enrollees qualifying on the basis of disabilities.
- Nearly half (45%) of such individuals were diagnosed with three or more chronic conditions; they accounted for 75 percent of the spending on Medicaid-only enrollees with disabilities.
- Eighty-seven percent of the enrollees with the highest Medicaid costs had three or more chronic conditions, and 67 percent had five or more chronic conditions.

Behavioral health needs are particularly pervasive among Medicaid enrollees who qualify on the basis of disability. One study found that 47 percent of Medicaid-only enrollees with a qualifying disability also were diagnosed with bipolar disorder, psychosis, depression, or another form of mental illness. Furthermore, an analysis of Medicaid claims data revealed that 29 percent of such beneficiaries were treated for a mental illness and another 18 percent had used a prescription medication to address a behavioral disorder, suggesting unmet mental health treatment needs among the latter group.⁴⁴

Mental illnesses also occur frequently among Medicaid beneficiaries who are most expensive to serve. In studying the most common clusters of health conditions among Medicaid-only enrollees with chronic disabilities, Kronick and colleagues found that mental illness was included in three of the top five pairings among the highest-cost beneficiaries (i.e., those in the upper five percent of the per capita cost range). Another researcher discovered that approximately two-thirds of Medicaid-only beneficiaries with disabilities and one or more of the five most common physical conditions also had a mental illness.⁴⁵ In addition, 20 percent of such individuals had both a mental illness and an alcohol or other drug use disorder. For those with the most common chronic physical health conditions, health care spending is 60 to 75 percent higher for those with a mental

illness than for those without one. The addition of a substance use disorder doubles or triples health care spending, depending on the conditions involved.

Medicaid Expansion

The impact of the expansion of Medicaid eligibility called for under the ACA is unknown at present and probably will not be known for several years after states begin enrolling newly eligible people in 2014. Many analysts, however, expect some people with disabilities to be among the millions of newly eligible enrollees. CMS has made clear in final regulations governing expanded Medicaid and Children's Health Insurance Program (CHIP) eligibility under the 2010 ACA legislation that people with disabilities, including those requiring LTSS, will be permitted to enroll in an existing Medicaid eligibility category to ensure that they receive the coverage that best meets their needs.⁴⁶ The growth in enrollment is expected to be especially evident among adults with behavioral disabilities, either alone or in combination with chronic medical conditions, due to the ACA's mental health parity provisions, the designation of mental health services as an essential benefit, and the prohibition against denying services on the basis of a pre-existing condition.

In summary, co-occurring conditions—especially mental illnesses—are a major contributing factor to the cost of serving Medicaid beneficiaries with disability-based eligibility. The presence of a mental illness also adds to the complexity of the treatment process because (a) coordinating the full spectrum of the individual's care and support and controlling expenditures across multiple treatment and care settings pose a major challenge; and (b) adherence to treatment regimens is often difficult to achieve in this population. When such people also struggle with a substance use disorder, the complexities involved in delivering services and supports escalate even further.

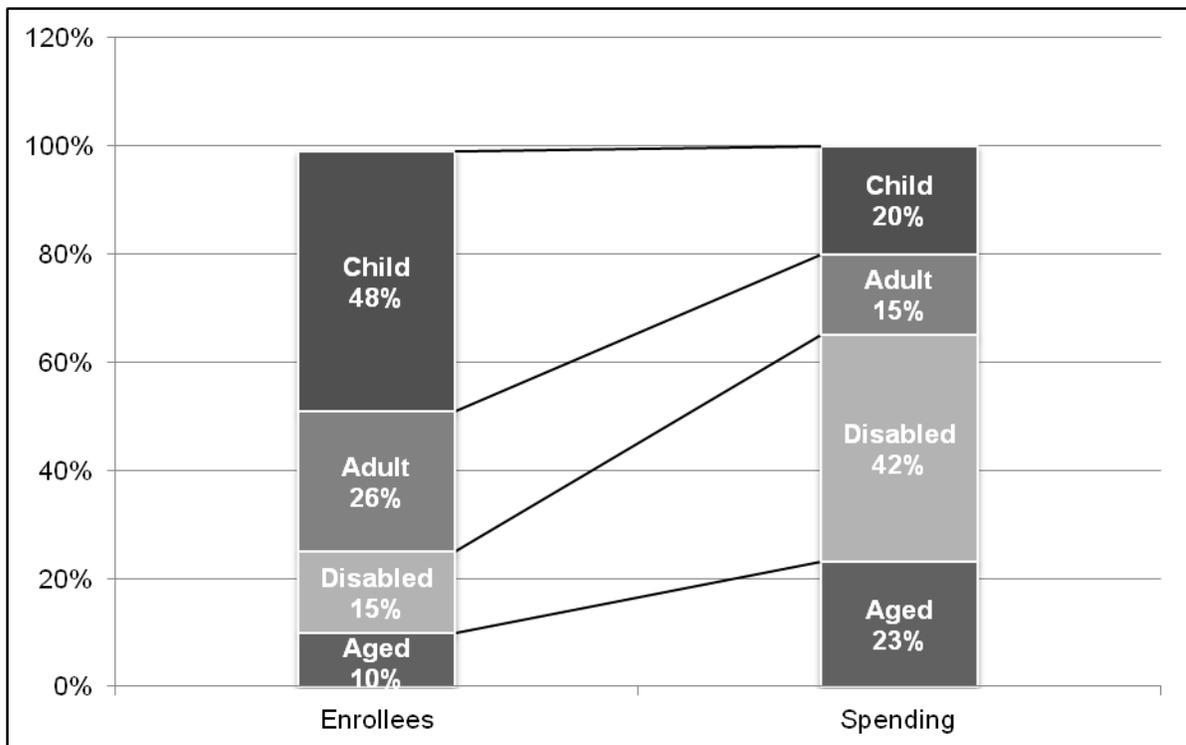
Medicaid Spending on People with Disabilities

In addition to covering preventive, primary, and acute health care services, Medicaid offers other benefits of particular importance to eligible individuals with disabilities

(see appendix F for an overview of disability-related Medicaid service coverages). For some recipients, the Medicaid program provides a much wider array of benefits than either the Medicare program or the vast majority of commercial health plans. In particular, Medicaid pays for institutional and HCB long-term supports to help beneficiaries with disabilities deal with chronic illnesses and disabilities while maintaining their independence.

During FY 2008, combined federal-state Medicaid expenditures totaled \$339 billion. Although people under age 65 enrolled on the basis of disability made up 15 percent of all Medicaid beneficiaries that year, they accounted for 42 percent of program expenditures, or \$142 billion. In contrast, children and adults under 65 years of age without disabilities accounted for approximately 75 percent of Medicaid enrollees but only about one-third of program outlays (see chart 2-C).

Chart 2-C. Medicaid Enrollment and Spending by Eligibility Group, FY 2008



Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress on Medicaid and CHIP* (Washington, DC: Medicaid and CHIP Payment and Access Commission, March 2012), <http://www.macpac.gov/reports>.

The disproportionate share of Medicaid expenditures attributed to nonelderly people enrolled on the basis of disability can be attributed to the higher per capita costs of providing services to these recipients, which averaged \$17,412 for a full-time equivalent enrollee during FY 2008. Average annual per enrollee expenditures were considerably lower for children without disabilities (\$3,025) and adults under 65 years of age without disabilities (\$4,651) (see table 2-B).

Table 2-B. Medicaid Enrollment and Spending by Eligibility Group, FY 2008

Eligibility Group	No. of Enrollees (in millions)	Total Medicaid Spending (in billions)	Annualized Spending Per Enrollee
Children	28.3	\$68.1	\$3,025
Adults	15.4	49.5	4,651
Aged	6.0	78.9	14,945
Disabled	9.1	142.0	17,412
<i>Medicaid-only</i>	5.6	98.2	19,682
<i>Dual Eligibles</i>	3.5	43.8	13,835
All Enrollees	58.8	\$338.6	\$ 7,267

Source: Medicaid and CHIP Payment and Access Commission, *Report to Congress on Medicaid and CHIP* (Washington, DC: Medicaid and CHIP Payment and Access Commission, March 2012), <http://www.macpac.gov/reports>.

As is the case for other Medicaid eligibility groups, expenditures on behalf of people who qualify on the basis of disability tend to be concentrated among a relatively small proportion of beneficiaries. Average per recipient expenditures for the top five percent of enrollees with disability-based eligibility topped \$100,000 during FY 2008. These people accounted for almost half of total Medicaid spending on people enrolled in the program on the basis of disability.⁴⁷

Slightly more than one-third of federal-state Medicaid expenditures in FY 2009 (35%; \$125 billion) paid for LTSS on behalf of children and adults with chronic disabilities. The LTSS share of overall Medicaid spending has remained relatively constant over the past 15 years (ranging from a high of 39% to a low of 33%). However, the proportion of expenditures on HCBS has increased steadily compared with institutional LTSS. In FY 2009, 44 percent of Medicaid LTSS outlays (\$55.9 billion) paid for HCBS, up from 18 percent in FY 1995.⁴⁸

Medicaid is by far the primary source of financing for LTSS, accounting for 61.5 percent of the \$203 billion expended by all sources in FY 2009. The program paid all or part of the costs of nearly 1.5 million nursing home residents and purchased HCBS for some 2.3 million low-income Americans with disabilities.⁴⁹ Access to Medicaid-financed LTSS, however, varies widely from state to state. One study found that only about 20 percent of low-income adults with long-term service needs received Medicaid-funded supports in the five states with the tightest eligibility and coverage standards, compared with 36 percent in the median state and 63 percent in the five states with the most generous Medicaid eligibility and coverage standards.⁵⁰ Even greater interstate variations are evident when average per capita spending levels are compared. Overall per capita spending on LTSS, including both seniors and nonelderly recipients, averaged \$527 per recipient in the five lowest states, compared with \$1,118 in the median state and \$3,152 in the five highest states. The pattern was similar when Medicaid HCBS were compared. Average per capita expenditures in the five highest states was \$1,613, compared with \$501 in the median state and \$191 in the five lowest states.⁵¹

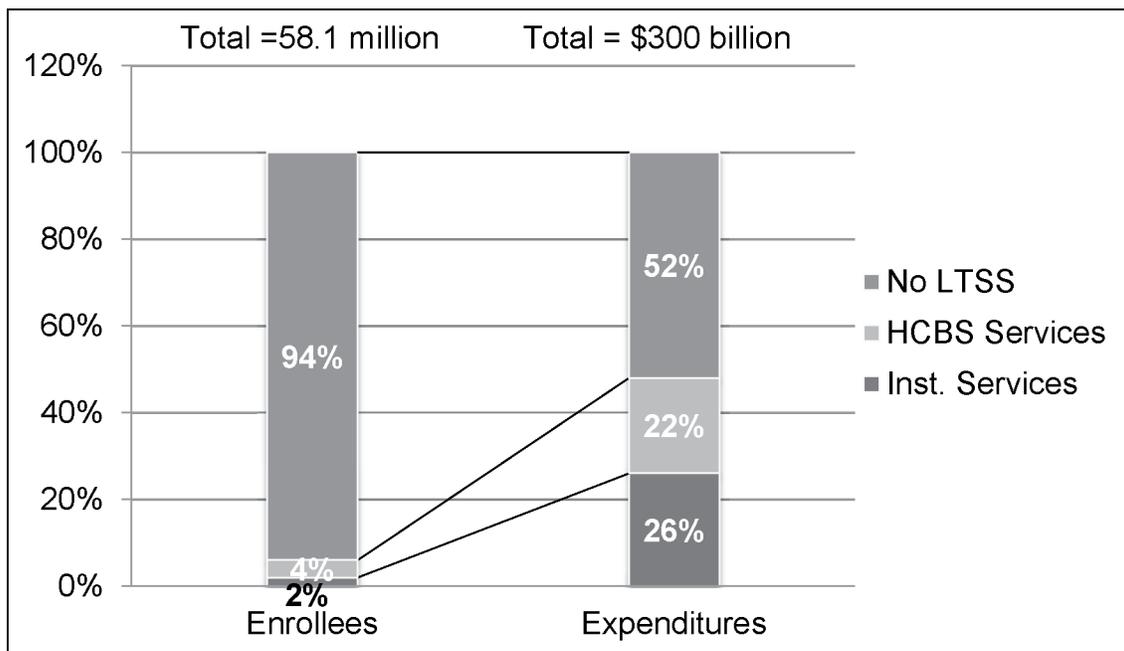
The majority of Medicaid enrollees under age 65 whose enrollment is based on disability (62% in FY 2008) are Medicaid-only enrollees. Likewise, the Medicaid-only group accounts for more than two-thirds of expenditures on behalf of people enrolled in the program on the basis of disability (69% in FY 2008). As indicated in table 2-B, average annual per capita expenditures are higher on behalf of Medicaid-only enrollees (\$19,682 in FY 2008) than on behalf of dual eligibles (\$13,835). The difference reflects the fact that Medicare is the primary payer for most of the acute health care services (e.g., physician and hospital services, prescription medications) that dual eligibles receive, with Medicaid assuming the cost of long-term supports and other services not covered by Medicare.

The average annual expenditures for LTSS in FY 2008 was lower among Medicaid-only enrollees (\$5,040) than among dual eligibles (\$8,784). The difference reflects, in part, a higher overall utilization of LTSS among dual eligibles vs. Medicaid-only beneficiaries, and in part, the proportionally greater use of high-cost institutional services by dual eligibles (44% of total LTSS expenditures in FY 2008) compared with Medicaid-only enrollees (34% of total LTSS expenditures in FY 2008).⁵²

LTSS expenditures account for a smaller share of total Medicaid outlays on behalf of Medicaid-only, nonelderly beneficiaries with disabilities (26%) than they do for dual-eligible, nonelderly beneficiaries (63%). This difference is driven largely by the fact that the Medicare program assumes primary responsibility for covering the acute care costs of dual eligibles. Sixteen percent of Medicaid-only enrollees under 65 with qualifying disabilities were LTSS users during FY 2008, compared with 22 percent of dual eligibles.

The picture changes, however, when the focus is limited to recipients of LTSS. Users of Medicaid LTSS were 6 percent of all Medicaid enrollees in FY 2007, but were the source of nearly half of total Medicaid spending that year (as shown in chart 2-D). Most users of LTSS relied on community-based services but, due to the higher average per capita cost of institutional services, the percentage of total expenditures devoted to institutional care (26%) was slightly higher than the percentage devoted to HCBS (22%).⁵³

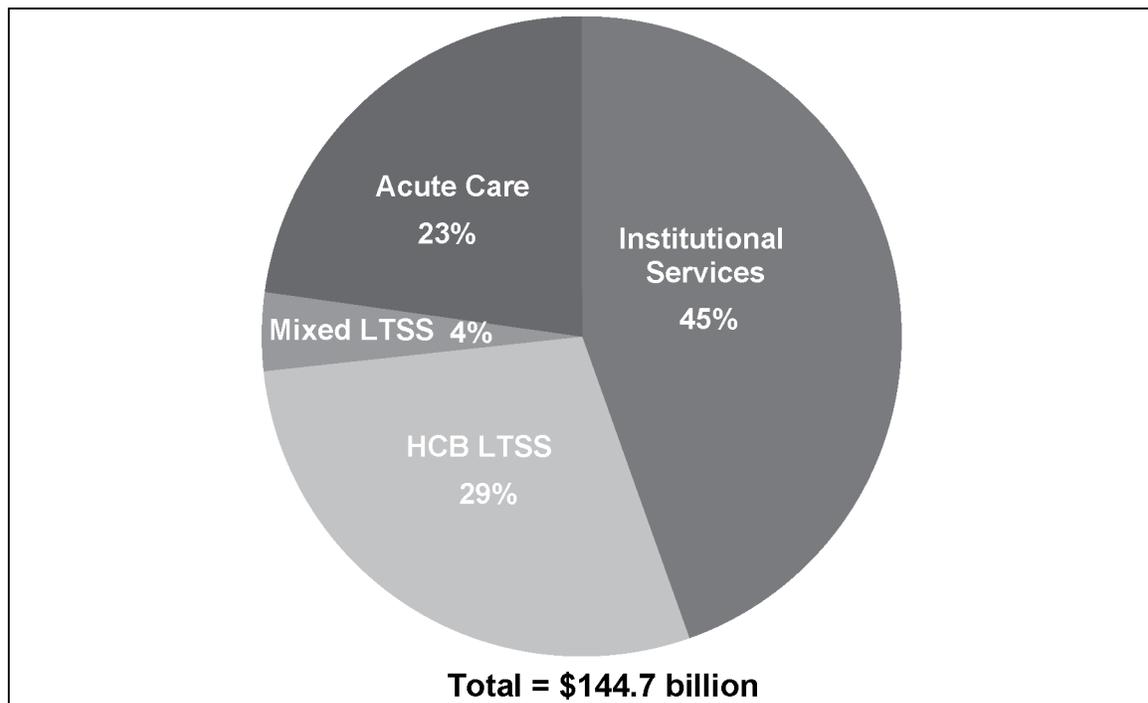
Chart 2-D. Medicaid LTSS Users by Type and Expenditures, FY 2007



Source: Kaiser Commission on Medicaid and the Uninsured, *Medicaid Long-Term Care Users: Spending Patterns Across Institutional and Community-based Settings* (Washington, DC: Kaiser Family Foundation, October 2011).

Moreover, nearly three-quarters of expenditures for the 3.6 million Medicaid recipients who received LTSS during FY 2007 were directed to long-term supports, as opposed to acute health services (see chart 2-E). Medicaid beneficiaries who used LTSS that year cost the Medicaid program an average of \$43,296, compared with the average of \$3,694 for nonrecipients of LTSS. A majority of Medicaid long-term care users were seniors (52%), with the balance (40%) being made up primarily of people with disabilities. Average annual per recipient costs were considerably higher for users of institutional services (\$62,750), compared with recipients who predominately used HCBS (\$31,341). Annual per capita spending on behalf of nonelderly people qualifying on the basis of disability was higher than per capita spending on behalf of older recipients of LTSS, primarily due to the much greater reliance of the latter group on Medicaid to pay for their acute care services.⁵⁴

Chart 2-E. Medicaid Spending by Users of LTSS



Source: Kaiser Commission on Medicaid and the Uninsured, *Medicaid Long-Term Care Users: Spending Patterns Across Institutional and Community-based Settings* (Washington, DC: Kaiser Family Foundation, October 2011).

Coordination of acute care and LTSS is often cited as a major barrier to improving the quality and cost-effectiveness of services and supports for dual eligibles. But states face similar hurdles in attempting to improve the quality and cost-effectiveness of services to Medicaid-only recipients of LTSS. As Gifford and colleagues pointed out in a recent survey report of trends in state Medicaid programs, only a few states operate managed care programs that integrate acute care and long-term supports for beneficiaries with disabilities under a unified system of capitated payments.⁵⁵

The Future of Managed Care for People with Disabilities

Three factors are driving states to expand managed care enrollments: (1) the severe budget constraints under which most states presently operate and predictions that budget shortfalls will continue to plague states for at least the next few years; (2) the impending expansion of Medicaid roles in 2014 under the ACA; and (3) a growing consensus among health experts and government officials that high-cost Medicaid recipients—including frail seniors and people with disabilities and chronic diseases—can be served more effectively and at lower costs through managed care plans.

The states' fiscal outlook has improved somewhat over the past year, at least compared with the precarious situation many states faced during 2009 and 2010.⁵⁶ However, multiple challenges lie ahead as states enter FY 2013. The phase-out of federal stimulus funding under the American Recovery and Reinvestment Act of 2009 (ARRA) forced states to replace federal funds with state dollars in order to balance their FY 2012 budgets. State Medicaid programs were especially hard hit by the loss of ARRA funding. During FY 2012, state general revenue outlays for Medicaid services were expected to increase by an average of 29 percent over the previous fiscal year, primarily because of the loss of enhanced federal Medicaid matching funds.⁵⁷ Moreover, because of persistently high levels of unemployment and the normal lag between economic recovery and higher tax revenues, total state revenues remain below FY 2008 levels despite recent revenue gains in 38 states.⁵⁸ Meanwhile, estimates of the total unfunded indebtedness of state and local governments range between \$885 billion and \$4.6 trillion, depending on estimates of

future returns on pension funds and other investments.⁵⁹ For state officials, replenishing depleted public employee pension funds and paying off other outstanding debts is a key to stabilizing state finances over the long term. The long-term obligations of state and local governments remain a challenge that extends far beyond the exigencies of balancing current operating budgets.

Second, as a result of the passage of the ACA, eligibility for Medicaid services is scheduled to be extended to all people under 65 years of age with income below 133 percent of the FPL effective January 1, 2014 (P. L. 111-148). These impending enrollment increases, which will come on top of the 7.6 million recession-induced increase in total enrollments between December 2007 and June 2010,⁶⁰ pose a major challenge for state Medicaid officials as they simultaneously struggle with continuing inflationary growth in program costs. The U.S. Supreme Court recently added another element of uncertainty to these calculations by prohibiting the total withdrawal of federal funds from states that do not expand Medicaid coverage, thereby making the planned expansion, in effect, a state option.⁶¹ After the Supreme Court's decision, the Congressional Budget Office projected that some states will not expand Medicaid at all, or will not expand Medicaid roles to the full extent authorized by the ACA.⁶²

Third, in addition to near-term reductions in Medicaid spending, state officials intend to restructure the delivery of health and long-term services in order to place program expenditures on a more sustainable course. State budget-cutting strategies over the past three years have focused primarily on reducing provider payment rates, cutting and restricting access to program benefits, and instituting new and higher beneficiary copayments. Meanwhile, service delivery restructuring initiatives have revolved around three major themes: (a) expanding the geographic scope of managed care services, as well as the types of recipients enrolled in such plans; (b) continuing to shift the locus of long-term service delivery from institutional to HCB settings; and (c) coordinating the delivery of health and LTSS to dual eligibles.⁶³

Viewed from a disability perspective, federal and state Medicaid officials see Medicaid as a key device for accomplishing all of the aforementioned service delivery reforms. As will

be discussed in greater detail in chapter 3, state officials hope to significantly improve the cost-effectiveness of health services provided to high-cost beneficiaries by enrolling more people with chronic illnesses and disabilities in Medicaid managed care programs. Moreover, a growing number of states see managed care as a more effective and less costly approach to (a) delivering behavioral health services to people with serious mental illnesses and substance use disorders; (b) providing LTSS to people with physical, sensory, and developmental disabilities; and (c) providing a coordinated array of health services and long-term supports to dual eligibles.

All of the signs indicate that Medicaid services to beneficiaries with disabilities are on the cusp of a major transformation, driven primarily by the introduction of managed care principles to the financing and delivery of such services. The changes inherent in a managed care approach pose both opportunities and challenges. For this reason, chapter 3 articulates and elaborates upon a series of principles that should guide the design and implementation of managed care services for people with disabilities, whether they are eligible for Medicaid services only or for both Medicare and Medicaid services.

CHAPTER 3. **Guiding Principles for Successfully Enrolling People with Disabilities in Managed Care Plans**

Faced with growing caseloads, declining federal aid, and escalating health care costs, many states are electing to enroll high-cost people with chronic disabilities in Medicaid managed health and long-term service plans. They are doing so in an attempt to place program expenditures on a more sustainable course while simultaneously improving the quality and accessibility of services. NCD recognizes that managed care techniques can create a pathway toward higher-quality services and more predictable costs, but only if service delivery policies are well designed and effectively implemented—and achieve cost savings by improving health outcomes and eliminating inefficiencies, not by reducing the quality or availability of services. Designing and operating a managed care system for children and adults with chronic disabilities poses unique challenges given the highly diverse, wide-ranging health and long-term support needs of the population. These challenges multiply when a state attempts to create a unified system of acute health and long-term services that merges Medicare and Medicaid funding streams.

In the current state and federal policy environment, where reducing public expenditures is a primary aim of public policy, there is a significant risk that vulnerable people with disabilities will be the victims of poorly conceived and executed public policies that fail to meet their needs. If such results are to be avoided, it is essential that the principles articulated below are meticulously observed in designing and carrying out managed care initiatives involving people with chronic disabilities. Done right, all stakeholders will benefit.

Personal Experience and Outcomes

Reacting to a long history of dehumanization and disempowerment by the medical establishment, over the past 30 years, the disability movement in the United States has

embraced the core principles of independence, societal integration, self-direction, and productivity. While sometimes expressed in different words, these principles form the foundation of the independent living movement for people with physical disabilities, the recovery model for people with mental illnesses and substance use conditions, and self-directed and family-centered supports for people with lifelong disabilities. These principles and the values upon which they are based should be preserved as people with chronic disabilities are transitioned to Medicaid managed care plans. The restructured service delivery system should be rooted in a contemporary understanding of the social, personal, and environmental factors that lead to poor health outcomes and isolation from the mainstream of American life. Moreover, managed services and supports should be built around and linked to existing community-based disability structures, such as independent living centers, recovery learning communities, and community-based developmental disabilities and mental health agencies.

Principle #1. Community Living

The central organizing goal of system reform must be to assist people with disabilities to live full, healthy, participatory lives in the community.

Medicaid expenditures on HCBS have risen steadily over the past two decades, as ever-increasing numbers of eligible people are supported in the community rather than institutional settings. As pointed out in chapter 2, federal-state Medicaid expenditures on HCBS climbed to \$55.9 billion in FY 2009, while the proportion of overall LTSS expenditures devoted to HCBS reached 44 percent, up from 18 percent in FY1995.⁶⁴ The ascendancy of HCBS has occurred more slowly for certain segments of the population with disabilities. For older beneficiaries and adults with physical disabilities, noninstitutional Medicaid expenditures represented 36 percent of total LTSS outlays in FY 2009. By contrast, during the same year 66 percent of Medicaid LTSS expenditures for people with intellectual and developmental disabilities were supporting noninstitutional services.⁶⁵

Moreover, as pointed out in chapter 2, growth in noninstitutional expenditures has advanced much more rapidly in some states than in others, creating significant variations among states in the number and percentage of people served in HCBS versus institutional settings. In FY 2009, for example, the percentage of Medicaid expenditures devoted to noninstitutional services and supports ranged from 88.2 percent in New Mexico to 14.4 percent in Mississippi—a range of more than six to one.⁶⁶ When the focus is limited to older adults and people with disabilities, Feder and Komisar report that average expenditures on noninstitutional services in the five lowest-ranked states constituted 11 percent of total LTSS outlays in FY 2009, compared with 63 percent in the five highest-ranked states.⁶⁷

Over the past decade, the Bush and Obama Administrations, in collaboration with Congress, have taken a number of steps to improve access to Medicaid-funded HCBS. These bipartisan efforts culminated in the inclusion of several provisions in the ACA designed to furnish states with incentives to serve people with chronic disabilities in HCB settings:

- Section 2403 of the ACA extends the ***Money Follows the Person (MFP) Demonstration Program*** through 2016, setting aside \$2.25 billion to fund MFP projects between FYs 2012 and 2016. Thus far, 42 states plus the District of Columbia have participated in the program, originally funded as Real Choice, System Change grants and later authorized as a separate grant program in 2005. States receive a temporary increase in their federal matching ratio for transitioning people from institutions to the community. These funds in turn are to be used to improve the state's community service delivery infrastructure.
- The ***State Balancing Incentive Payment Program***, authorized under Section 10202 of the ACA, provides states with enhanced FFP for increasing the share of LTSS expenditures used to pay for HCBS. States with the lowest proportion of LTSS dollars devoted to HCBS are eligible to receive a 5 percent increase in their federal medical assistance percentage (FMAP) if they increase the proportion spent on HCBS services to at least 25 percent by October 1, 2015. States with

HCBS expenditures of between 25 percent and 50 percent are eligible to receive a 2 percent bump in FMAP if they raise the percentage expended on HCBS to at least 50 percent by October 1, 2015.

- Section 2401 of the ACA authorizes a new state plan option for community-based attendant services for qualified Medicaid recipients with incomes of up to 150 percent of the FPL, or up to 300 percent of the FPL for people meeting NF level of care criteria. This **Community First Choice Option** qualifies participating states to receive a 6 percent increase in their FMAP rates for such services, but they must offer services on an entitlement basis and maintain their prior level of fiscal effort. A number of other requirements are associated with this new coverage option, including a requirement that participants be afforded an opportunity to self-direct their services.
- Section 2402 of the ACA amends the **Medicaid Home and Community-Based Services State Plan Option** by (a) allowing states to target benefits to particular groups of individuals with disabilities; (b) modifying income eligibility criteria; and (c) requiring states electing this coverage option to make services available statewide and on an entitlement basis (i.e., without imposing utilization or expenditure caps). The aim of these changes is to offer states a stronger incentive to adopt the HCBS state plan option. Even though states now have the option of targeting specific populations by applying need-based eligibility criteria, few states have taken advantage of the Section 1915(i) state plan option thus far, due mainly to the fiscal uncertainties associated with offering such services on an open-ended entitlement basis.
- Two new CMS units created under provisions of the ACA (the Medicare-Medicaid Coordination Office and the Center for Medicare and Medicaid Innovation) are planning to approve a series of three-year demonstration projects beginning in the fall of 2012 to **test innovative service delivery and payment models for people with chronic disabilities who are dually eligible for Medicare and Medicaid benefits**. States selected to participate in this demonstration program

may qualify for federal assistance in implementing components of their dual-eligible demonstration programs. Either an FFS or capitated payment model may be used as the basis for a state's demonstration proposal. As of March 2012, more than half of the states had submitted preliminary or final proposals to participate in this demonstration program.

- Section 2703 of the ACA established a new ***Health Home State Medicaid Plan Option*** to provide a comprehensive system of care coordination for Medicaid beneficiaries with two or more chronic illnesses or disabilities. Health home providers are responsible for coordinating and integrating all primary, acute, behavioral health, and long-term services for enrollees. The state FMAP rate for this new coverage option, which went into effect on January 1, 2012, is 90 percent for the first two years the state plan amendment is in effect. States exploring this option may qualify for federal planning grants of up to \$500,000 to line up qualified home health providers, develop payment methodologies, and complete other preinitiation activities.

These and other statutory, regulatory, and administrative changes over the past two decades have shifted the focus of Medicaid policy from a medical orientation to encompass a strong emphasis on helping people with disabilities live full, inclusive, healthy lives in the community of their choice. It is essential that this emphasis be carried forward as people with disabilities are enrolled in Medicaid managed care plans. The overarching goal of providing such people with a coordinated array of medical and nonmedical supports is not only to promote health and wellness but also to improve the capacity of beneficiaries to live as independently as possible in fully integrated community settings.

Principle #2. Personal Control

Managed care systems must be designed to support and implement person-centered practices, consumer choice, and self-direction.

Historically, people with disabilities have been afforded few opportunities to control their own lives, in large part because service providers and the public at large doubted their capacity to make wise, well-informed decisions. We have learned in recent years, however, that the vast majority of people with disabilities are fully capable of directing their own lives, provided they receive the necessary information and support.

People with disabilities must be afforded the chance to control their own lives and choose services and supports consistent with their personal goals and aspirations. To accomplish this goal, Medicaid service policies and practices must be person-centered, and equal attention and resources must be assigned to meeting an individual's health care and long-term support needs. The individual's preferences must be honored, and the right of the individual to control his/her own life must be respected by offering a flexible array of high-quality, personalized services and supports from which to choose.

Person-centered Practices

Person-centered approaches are designed to (a) help an individual map out his/her life goals and identify the supports required to achieve them; (b) help an individual exert greater control over his/her life and live as independently as possible; and (c) promote social inclusion in the community. The provision of health care and long-term supports must be designed and delivered through a person-centered lens. Health services must be carefully synchronized with long-term supports based on a common set of goals and desired outcomes spelled out in each participant's person-centered plan. The plan must enable the person to exercise decision-making authority over activities of daily living and health maintenance functions.

Person-centered planning (PCP) was formally introduced to federal Medicaid policy in May 2002 when CMS issued the Independence Plus waiver template, a set of policies,

procedures, and an application form that states could use to submit family- and self-directed HCB waiver requests under Section 1915(c) or Section 1115 of the Social Security Act.⁶⁸ However, for more than a decade prior to the issuance of the Independence Plus waiver template, a number of states (with CMS' approval) had employed PCP in their personal assistance/attendant care and Section 1915(c) waiver programs.

In November 2005, PCP and self-directed services became a discrete option under all HCBS waiver services when CMS released a revised set of instructions governing the operation of Section 1915(c) waiver programs that incorporated all of the key components of the Independence Plus template, including a requirement that the individual service plans be person-centered.⁶⁹ In 2006, Congress added two new state plan options—one focused on HCBS and the other on self-directed attendant care services.⁷⁰ PCP was a key statutory feature of both of these state plan options. The Money-Follows-the-Person Demonstration program, authorized under the same 2006 legislation, also mandates the use of PCP.⁷¹

Today, the use of PCP is virtually ubiquitous in Medicaid-funded HCBS. Too often, however, person-centeredness ends with the preparation of a person's individual plan, rather than extending into day-to-day service and support practices. Barriers to person-centered practices are deep-seated and no doubt will continue to be a major challenge as states enroll recipients of LTSS in managed care plans. Commenting on the difficulties involved, one well-known team of PCP trainers noted,

The problems do not lie in the quality of the people in the [service] system but in the system itself. There is no "value deficit" among the people who write the [person-centered] plans nor in the inherent qualities of the persons who are expected to implement them. The gaps occur with the systems in which both work.⁷²

Recognizing the inefficiencies of using multiple assessment tools as the basis for PCP, a number of states have adopted, or are planning to adopt, standardized, automated assessment tools for use with multiple populations and programs. Such tools aim to

streamline and standardize the assessment process while simultaneously achieving greater equity in the distribution of finite resources systemwide.⁷³ Unless such instruments are adapted to the varied needs and aspirations represented within each target population, however, the danger is that assessment results will be a poor reflection of the real needs and aspirations of certain subpopulations and the focus on the whole person will be dissipated. Further research is needed to verify the “fit” between standardized assessment results and the medical and LTSS needs of various subpopulations of people with disabilities.

Another issue that needs to be addressed is how assessment results are interpreted and translated into individualized service plans, with the aim of ensuring that care team decisions and the resulting resource allocations are in keeping with the life goals and desired outcomes of the individual enrollee. For the past several years, Wisconsin, as part of its Family Care program, has been using a tool called the Resource Allocation Decision Method, a system for determining the most effective means of providing LTSS to achieve enrollee-defined goals and outcomes.⁷⁴ States planning to enroll people with disabilities in managed LTSS plans should employ tools and strategies to ensure that the individual planning process is truly person-centered and outcome-oriented.

Self-Direction

The concept of consumer-directed services dates back to the 1970s, during the early days of the disability rights movement in the United States. Consumer direction soon became a core operating principle of attendant care programs in California, Massachusetts, and other states and later migrated to the developmental disabilities sector under the banner of self-determination⁷⁵ and to the mental health sector under the rubric of consumer- and family-driven care (although to date examples of self-direction remain sparse in the behavioral health arena).⁷⁶ As noted above, self-direction became a formal part of federal policy in 2002, although the basic concept had been used earlier in Medicaid-funded HCBS service.⁷⁷

Under certain Medicaid authorities, a state must offer managed care enrollees with disabilities the option of overseeing their own direct services and supports and controlling their own budgets, consistent with the provisions of PCP. This option must include the exercise of control over services and supports related to critical life functions, including activities of daily living, health maintenance, community participation, and employment. In addition, people choosing to self-direct their services must receive the training and support needed to perform the required functions. To promote maximum independence, state officials and representatives of MCOs should join people with disabilities in advocating for amendments to overly restrictive nurse practice laws and regulations that limit the performance of tasks such as catheterization and g-tube management to registered nurses. Flexibility in these areas will open opportunities for creative approaches to self-directed supports, which, when directed by the affected individual, may greatly improve health outcomes and prove to be more cost-effective over the long term.

The role of a case manager changes when Medicaid recipients of LTSS choose to self-direct their services and supports. When an individual chooses the provider of service, the case manager frequently is asked to assume enhanced responsibilities for counseling, training, and monitoring the quality and appropriateness of services, while being less involved in direct decision making than traditionally has been the case within disability service systems. Counseling and support managers in Arkansas' HCBS waiver program for adults with physical disabilities, for example, are responsible for introducing program participants to the key concepts of consumer direction and training people who choose to self-direct in recruiting, interviewing, selecting, supervising, evaluating, and dismissing personal attendants.⁷⁸

Individual Choice

A key aim of managed care is to replace high-cost services or programs with equally effective lower-cost alternatives. The intimate nature of long-term supports furnished to people with intensive needs requires the direct involvement of consumers in selecting the individuals to provide the services as well as the services to be delivered. Moreover,

the use of family- and self-direction often opens up a considerably broader range of support options because family members, friends, and neighbors can be enlisted to perform tasks otherwise furnished exclusively by certified home health and personal care agencies. The ability to choose among a wide array of services and support alternatives is a key to the success of self-directed and person-centered services. For this reason, managed care plan enrollees should be permitted to choose among in-network providers as well as out-of-network providers who agree to abide by reasonable MCO stipulations governing payment rates and service coordination (see also a related discussion under Principle #8, Provider Networks).

Principle #3. Employment

For working-age adults with disabilities, employment is a critical pathway toward independence and community integration. Working-age enrollees, consequently, must receive the supports necessary to secure and retain competitive employment.

Competitive employment at prevailing wages not only enhances an individual's sense of self-worth and economic well-being but often results in reductions—sometimes sharp reductions—in service costs and support needs. Employees also have opportunities to build relationships that strengthen their social ties with others and enable them to become contributing, valued members of the community. One key policy aim, therefore, must be to broaden employment among adults with disabilities by targeting supports and providing incentives that enable them to enter the workforce and retain a job once employed.

Multiple studies over the past 30 years have documented the cost-effectiveness of supported employment services for adults with significant, multiple disabilities.⁷⁹ In general, these studies have found that, over time, supported employment generates lower per capita costs and enhanced skill development and socialization compared with sheltered employment. In a comparison of matched groups of people with severe disabilities, Cimera found that the per capita cost of supported employment services (\$6,619) was substantially lower than the per capita cost of sheltered workshop services when tracked across an entire

(three-year) employment cycle. Stated differently, the funds required to maintain one sheltered employee in a workshop setting would finance nearly three supported workers in integrated employment settings.⁸⁰ In a later study of the cost of Medicaid long-term supports for adults with intellectual and developmental disabilities in Wisconsin, Cimera found that, over an eight-and-a-half-year period, the average cost of providing follow-along services to supported employees (\$9,130) was more than three times lower than the average cost of maintaining similar people in center-based work settings (\$32,353). Yet, when the hours worked by 22 people who engaged in both supported and center-based employment during the September 2009 were compared, he discovered that the costs of assisting supported employees was \$8.01 per hour worked, compared to \$13.40 for center-based employees.⁸¹

On average, people with intellectual disabilities who engage in integrated community employment earn more and cost less to support, regardless of where they live and whether they have secondary disabilities. By analyzing data on 104,213 people served by state vocational rehabilitation agencies between 2002 and 2007, Chimera discovered that supported employment participants who became successfully employed in community settings gained greater monetary benefits (i.e., wages earned) than the resulting monetary costs (i.e., forgone wages, taxes paid, reduction in subsidies) regardless of (a) their state of residence or (b) the number of disabling conditions. Cost efficiency, however, varied considerably across the country, ranging from an average benefit-cost ratio of 13.54 and a net monthly benefit of \$561.04 in Washington to a ratio of 1.86 and a net monthly benefit of \$217.92 in Wisconsin.⁸²

The benefits of integrated employment extend beyond enhanced earnings and lower support costs. Once employed, workers with disabilities contribute to the nation's economic productivity and become taxpayers. Plus, numerous studies have noted the intangible benefits associated with employment. For example, through a series of semistructured interviews with people with psychiatric disabilities, Dunn and colleagues identified myriad benefits associated with paid employment, including enhanced pride and self-esteem and the chance to develop coping skills, which ultimately facilitated the process of recovery.⁸³ In addition, an analysis of FY 2009–10 employment data on 11,292 people with intellectual and developmental disabilities in 16 states found positive benefits of work on personal and

service-related choice, community participation, personal relationships, outcomes, safety, and other areas, as compared with people who were not employed.⁸⁴

During December 2011, approximately 21 percent of working-age adults with disabilities participated in the labor force, compared with 69 percent of adults without a work-related disability.⁸⁵ Yet only a small fraction (1.2%) of the estimated \$429 billion the Federal Government and the states expended on people with disabilities in FY 2008 was used to improve prospects for employment and economic independence. Indeed, more than 95 percent of federal-state disability expenditures paid for health care expenses and income maintenance benefits, with more than half the total (55%) devoted to health care spending (primarily Medicare and Medicaid payments) and most of the remainder (41%) to Social Security, SSI, and other government benefit payments. As the authors of this recent analysis pointed out, the existing “complex, many program model devotes far more spending on a safety net than on programs to directly advance the goals of ‘equality of opportunity, full participation, independent living, and economic self-sufficiency for people with disabilities as articulated in the 1990 Americans with Disabilities Act.’”⁸⁶

The provision of lifelong supports to people with disabilities represents a significant investment in their lives. From a public policy perspective, it makes sense to ensure that the services and supports that are offered are designed to enable people to become productive and contributing members of society to the fullest extent possible. One important step toward creating a twenty-first century health care and long-term support delivery system involves abandoning the caretaker model of disability policy that is embedded in many major government programs originating during the Eisenhower, Kennedy, Johnson, and Nixon Administrations. The focus of government policy instead needs to shift toward helping people with disabilities become more independent and productive, both socially and economically. Improving employment opportunities is an essential component of any successful strategy for achieving these goals.

Employment: Washington

For years, Washington has been recognized as a leader in creating integrated employment opportunities for adults with intellectual and developmental disabilities (I/DD). In 2009, 88 percent of adults receiving day and employment services through the state Division of Developmental Disabilities (DDD) were working in integrated employment settings, or more than four times the national average for all state I/DD agencies (20.3%). These results are the product of a conscious policy that Washington officials have pursued relentlessly over the past three decades in partnership with county officials, provider agencies, and consumers and family members.

Washington's emphasis on employment outcomes began in the late 1970s with a series of value-based workshops attended by key state and county officials as well as day provider agency staff. One of the early results was the issuance of a set of county guidelines spelling out a process for achieving integrated employment outcomes. In 1985, DDD received a systems change grant from the federal Rehabilitation Services Administration that allowed it to refine the process of funding employment supports and establish statewide and county-specific outcome targets. After years of building a solid infrastructure for delivering employment supports, DDD adopted a policy in 2008 stating that "Supports to pursue and maintain gainful employment in integrated settings in the community shall be the primary service option for working age adults" (DDD Policy 4.11, as amended on September 15, 2011). The cost-effectiveness of the state's emphasis on employment outcomes is underscored by the results of Cimera's analysis of national data trends cited above.

DDD contracts with county developmental disabilities offices to administer state-funded day and employment services. Most counties, in turn, subcontract with private provider agencies to furnish services and supports to eligible people.

A flexible array of funding for supported employment and other community services is made available through four Medicaid HCBS waiver programs targeted to people with developmental disabilities. DDD also funds a wide array of training and technical assistance activities to promote continued employment-related learning activities through the Washington Initiative for Supported Employment (WISE). Last year, WISE completed three CMS-funded system change grant projects aimed at building careers and community involvement for adults with developmental disabilities.

In the spring of 2010, Washington was one of 15 states selected by CMS to receive a planning grant to design integrated services for dual eligibles. Officials of the state Department of Social and Health Services (DSHS) and the Health Care Authority (HCA) submitted a dual-eligible demonstration grant application to CMS in April 2012. This grant project will build upon the state's prior managed care experience to phase in innovative service delivery and payment models that integrate physical and behavioral health services and long-term supports for people who are dually eligible for Medicare and Medicaid services. With the exception of about 900 residents of state-run Residential Habilitation Centers (state institutions), dual eligibles with developmental disabilities will be enrolled in the demonstration project and receive health care services through managed care plans, but DSHS will continue to furnish services provided through Section 1915(c) waiver programs to this population. The state's proposal indicates that community-based DD waiver services were carved out of the demonstration because of "significant concern" among DD stakeholders "about health plan readiness to provide habilitative and employment services provided under state and federal Section 1915(c) authorities." As the demonstration project is implemented, discussions will continue regarding the "competencies, outcomes and other factors" that need to be in place before HCB services for the population with DD can be transitioned to the integrated health plans.

Sources:

John Butterworth et al., *State Data: The National Report on Employment Services and Outcomes* (Boston, MA: Institute for Community Inclusion, University of Massachusetts/Boston, Winter 2011), http://www.communityinclusion.org/pdf/statedata2010_finaldraft.pdf.

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Washington Department of Social and Health Services and the Health Care Authority, *Design Proposal: HealthPlanWashington* (formerly *Pathways to Health: A Medicare & Medicaid Integration Project*) (April 26, 2012), <http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/WashingtonProposal.pdf>.

Principle #4. Support for Family Caregivers

Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.

Family members play critical roles in supporting and advocating on behalf of people with disabilities. According to an AARP Public Policy Institute study, in 2009 there were approximately 42.1 million family caregivers in the United States providing care to senior citizens and other adults with limitations in activities of daily living. The estimated economic value of their unpaid contributions was roughly \$450 billion in 2009, up from \$375 billion in 2007.⁸⁷ The continued growth in family caregiving is, in large part, a reflection of the changing demographics of the U.S. population and the growing cost of publicly and privately funded LTSS. The average lifespan in 1900 was only 47 years. Today, the average life expectancy of an American is 78 years, and demographers expect this figure to rise to 80 years by 2020.⁸⁸

The growth in family caregiving for people with chronic disabilities applies across the age spectrum. The most recent data released by the University of Minnesota's Rehabilitation Research and Training Center on Community Living indicate that 57.7 percent of people receiving publicly funded services for developmental disabilities (or 592,180 people) were living in the home of a family member in 2010, up from 51 percent (of 391,859 people) in 2000.⁸⁹

The renewed emphasis on person- and family-centered care (PFCC) has yet to be integrated within the changes occurring in health care and long-term service delivery systems, especially the move away from disease-specific and provider-focused models toward creating incentives to improve cross-system coordination, communications, and continuity of care. However, as these two trends merge, person- and family-centered models are likely to proliferate.

Under a person- and family-centered approach, health care and ongoing supports are based on the individual's needs, goals, preferences, cultural traditions, family situation,

and values. This approach places the individual and the family at the center of the care team, along with clinicians, direct support professionals, and the service coordinator, and seeks to deliver services and supports from the perspective of the individual and, as appropriate, his or her family. The conventional medical model of health care is organized around service providers, specific diseases, episodes of care, and visits to clinicians' offices. In contrast, PFCC seeks to focus on the whole person, recognizing and supporting the social network within which the person with the disability lives. The aim is to help the person build and expand opportunities to lead a productive, meaningful life as an integrated and valued member of his or her community.⁹⁰ A family-centered approach builds on the concept of person-centered services by emphasizing the essential role played by the family and, as such, is a logical extension of the disability rights movement. PFCC also takes into account the essential principles of supporting people with disabilities by building upon the strengths of family connections.⁹¹

For people who experience disabilities early in life, it is important to keep in mind that the needs of family caretakers—like those of the person with disabilities—change over time. As these changes occur, the service delivery system must be prepared to modify the supports made available to the person, as well as to the family caretaker(s).

Given the growing shortage of trained workers available to provide direct, hands-on supports, the role of the family is likely to assume added significance in the years ahead unless government funding is substantially increased. It is, therefore, essential that states build into their managed care plans provisions to ensure that family members receive the information, counseling, training, and support they need to carry out their responsibilities. State and MCO policies also should permit family caregivers to be paid for providing services when such remuneration is in the best interest of the person with a disability and the family.⁹²

Designing and Operating a Managed Care System

Managing a health care system is a complex undertaking involving an intricate web of relationships that must be effectively synchronized to achieve the desired results. Every operating component has to dovetail with other components if services and supports are to be provided in a timely, efficient, and effective manner. The need for well-conceived, detailed organizational and operational structures is underscored when health care and long-term supports for people with disabilities are placed under a single managed care umbrella based on a capitated payment structure. In addition to the challenges of coordinating the delivery services across service sectors, resources have to be equitably distributed between health care and long-term supports if “overmedicalization” of services is to be avoided.

Design features have to be worked out in advance, down to the minutest detail, and carefully monitored to ensure that the system continues to function as intended. The price of failure is measured in the lives of highly vulnerable service recipients. As the National Disability Leadership Alliance recently observed, “If states do not design [their managed care] programs well, beneficiaries with disabilities could, among other things, be denied needed coverage, lose continuity of care and services with their current providers and be forced to sacrifice consumer direction.”⁹³

Principle #5. Stakeholder Involvement

States must ensure that key disability stakeholders—including people with disabilities, family members, support agency representatives, and advocates—are fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of Medicaid managed care services and service delivery systems.

Active, open, and continuous dialogue with all affected parties offers the best prospects for creating and maintaining a service delivery system that meets the needs of people with disabilities. All participants must be confident that the transition to a managed care

system will yield better outcomes for people with disabilities. The involvement of disability stakeholders should not end with approval of a state's managed care plan. Instead, stakeholders should participate in monitoring implementation of the plan and provide feedback on system performance and needed plan modifications on an ongoing basis.

There are multiple reasons for states to involve disability stakeholders in designing and overseeing their managed care delivery systems. Among these reasons are that state officials can—

- Obtain from Medicaid beneficiaries and disability service providers valuable insights into the strengths and weaknesses of existing payment and service delivery arrangements.
- Gain an opportunity to explain their vision of a restructured service delivery system and the benefits to be derived by enrollees with disabilities and their families.
- Obtain a grassroots perspective on dysfunctional aspects of current service delivery practices that need to be addressed, as well as effective practices that should be retained.
- Help stakeholders prepare for the future by explaining how and when changes in service delivery and payment practices are likely to occur and how stakeholders are likely to be affected.
- Forge ongoing relationships with stakeholder groups and enlist them as allies in resolving the inevitable roadblocks that will arise during implementation of the planned managed care program.

A variety of stakeholders should be involved in developing and vetting state managed care proposals, including program beneficiaries, advocacy organizations, providers of medical care and social supports, trade associations, unions, and, in some states,

county governments. Each group can be expected to bring different goals and priorities to the table, and as a result, state officials will need to employ distinct strategies in reaching out to different target audiences. Efforts to promote understanding of the broad aims of the managed care initiative can be targeted to the general public and its elected representatives, while efforts to obtain input from specific groups of prospective plan beneficiaries may be accomplished best by arranging a series of more targeted forums. The messages a state crafts should be tailored to the principal interests of the particular group and aimed at answering the following questions: What are the target group's principal values? What actions should members of the group take? What are the barriers standing in the way of the group taking such actions, and what information can you provide to counter arguments against doing so? What goals do the target group and the state share?

Target audiences differ and so do the methods available to reach these groups. Here are a few of the approaches states have used to engage stakeholders:⁹⁴

- **Focus groups** are a useful means of obtaining firsthand feedback from beneficiaries and, where relevant, from their family members. States can bring together a group of beneficiaries who otherwise would be hard to reach by holding meetings at locations where such beneficiaries regularly gather (e.g., community health or mental health centers, churches) in various areas of the state.
- **Cross-stakeholder meetings** can foster the cross-pollination of approaches to addressing issues of mutual concern. Diverse perspectives on a particular issue do not always emerge from large, general-purpose meetings, where a relatively small number of speakers tend to dominate the discussion. This limitation can be addressed by purposely bringing together stakeholders with differing perspectives on a selected set of topics. State officials need to think through the best way of organizing and conducting such sessions, however, if they are to be productive, including arranging times (e.g., evenings/weekends) and locations convenient for participating stakeholders.

- **Public webinars** are an inexpensive way of conveying information to and receiving feedback from stakeholders. By using structured (e.g., PowerPoint) presentations followed by question-and-answer sessions, a state can tailor its communications to specific target audiences, involve stakeholders who are unable to travel, and accommodate the special communication needs of selected stakeholders. For example, in the spring of 2011, the California Department of Health Care held a series of public webinars for Medicaid beneficiaries with disabilities prior to activating a plan to transition people qualifying for benefits on the basis of age, blindness, or disability to managed health care plans.
- Establishing **project-specific Web sites** where stakeholders can access the latest information on state-level planning and related managed care development activities. Oregon, for example, formed four cross-stakeholder work groups to advise state officials on the preparation of the state's Medicare-Medicaid integration demonstration project. Information generated by these work groups, plus a variety of other documents related to the state's planning activities, were posted on a Web site so interested citizens could stay abreast of developments.
- A **request for information** (RFI) can be a useful method of gathering information on new models of care delivery, determining whether a proposed approach is acceptable to stakeholders, and eliciting information from organized constituencies. When the Massachusetts Division of Health Care Policy and Finance released an RFI on its under-65 dual-eligible project proposal in May 2011, more than 50 organizations, including a newly formed coalition of cross-disability advocates, responded to a series of questions posed by the agency. All responses to the RFI were posted on a special Web site, where they were available to be read by any interested citizen. The comments were used by Division of Health Care Policy and Finance officials in crafting the state's demonstration proposal.

States, as well as the Federal Government, have an obligation to carefully review and act upon stakeholder input in a genuine and committed manner, rather than simply organizing a public input process to fulfill a federal regulatory requirement.

Stakeholder Involvement: Massachusetts

Disability stakeholders in Massachusetts have played an active role in shaping the state's plans to launch a demonstration project to test new approaches to integrating the delivery and financing of acute health and long-term services to nonelderly adults with disabilities who are dually eligible for Medicare and Medicaid benefits. Key provisions of the proposal the state submitted to CMS in February 2012 were forged as a result of a series of meetings and public forums over two-year period involving disability advocates and officials of the state Executive Office of Health and Human Services (EOHHS).

Input from the disability community was coordinated by Disability Advocates Advancing Our Healthcare Rights (DAAHR), a statewide coalition of disability, elder, and health care advocacy groups formed in March 2011 to ensure that people with disabilities had a strong, unified voice in shaping health reform initiatives in Massachusetts. The following are among the most noteworthy products of the collaboration between DAAHR representatives and EOHHS officials:

- A requirement that integrated care organizations (ICOs), the accountable entities within a restructured, capitated managed care system, establish relationships with organizations that are knowledgeable about recovery models and the delivery of integrated behavioral health services, including services to hard-to-reach subpopulations such as homeless people.
- A requirement that ICOs contract with independent community-based disability organizations for independent living supports and LTSS coordinators. These LTSS coordinators, with no financial connections to the ICO, will function as part of an individual's care team, with responsibility for ensuring that (a) the person receives the supports needed to live independently and (b) such supports are part of the care plan and dovetail with other plan components.

- Stronger ADA compliance requirements, including physical accessibility standards and interpreters for people who are deaf, hard of hearing, or non-English speakers.
- An enrollment phase-in process to ensure that state, federal, and ICO officials have adequate resources to work with plan members during the transition from FFS payments.
- A requirement that enrollees qualifying for personal care attendant (PCA) services have the option of self-directing their services.
- A decision to continue to pay for HCB waiver services, targeted case management services, and psychiatric rehabilitation state plan services on an FFS basis outside of (but coordinated with) the dual eligibles demonstration project.

While applauding these revisions and expressing appreciation for the cooperation of EOHHS officials, DAAHR has identified a number of additional modifications it would like to see made in the state's proposal before it is approved. These changes are outlined in a March 25, 2012, letter to CMS.

Sources:

Memorandum from J. A. Bigby, Executive Office of Health and Human Services, Commonwealth of Massachusetts, to M. Bella, Medicare-Medicaid Coordination Office, Centers for Medicare and Medicaid Services (February 16, 2012), <http://www.dpcma.org/Issues/HealthCareReformII/tabid/846/Default.aspx>.

Letter from DAAHR cochairs Dennis Heaphy and Bill Henning to Melanie Bella, Office of Medicare and Medicaid Coordination, CMS (March 25, 2012), <http://www.dpcma.org/Issues/HealthCareReformII/tabid/846/Default.aspx>.

Principle #6. Cross-Disability, Lifespan Focus

The service delivery system must be capable of addressing the diverse needs of all plan enrollees on an individualized basis, including, as applicable, children, adolescents, nonelderly adults, and seniors with physical disabilities, intellectual and developmental disabilities, traumatic brain injuries, mental illnesses, substance use disorders, and other types of severe, chronic disabilities.

The demographic and need profiles of Medicaid beneficiaries with disabilities are incredibly diverse. The types of services and supports required by an 85-year-old widow with advanced Alzheimer's disease are entirely different from those needed by a teenager with significant behavioral and communication challenges caused by autism or another serious neurological disorder. Both may require specialized medical services and prescription medications in combination with ongoing personal assistance. But the composition and competencies of the team assembled to deliver those services will be radically different, as will the types of medical, psychological, pharmacological, and social interventions deemed appropriate. A key test of the potential effectiveness of a state's managed care plan, therefore, is the extent to which it includes credible strategies for serving ALL subpopulations of Medicaid beneficiaries with disabilities who are to be enrolled in the plan. One-size-fits-all approaches will not work.

As pointed out in chapter 2, the nine million people who qualify for Medicaid benefits on the basis of disability include children and adults with traumatic brain injuries, physical, sensory, mental, and/or intellectual and developmental disabilities. In each instance, however, the functional impacts of the person's disability as well as the types of interventions and ongoing supports he/she requires are influenced by such factors as the age of onset of the disabling condition, the nature and extent of any co-occurring conditions, the adequacy and appropriateness of services and supports that historically have been available (e.g., accessible medical facilities and equipment; durable medical equipment; paid personal care workers), and the resiliency of the informal support network surrounding the individual. Consequently, disability should be viewed as the

product of complex interactions between social and medical factors, rather than a series of fixed diagnostic categories that predict the mix of interventions required.

Service needs are influenced by a host of factors other than a person's diagnosis, including the age of onset and severity of the disability, whether other, co-occurring disabilities or chronic illnesses are present, cultural differences, and the capacity of family and friends to provide informal support and lend continuity to the person's life. These factors, however, merely scratch the surface of the complexities involved. Within each broad category (age of onset, severity, co-occurring condition/chronic illnesses, and family support capacity), a significant number of factors come into play in crafting a treatment and support plan tailored to the needs and circumstances of the beneficiary. The fact that a person has a qualifying mental disorder, for example, tells little about the types and extent of interventions that may be required. The current edition of the *Diagnostic and Statistical Manual of Mental Disorders*,⁹⁵ for example, identifies 297 mental disorders, each with its own unique signs, symptoms, and accepted treatment regimens. As with any health condition, diagnosing the nature of the person's disorder is just an initial step in the process of assessing his/her needs and developing an individually tailored treatment and support plan. In addition to clinical assessment data, many social and environmental factors must be taken into account in determining the appropriate interventions. It is particularly important that people in need of LTSS receive a person-centered assessment of support needs in addition to any functional or diagnostic evaluations.

Among the major challenges of serving people with disabilities through a capitated managed care plan are (a) the establishment and maintenance of a robust provider network that is capable of addressing all of the diverse, wide-ranging treatment and support needs of enrollees with chronic disabilities (see discussion under Principle #8, Provider Networks); (b) the development of a sound methodology for establishing and adjusting capitation rates that accounts for all essential costs involved in treating and supporting the entire spectrum of needs among plan enrollees with disabilities (see discussion under Principle #13, Capitated Payments); (c) information and data to be gathered and reported to state and federal officials on encounters, service trends, system performance, and outcomes (see discussion under

Principle #12, Information Technology); and (d) forging effective working relations with nonplan providers of services and supports to people with disabilities, including families, public schools, community mental health and substance use programs, vocational rehabilitation agencies, developmental disabilities agencies, and agencies serving people who are blind, deaf, or hard of hearing (see discussion under Principle #16, Coordination of Services and Supports).

Over the past 50 years, services to Americans with physical, mental, and intellectual/developmental disabilities have evolved along separate but parallel lines. The differences in the way services are organized, financed, and delivered today are both a reflection of the distinct characteristics and needs of discrete subpopulations as well as a product of the divergent social and political forces that shaped them. Creating a more integrated service delivery system that achieves efficiencies while retaining the best attributes of existing services will require time and extraordinary skills.

A state's managed care plan must include administrative, financing, and service delivery arrangements that accommodate the wide-ranging service and support needs of distinct segments of the population with disabilities, including both primary and specialty health services and long-term supports. Where health care and LTSS are separately financed and administered, written agreements must be in place spelling out the collaborative steps each system will take to ensure that the health care and long-term support needs of beneficiaries are properly synchronized. Other approaches to cross-system coordination include using specially trained workers to perform bridging and navigational roles on service and support teams and training beneficiaries to gain access to needed services.

Principle #7. Readiness Assessment and Phase-in Schedule

States should complete a readiness assessment before deciding when and how various subgroups of people with disabilities should be enrolled in managed care plans. The assessment needs to occur at two levels: a global evaluation of the state's readiness to move to a managed care system; and a more targeted assessment of the capabilities of selected managed care organizations to begin enrolling eligible individuals with disabilities in their plans. A state's phase-in plans, in turn, should be based on the results of these assessments.

Existing disability service systems are highly complex, with administrative structures, operational capabilities, and funding mechanisms that vary widely from population group to population group and from state to state. Creating a unified financing and service delivery system capable of addressing the diverse health and long-term support needs of people with disabilities, consequently, is an enormously complicated undertaking. Managed care plan components, therefore, must be designed and implemented with great care if disastrous consequences are to be avoided.

Disability advocates and outside experts have raised serious concerns about several pending state proposals to convert existing disability services and supports to a managed care framework.⁹⁶ They point out that most managed care firms have had limited experience in serving people with chronic disabilities, especially in coordinating the delivery of health care and long-term supports to children and young to middle-aged adults with disabilities. For this reason, it is important that state officials work closely with disability stakeholders to assess existing methods of financing and delivering specialized services to subpopulations of people with disabilities encompassed by the plan (e.g., people with physical disabilities; children and adults with intellectual and developmental disabilities; people with serious mental illnesses and substance use disorders). An in-depth readiness assessment is especially important if a state's ultimate goal is to administer Medicare- and Medicaid-funded health services and long-term supports under a single managed care umbrella.

The aim of the assessment should be to pinpoint modifications in existing administrative policies and practices that will have to occur prior to (and during) conversion to a managed care format. The results of the assessment should be used in establishing a synchronized implementation schedule. Consideration should be given to population-based or geographic-based phase-in schedules to ensure that adequate time and attention are devoted to essential implementation activities and compliance with related contractual obligations and state regulations. The purpose of a readiness assessment is to ensure that all of the essential pieces are in place before the transition to managed health services and/or long-term supports occurs.

The global evaluation should focus on potential barriers to serving identified subpopulations of people with disabilities. It should be carried out in partnership with officials from state disability agencies as well as other stakeholders and should include an examination of the adequacy of at least the following core elements of the state's proposal:

- The extent of disability stakeholder involvement in developing the state's managed care proposal and the state's plans for continuing such involvement during the implementation and ongoing operations of the program (see Principle #5: Stakeholder Involvement).
- The strengths and weaknesses of the state's existing HCBS network for addressing the needs of discrete segments of the population with disabilities targeted for inclusion in the planned managed care delivery system (see Principle #8: Provider Networks).
- The state's overarching system reform goals and strategies for addressing identified gaps and weaknesses in its existing HCBS network.
- The existence (or lack) of valid and reliable instruments to assess the service/support needs of eligible people with disabilities *and* predict the resources likely to be required to address those needs (see Principle #18: Quality Management).

- The strengths and weaknesses of the state’s plans to reduce its reliance on round-the-clock institutional care and emphasize individualized HCB supports (see Principle #9: Transitioning to Community-Based Services).
- The availability of community housing to meet the varied needs of people with disabilities who are transitioning from institutions to the community or being diverted from institutional placements (see Principle #1: Community Living and Principle #15: Maintenance of Effort and Reinvesting Savings).
- The state’s capacity to support family caregivers as critical actors in building a social network around individuals and helping them lead productive, meaningful lives as valued and participating members of the community (see Principle #4).
- The state’s capacity to provide conflict-free service coordination (case management) for all people with disabilities who need assistance in developing, implementing, and monitoring the effectiveness of their person-centered plans (see Principle #16: Coordination of Services and Supports).
- Evidence that sufficient state personnel (both in numbers and qualifications) will be available to implement, oversee, and regularly evaluate the operation of the state’s managed care system (see Principle #10: Competency and Expertise and Principle #11: Operational Responsibility and Oversight).
- Plan provisions aimed at guaranteeing participants a choice among two or more health plans as well as the supports needed to participate fully in a PCP process and, if they choose, to self-direct their own supports (see Principle #2: Personal Control).
- Plans for ensuring that managed care enrollees receive timely, complete, and accessible information on how to obtain needed services and the rights, privileges, and obligations that accompany participation in the state’s managed care program in accordance with Section 1932(b)(5) of the Social Security Act and 42 CFR 438.207 (see Principle #8: Provider Networks).

- The state’s information-gathering and reporting capabilities, including a description of the data collection, management, and report generation capacity of the state, participating MCOs, and contractual service providers (see Principle #12: Information Technology).
- The comprehensiveness of the state’s quality management strategy, including the methods and performance benchmarks to be used in assessing service outcomes, the quality and accessibility of services, the adequacy of health and safety safeguards, and compliance with the ADA (see Principle #18: Quality Management).
- Provisions designed to safeguard the rights of program participants with disabilities, including appeal rights (see discussion under Principle #21: Right to Due Process and Principle #22: Grievance and Appeals).
- Plan provisions to ensure the safe and effective transition of Medicaid beneficiaries from existing care/support arrangements to the state’s planned managed health and/or long-term support program.
- Plans to evaluate the state’s proposed managed care program at regular intervals, summarize evaluation findings, conclusions, and recommendations, make such information available to the public, and take steps to rectify program weaknesses identified by such evaluations.

The results of a state’s readiness assessment should be incorporated into its request for waivers of Medicaid (and, where applicable, Medicare) law; CMS should use the findings and conclusions of the state’s assessment to determine whether to approve such waivers, as well as any terms and conditions that should be attached to the approval.

Once a state has obtained the necessary federal waivers to operate health and/or long-term supports under a managed care framework, it should conduct a readiness assessment of the selected MCOs before allowing them to begin enrolling people with disabilities. The general purpose of this review should be to determine whether the MCO

(a) has the capacity to carry out all contractually specified functions effectively and efficiently, including data collection, management, and reporting; (b) has experience of providing a similar array of services and supports either in the state or in other states; and (c) has developed a broad enough provider network to address the service and support needs of all enrollees. The state should develop a standardized readiness review protocol to ensure uniformity in determinations concerning each MCO's compliance with contractual requirements and their capacity to perform all required functions. The assessment should consist of a desk audit of informational materials furnished by the MCO, followed by an on-site review.

At a minimum, an MCO long-term services readiness review should include an assessment of the organization's capabilities in the following areas:

- PCP and service delivery, including risk assessment and mitigation actions aimed at ensuring safety without compromising a participant's autonomy; and plan monitoring to ensure that adequate supports are in place to meet each individual's needs and that such supports are delivered as planned.
- Service/care coordination to ensure the seamless integration of supports across providers; and evidence that service coordinators are trained in, and supervised to carry out, person-centered delivery of services (see Principle #16: Coordination of Services and Supports).
- A full description of the services and supports to be made available to enrollees and, where applicable, family members. This description should specify provider qualifications and the processes to be used to ensure that providers remain qualified. In addition, the MCO should spell out the procedures to be used in conducting criminal background checks of workers and establishing and maintaining abuse registries.
- A clear delineation of service plan approval standards and processes.
- Participant grievance and appeal processes.

- The process of ensuring consumer choice among qualified providers and ensuring that enrollees have the option of self-directing their services, regardless of the severity of their disabilities.
- Compliance with state policies governing the use of mechanical and chemical restraints as well as aversive and restrictive procedures, including the steps to be taken to minimize the use of such procedures.
- A description of the system to be used in reporting and investigating critical incidents such as abuse, neglect, exploitation, injuries, the use of restraints, and aversive and other restrictive procedures.
- Policies governing the administration of medications, including self-administered medications.
- Policies governing advanced directives on the receipt of medical and psychiatric treatment, including the circumstances under which third party surrogate decision making is permitted.
- A description of the MCO's quality assessment and performance improvement plans, including the steps to be taken to (a) measure and monitor service access and quality; (b) summarize and report on monitoring results, including outcome data, to the state on a prescribed basis; (c) describe the discovery and remediation process to be used; and (d) describe the process for determining and carrying out quality improvement projects.
- Specifications for developing and implementing corrective action plans required by the state, including the steps to be taken to remediate identified deficiencies in plan performance.
- A summary of the interagency operating agreement that the MCO has executed with local and areawide agencies assisting people with disabilities, including public school systems, mental health and developmental disabilities agencies, agencies

serving people who are blind or deaf, vocational rehabilitation agencies, workforce investment boards, public housing agencies, and independent living centers.

MCOs should not be permitted to enroll participants in LTSS until they have satisfied the state Medicaid agency (and CMS through its MCO contract review authority) that the above requirements have been met.

Readiness Assessment: New Jersey

For more than a decade, New Jersey, unlike many other states, has enrolled most qualified low-income seniors and people with disabilities in Medicaid managed health care plans. So when state officials decided to consolidate multiple Medicaid funding streams under a single management structure, it seemed logical to add behavioral health services and long-term supports to the state's existing contracts with Medicaid managed MCOs. In doing so, state officials decided to phase in these new MCO responsibilities based on the results of a readiness assessment conducted by the state Division of Medical Assistance and Health Services (DMAHS) in concert with officials from several state aging and disability agencies. The proposed phase-in schedule called for the following:

- Shifting responsibility to the MCOs for overseeing the delivery of the following state plan services as of July 1, 2011: pharmacy services; adult and pediatric medical day care services; home health services for seniors and people with disabilities; and physical, occupational, and speech therapies and personal care assistant services. All of these services had previously been carved out of MCO contracts and paid for on an FFS basis.
- Permitting Medicare Special Needs Plan services to be provided through Medicaid MCOs (and permitting auto-enrollment with a beneficiary opt-out option) as of January 1, 2012.

- Adding NF and HCB services for seniors and adults with physical disabilities to MCO contracts as of July 1, 2012. Currently, NFs are offered as a state plan coverage, while HCB services are furnished through several Section 1915(c) waiver programs.
- Shifting children’s behavioral health services, currently paid for by DMAHS, to the Children’s System of Care program managed by an administrative services organization (ASO) as of July 1, 2012.
- Transferring responsibility for administering adult mental health and addiction services to a managed behavioral health organization (MBHO) as of January 1, 2013.
- Mandating the enrollment of all non-dual-eligible seniors and adults with physical disabilities in MCOs, as of August 2011, for the receipt of primary and acute care services.
- Mandating the enrollment of all dual eligibles in Medicaid MCOs for the receipt of primary and acute care services as of October 2011.

New Jersey officials concluded, based on the state’s assessment, that the prudent course of action would be to continue paying for LTSS on behalf of people with I/DD on a FFS basis, rather than shifting such services to the MCOs, until certain problems are addressed. Over the next five years DMAHS, in collaboration with the state Division of Developmental Disabilities (DDD), plans to—

- Resolve current Medicaid eligibility and enrollment issues.
- Rebalance the state’s reliance on institutional vs. HCB services.
- Pursue opportunities to qualify for additional federal matching funds.

- Develop statewide rate schedules that are not cost-based.
- Adopt a systemwide assessment tool or develop and validate a state-specific tool.
- Integrate existing DDD financial management systems with the state's Medicaid management information system (MMIS).

In addition, while taking steps to integrate behavioral health services into managed health care plans, New Jersey officials decided to phase in risk-based, capitated payment systems for such services over the course of the proposed five-year demonstration period. Plans call for selecting a single, statewide MBHO during FY 2012, with implementation beginning on January 1, 2013. Initially, the state will share responsibility with the MBHO and the existing ASO for managing the service provider network for adult and child beneficiaries and will pay such providers. Then, over the course of the five-year demonstration period, increasing levels of responsibility and financial risk will be shifted to the MBHO. Consumers of I/DD, behavioral health, and addiction services and supports will continue to receive their primary and acute health services through four existing MCOs.

Many of the reforms New Jersey intends to pursue (including implementation of the timelines outlined above), along with myriad other operational and policy changes not discussed here, are subject to federal approval of a Section 1115 waiver/demonstration plan currently pending before CMS. The overarching aim of the state's Comprehensive Waiver request is to consolidate a variety of Medicaid funding authorities under a uniform, streamlined management structure, thereby achieving enhanced systemwide efficiencies and cost-effectiveness in the delivery of health services and long-term supports.

Source:

State of New Jersey, Department of Human Services, in cooperation with the Department of Health and Senior Services and the Department of Children and Families, *Section 1115 Demonstration Comprehensive Waiver* (September 9, 2011), <http://www.state.nj.us/humanservices/dmahs/home/waiver.html>.

Principle #8. Provider Networks

The provider network of each MCO should be sufficiently robust and diverse to meet the health care, behavioral health, and, where applicable, long-term support needs of all enrollees with disabilities. When a state plans to cover LTSS as part of its managed care initiative, its network must encompass both providers of institutional and HCB services. Each network should have a sufficient number of qualified providers, as well as fully accessible facilities and programs in each specialty area, to allow participants to choose among alternatives.

Beneficiaries with physical, sensory, behavioral, intellectual, and developmental disabilities require a far more varied set of providers and a wider range of services than the general Medicaid population—especially those beneficiaries who need preventive and acute health services as well as LTSS. The diversity of needs is a direct analog of the variety within the population with disabilities in terms of causation, age of onset, functional limitations, and co-occurring disorders (see related discussion in chapter 2 and under Principle #6). Consequently, states must carefully analyze the types of providers and service needs represented among the target population of enrollees, as well as current levels of access to providers and potential problems in ensuring network adequacy.

In addition, special attention is needed to ensure that service providers have the capacity and expertise to address the racial and ethnic diversity of populations targeted for services, as well as cultural and linguistic barriers to access. Steps must be taken to (a) establish and maintain adequate provider networks in rural areas of a state; (b) reach out to homeless people; (c) afford people with disabilities a voice in the selection of network providers (possibly through advisory bodies at the state and MCO levels); and (d) provide access to out-of-network services when necessary to enable enrollees to receive all needed services.

Section 1932(b)(5) of the Social Security Act specifies that a state must provide assurances acceptable to the secretary of Health and Human Services that each managed care service network “has the capacity to serve the expected enrollment” and

- (A) “Offers an appropriate range of services and access to preventive and primary care for the population expected to be enrolled...and
- (B) Maintains a sufficient number, mix, and geographic distribution of providers of services.”

Federal regulations implementing Section 1932(b)(5) of the Social Security Act (42 CFR 438.207) elaborate on the assurances a state must provide that its managed care contractors are in compliance with the above statutory requirements governing the range and capacity of available services.

To ensure that a complete range of services and supports are available to enrollees with disabilities, a state should—⁹⁷

- Identify the diagnostic characteristics and service use patterns among the various subgroups of people with disabilities who are targeted for enrollment in the plan.
- Determine the most critical service needs among the target population and any problems they are likely to encounter in gaining access to such services.

- Examine network adequacy in the context of the overall operation of the system of services, taking into account such related factors as payment rates and incentives, understanding the needs of the enrolled population, care coordination, linkages with other appropriate, non-network providers, and the views of system stakeholders.
- Monitor adherence to quantitative and qualitative access standards.

MCOs responsible for providing LTSS should be required to accept into their networks community disability provider agencies currently serving people with disabilities who are targeted for plan enrollment (e.g., independent living centers, community developmental disability agencies, community mental health centers, recovery communities). These agencies typically have long-standing relationships with the people they serve and have forged a bond of trust that would be difficult to replicate—especially among people with a history of mental illness and brain trauma, for whom continuity of relationships is so critical.

Furthermore, enrollees in such plans should be free to choose out-of-network providers who agree to the MCO's terms governing participation, including payment schedules, care coordination, and data collection/reporting requirements, on a single-case agreement basis. Limited networks remove one of the most effective, real-time quality assurance tools by restricting the number of providers available to beneficiaries. If enrollees are satisfied with the in-network care and support options available to them, the use of out-of-network options will be limited. But if the MCO's network is inadequate or offers substandard care and support, enrollees will provide the MCO and responsible state officials with immediate feedback by seeking out-of-network providers.

Principle #9. Transitioning to Community-based Services

CMS should require states planning to enroll Medicaid recipients of LTSS in managed care plans to include within the scope of coverage both institutional services and HCB services and supports. This requirement should be built into CMS’s standard “terms and conditions” governing waiver approvals.

Over the past two decades, Medicaid expenditures on HCBS have grown at a faster pace than expenditures on long-term institutional services. Yet more than 1.5 million Medicaid beneficiaries continue to reside in NFs, and nearly two-thirds of Title XIX expenditures on LTSS for seniors and other adults with physical disabilities still occur in institutional settings (see details in chapter 2 and the discussion under Principle #1).⁹⁸ As a result, it is important that states that are planning to shift the financing and delivery of long-term services to a capitated managed care format (a) develop capitation rates that wrap around both institutional and HCB services (see additional discussion under Principle #13) and (b) include explicit strategies for preventing unnecessary or premature institutionalization and facilitating the transition of eligible people from institutional to HCBS settings. Ensuring the inclusion of these elements in a state’s plan makes sense in both human and economic terms, since the net effect is to minimize the number of people who require services in the most expensive care settings. The author of a recently completed analysis of state Medicaid LTSS expenditures between 1995 and 2009 concluded that optimal systemwide savings are achieved in states choosing to gradually rebalance their financial commitments to institutional versus HCBS over a multiyear period.⁹⁹

States planning to enroll people with severe disabilities in managed long-term services and supports (MLTSS) plans—whether enrollment is limited to Medicaid-only recipients or includes dually eligible beneficiaries as part of an integrated Medicare-Medicaid-funded plan—should design capitated payment methodologies that include incentives for serving people in HCB settings. Although experience in operating MLTSS plans remains

limited,¹⁰⁰ several workable strategies for encouraging HCB services as part of a MLTSS plan have emerged:¹⁰¹

- 1. Use the same reimbursement rate for institutional and HCB services.** The average per capita cost of institutional services typically is considerably higher than that of HCBS. When a state establishes the same acuity-adjusted PMPM payment rate for institutional and HCB services, at-risk MCOs have strong incentives to avoid institutional placements and to transition NF and other institutional residents to HCB settings. New Mexico adopted this strategy when it launched its Coordination of Long-Term Services (CoLTS) program. The CoLTS program uses a blended payment rate that incorporates NF and HCBS payment data for all beneficiaries who meet nursing home level of care criteria. This payment rate is not adjusted when a beneficiary enters an NF; consequently, participating, at-risk health plans have strong incentives to provide the additional supports that high-need enrollees require to avoid admission to a nursing home or to transition from a nursing home to the community. CoLTS payment rates are renegotiated annually based on service patterns. Arizona uses a similar approach in managing its Arizona Long Term Care System (see discussion under Principle #13).¹⁰²
- 2. Use partially capitated rates for institutional care.** In situations where the state concludes that full-risk sharing would destabilize the finances of private health plans, partial capitation of institutional services may be an alternative. Health plans participating in Minnesota's Senior Health Options (MSHO) program, for example, receive a blended PMPM payment rate that requires them to pay 180 days of NF care on behalf of any enrollee placed in an NF. After 180 days, the NF's per diem costs are reimbursed directly by the state on an FFS basis. To encourage health plans to serve high-need beneficiaries in HCB settings, Minnesota pays plans a "nursing facility add-on" rate. This supplemental payment ceases when a beneficiary is placed in an NF, and the plan must cover the higher

facility costs out of the previous revenues it has received from the state for the initial 180 days.¹⁰³

- 3. Reward health plans with high community transition rates.** In addition to holding health plans at full risk for NF admissions, the Arizona Long Term Care System (ALTCS) program employs an HCBS reconciliation process to encourage plans to return NF residents to the community with appropriate services and supports. The state establishes an assumed, plan-specific ratio of HCBS recipients to NF residents by geographic area. If a health plan serves a higher ratio of enrollees in HCB settings than the state benchmark, Arizona reimburses the plan for a portion of the savings achieved through a reconciliation process. Conversely, if a plan falls below the state-established target ratio, the state may recoup a portion of the differences in rates paid to the plan.¹⁰⁴

States also must build into their MLTSS plans provisions designed to deflect institutional placements. Crisis intervention services, for example, are an effective means of avoiding institutional placements, especially for people experiencing behavioral crises. Among the services that should be part of any comprehensive intervention system are interdisciplinary crisis stabilization teams, peer-run crisis alternatives, and short-term, therapeutic homes where beneficiaries can stay until the behavioral episode subsides and they are ready to return to their permanent place of residence.

Transitioning beneficiaries from long-term care institutions to HCB settings requires intentional planning and careful follow-through, as evidenced by the states' collective experience in operating Money Follows the Person (MFP) demonstration programs. A recently released analysis of the MFP program found that monthly HCBS costs incurred during the first 30 days following placement in the community were anywhere from 20 percent higher to double the costs during subsequent months. Among the initial costs commonly incurred are housing rental deposits, transitional service coordination, the purchase of essential household goods and supplies, and the purchase of an initial supply of medications. MFP program managers, it is important to point out, report that

these additional, up-front expenditures are critical to achieving higher transition rates and lower reinstitutionalization rates.¹⁰⁵

Other studies have found that 85 percent of early MFP participants have been able to live in the community for a year or more and self-report an improved—often substantially improved—quality of life one year after transition.¹⁰⁶ And, of equal importance, the average per capita cost of HCB services has been running 34 percent lower than NF costs for seniors and other adults with physical disabilities and 77 percent lower than intermediate care facility for the mentally retarded (ICF/MR) costs for people with developmental disabilities.¹⁰⁷

In recognition of the ADA requirements governing the “most integrated” living setting, as interpreted by the U.S. Supreme Court in its *Olmstead* ruling,¹⁰⁸ CMS should require states seeking approval to implement Medicaid managed LTSS to spell out in their proposals the steps that will be taken to prevent unnecessary or premature institutionalization and effectively transition eligible people with disabilities from long-term care institutions to HCB settings. These requirements should be spelled out in the terms and conditions accompanying CMS approval of the statutory waivers required to initiate the program.

It is important to point out that the transition to community-based services is likely to involve changes reaching considerably beyond minimizing placements in traditional long-term institutional settings. CMS recently published a proposed rule that would narrow the types of living settings in which Medicaid-funded HCBS may be provided.¹⁰⁹ In addition to ruling out nursing facilities, institutions for mental diseases (IMDs), and intermediate care facilities for people with intellectual and developmental disabilities (ICFs/DD)¹¹⁰ as qualified HCBS settings, the proposed rule identifies attributes that must be present for a setting to qualify, including the following:

- The setting is “integrated in, and facilitates the individual’s full access to, the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal

resources, and receive services in the community, like individuals without disabilities.”

- The setting is “selected by the individual among all available alternatives and identified in the [individual’s] person-centered plan.”
- An individual’s “essential personal rights of privacy, dignity and respect, and freedom from coercion and restraint are protected.”
- A person’s “[i]ndividual initiative, autonomy, and independence in making major life choices, including but not limited to, daily activities, physical environment, and with whom to interact are optimized and not regimented.”
- A person’s “[i]ndividual choice regarding services and supports, and who provides them, is facilitated.”

The proposed rule establishes further conditions applicable to provider-owned settings and requests public input on two additional criteria CMS is considering attaching to the definition of an HCB setting. The first additional criterion would add greater specificity to the attributes of a provider-owned or -controlled HCB setting, while the second would add that “receipt of any particular service or support could not be a condition for living in the unit” (i.e., residents would be free to select a provider other than the operator of the living unit to furnish their HCB services and supports).

It seems clear that CMS intends to narrow the definition of an acceptable setting for providing HCBS in ways that would rule out many adult care homes, assisted living facilities, and other types of licensed residential care facilities in favor of home and homelike settings where residents have choices and control over their lives and relationships.

Principle #10. Competency and Expertise

The existing reservoir of disability-specific expertise, both within and outside of state government, should be fully engaged in designing service delivery and financing strategies and in performing key roles within the restructured system.

State governments have lost more than 100,000 employees since the beginning of the Great Recession, while local governments have lost more than 500,000 workers over the same period.¹¹¹ The depth of government job losses was tempered by the receipt of federal stimulus dollars from the middle of 2009 through the middle of 2011. But since federal stimulus aid ended, some state and local governments have been forced to lay off additional workers in order to balance their budgets, despite a rebound in state and local revenues.

Human services agencies in some states have been hollowed out as a result of repeated personnel reductions, raising serious concerns about the capacity of their state Medicaid and affiliated agencies to oversee a capitated managed care system. It is not simply a question of having an adequate number of employees but also having employees with the specialized skills necessary to effectively administer such a system and ensure that it operates in the best interests of program enrollees. The types of positions states historically have had trouble filling—data system designers, managers and analysts, rate-setting specialists, and performance assessment system designers and managers—possess precisely the capabilities a state needs to operate a managed health care and long-term support system.

Moreover, state disability agencies and private sector disability stakeholders have been relegated to the sidelines during the design and implementation of managed care delivery systems in a number of states. When a state fails to marshal the expertise at its disposal in fashioning and operating a Medicaid managed care service system for people with chronic disabilities, there are sound reasons to be concerned about the sustainability of the resulting system.

State Medicaid officials should draw upon the knowledge and skills of their colleagues in state behavioral health, developmental disabilities, vocational rehabilitation, education, housing, transportation, and other agencies in designing a Medicaid managed care system that builds upon decades of experience in serving various subpopulations of people with disabilities. Lead responsibility for planning and overseeing the delivery of specialized services and supports to subpopulations should be assigned to these disability-specific agencies. CMS, in turn, should carefully scrutinize state managed care proposals to ensure that the state has articulated a well-thought-out strategy for making optimal use of the extensive knowledge and experience in disability services that exists within public and private sector agencies.

Principle #11. Operational Responsibility and Oversight

Responsibility for day-to-day oversight of the managed care delivery system must be assigned to highly qualified state and Federal Government personnel with the decision-making authority necessary to proactively administer the plan in the public interest.

Managed care should not be viewed as a means for state policymakers to divest themselves of their constitutional and statutory responsibilities to ensure that recipients of publicly funded services and supports, as well as the general taxpaying public, are effectively served. State policymakers must ensure that (a) an adequate number of qualified state personnel are available to monitor the system and hold MCOs and their subcontractors accountable for their performance and (b) such personnel have the tools to carry out their responsibilities. It is vitally important that managed care contracts contain clear, unambiguous performance standards, operating guidelines, data reporting requirements, and outcomes expectations so that contractors and subcontractors can be held to contract specifications (see discussion under Principle #7).

As noted above, severe budget pressures combined with antigovernment sentiment have led to a steady erosion of staffing levels and frequent leadership changes in state human services agencies over the past four years. A recent survey of state aging and disability

agencies, for example, found that between February and November 2011, 10 states and the District of Columbia appointed a new state Medicaid director. The turnover in state aging and disability agencies was even more dramatic, with 40 new state agency directors assuming their positions during 2011. In addition, more than half of state aging/disability (A/D) agencies have restructured or were in the process of restructuring at the time the survey was conducted. Key reasons cited for these reorganizations included the need for administrative simplification and personnel reductions. Since the beginning of the recession in late 2007, 82 percent of state A/D agencies have experienced significant personnel reductions in a broader staff downsizing trend.¹¹² According to the U.S. Bureau of Labor Statistics, state government personnel rolls declined by 71,000 positions between November 2010 and November 2011.¹¹³

These staffing reductions have occurred at a time when state Medicaid programs face unprecedented challenges, including the following:

- A rapid growth in enrollments due to the weak economy.
- Preparations for enrolling millions of new Medicaid beneficiaries beginning in 2014, at least in states that have decided to pursue the eligibility expansion authorized under the ACA.
- The loss of federal stimulus dollars provided under the ARRA.
- Per capita health care expenditures that are continuing to rise at a rate faster than the general economy.¹¹⁴

Some states have responded to personnel reductions by assigning to private contractors functions traditionally carried out by government employees. Wisconsin is one such state. In a recently released study, the state Legislative Audit Bureau found that, as of June 2011, at least three times as many contract workers were performing Medicaid administrative tasks as were employees of the state Department of Health Services. Based on its findings, the audit bureau raised questions about the department's capacity

to oversee the performance of its contractors as well as the state's \$7.5 billion Medicaid program.¹¹⁵

Principle #12. Information Technology

States, with assistance from HHS, should design, develop, and maintain state-of-the-art management information systems with the capabilities essential to operating an effective managed care delivery system.

Information technology (IT) is an essential tool in administering and overseeing a managed health and/or long-term services delivery system. With access to such technology, data management functions that otherwise would require extensive person-hours to complete can be automated and performed far more efficiently. Given the size and complexity of the administrative tasks involved, an effective MMIS must have at least the following core capabilities:

- An electronic recordkeeping system that allows authorized personnel to access the complete health care and, where applicable, long-term supports records of all plan enrollees instantaneously so treatment and intervention strategies can be effectively coordinated and sequenced.
- A system for collecting and analyzing performance and outcome data as part of comprehensive quality monitoring and improvement system (see discussion under Principle #18).
- An electronic system for reporting, tracking, investigating, and analyzing sentinel incidents (see discussion under Principle #18).
- A system for gathering and analyzing encounter data and using such data to develop actuarially sound, capitated payment rates (see discussion under Principle #13).

In February 2009, Congress enacted the Health Information Technology for Economic and Clinical Health Act as part of the American Recovery and Reinvestment Act (P. L. 111-5; better known as the stimulus legislation). The principal aim of this measure is to promote the adoption of electronic health records (EHRs) through federal incentive payments to hospitals, physicians, and other health care providers. These federal subsidies are expected to total as much as \$27 billion over a 10-year period.¹¹⁶ The Affordable Care Act added further pressure on health providers to adopt electronic records by mandating that participants in various health delivery reform initiatives (e.g., accountable care organizations, medical home providers, independence at home demonstration sites) meet EHR standards.

Spearheaded by the HHS Office of the National Coordinator of Health Information Technology, the Obama Administration has made significant strides in expanding the use of EHRs over the past three years. The percentage of physicians using EHRs in their practices doubled from 17 percent to 34 percent between 2008 and 2011, while office-based e-prescribing increased from 0.8 percent in December 2006 to 40.2 percent in September 2011.¹¹⁷

As high users of acute health care services, people with disabilities will be primary beneficiaries of the expanded use of EHRs. Still, to date the focus on EHR promotion efforts—including Medicare and Medicaid payment incentives—has been restricted to hospitals, physicians, and other providers of primary and acute care services. The promise of a seamless service delivery system for people with severe chronic disabilities who require a combination of acute health services and long-term supports will not be realized until the emphasis on employing modern health IT is extended to the long-term services sector and linked to the information systems of other critical disability service settings (e.g., early intervention programs, local school systems, vocational rehabilitation agencies). For example, family caregivers and providers of long-term supports are in a much better position to prevent repeated hospitalizations if they have access to detailed, timely information on prior hospital admissions.

A variety of thorny issues will have to be addressed as EHRs become the norm. Among these issues are (a) ensuring the confidentiality of personal data as health IT becomes increasingly

interoperable and (b) regulating personal access to records in ways that encourage people to play a more active role in managing services and maintaining their health and well-being. It will not be easy to maintain a reasonable balance between individual privacy and access to records. However, it will be worth the efforts required to resolve these issues.

Principle #13. Capitated Payment Systems

States electing to compensate managed care contractors through a capitated payment system should adopt a fair, equitable, and transparent methodology for calculating and adjusting PMPM payment rates. Capitation rates should be sufficient to allow a managed care contractor to recruit and maintain a robust provider network that (a) affords beneficiaries a choice between two or more qualified providers of any covered service and (b) is capable of addressing the full range of service and support needs among plan enrollees, including people with disabilities who require highly specialized health care and ongoing services and supports.

Establishing capitated payment rates for people with chronic disabilities poses unique challenges. Existing Medicaid FFS rates in most states are low compared with Medicare and commercial rates, and people with disabilities often have extensive unaddressed service needs, making FFS rates an inadequate basis for establishing a system of capitated payments. Moreover, while state Medicaid agencies frequently have experience in establishing capitated payment rates for comparatively healthy children and adults (primarily those eligible for Temporary Assistance to Needy Families), this experience is likely to be of limited utility in setting capitated payment rates for beneficiaries with disabilities, whose health care and long-term support needs are far more extensive and costly.

States electing to institute a risk-based, prospective payment system are required under Section 1903(m)(2)(A)(iii) of the Social Security Act and implementing CMS regulations (42 CFR 438.6(c)) to develop “actuarially sound” capitated payment rates. To meet this requirement, a state must develop a risk adjustment methodology using FFS claims

data, encounter data, and diagnostic information to tailor the rates paid to health plans based on their aggregate enrollee profile. Risk-adjusted rates militate against adverse selection (i.e., the tendency to exclude enrollees who are difficult and expensive to serve) and poor quality of care, thereby ensuring that health plans serving high-need enrollees are not penalized. Obtaining accurate, reliable, and timely data is one of the major challenges to building an effective risk adjustment methodology.

After reviewing available cost studies, researchers at the Kaiser Family Foundation's Commission on Medicaid and the Uninsured concluded that, while risk-based managed care arrangements for people with disabilities may increase budget predictability and result in savings down the road, in the near term, state Medicaid programs are unlikely to achieve savings due to the sizeable unmet needs among the target population, high initial utilization due to pent-up demands and improved care coordination, and up-front administrative costs. The authors also point out that "effective care coordination for disabled beneficiaries requires more intense and likely more expensive, multidisciplinary, team-based approaches that span health and social services, organizes and disseminates case information among providers and includes face-to-face case management with active and regular beneficiary outreach efforts."¹¹⁸

A 2010 report by the U.S. Government Accountability Office concluded that "CMS has been inconsistent in reviewing states' rate setting for compliance with the Medicaid managed care actuarial soundness requirements, which specify that rates must be developed in accordance with actuarial principles, appropriate for this population and services and certified by actuaries."¹¹⁹ More recently, Senator Charles E. Grassley (R-IA), ranking minority member of the Senate Finance Committee's Health Subcommittee, has requested information from all state Medicaid directors concerning managed care rate-setting practices in their respective states. As Grassley notes in his letter to state Medicaid directors, "[i]f a [managed care] entity is paid too little...access to and quality of care provided to beneficiaries is jeopardized. If an entity is paid too much, scarce Medicaid resources are diverted away from providing services to beneficiaries."¹²⁰

Capitated Payments: Arizona

No state has more experience in administering Medicaid services under a fully capitated, at-risk payment system than Arizona. The state has used this approach to pay for services since becoming part of the federal-state Medicaid program in 1982.

From the beginning, Arizona has operated Medicaid services under a Section 1115 research and demonstration program called the Arizona Health Care Cost Containment System (AHCCCS). The terms and conditions governing federal approval of the AHCCCS program permit the state to administer services under a capitated managed care format, provided it meets a wide variety of stipulations contained in its agreement with CMS. Initially, only primary and acute care services were covered under the AHCCCS program. But in 1987, Arizona received permission from CMS to add LTSS to the demonstration program.

Organization and Delivery of Services. The Arizona Long-Term Care System (ALTCS) includes two components: services for frail elders and people with physical disabilities (EPD); and services to children and adults with qualifying developmental disabilities (DD). The benefit package for both components includes primary and acute health care, HCBS, behavioral health services, and long-term institutional services (NF and intermediate care facility services for people with intellectual disabilities and related conditions). Applicants for both ALTCS/EPD and ALTCS/DD services must be in need of institutional care in the absence of HCBS. ALTCS/EPD services are administered by the single state Medicaid agency (AHCCCS) and delivered through a statewide network of three private managed care contractors. ALTCS/DD services, in contrast, are administered by the Division of Developmental Disabilities, a unit of the state Department of Economic Security, under a single statewide contract with the AHCCCS agency.

The Division of Behavioral Health Services (BHS), a unit of the state Department of Health, contracts separately with AHCCCS for the provision of mental health and substance abuse services to Medicaid-eligible people who require such services. These services are delivered through a statewide network of Regional Behavioral Health Authorities to ALTCS eligibles as well as other Medicaid beneficiaries. Because the ALTCS/DD benefit package includes behavioral health services, DDD, as the single statewide contractor, maintains a separate intergovernmental agreement with BHS for the provision of such services to people with intellectual and developmental disabilities, while behavioral health services are provided on an as-needed basis as part of the basic BHS/AHCCCS contract.

Capitated Rate-Setting Methodology. AHCCCS managed care contractors (including DDD) and health plans (for acute care services) receive a flat, monthly payment on behalf of each member receiving Medicaid-funded services and supports. For ALTCS enrollees, this payment includes separately calculated amounts for primary and acute care services, behavioral health services (in the case of ALTCS/DD), LTSS, case management, risk and contingency, and administrative overhead. Habilitation services for ALTCS/DD participants, including employment, day activity, and residential, family, and in-home supports, make up a significant part of the LTSS portion of the rate. Capitation rates are actuarially certified and reflect negotiated decisions regarding the various rate components. The final, combined PMPM capitation rate is specified in AHCCCS's contracts with the managed care contractors.

ALTCS/DD capitation rates use both a rebase and rate update methodology that takes into account historical encounter data, financial statements, supplemental information from DDD, provider rates, state and national expenditure reports, and benchmark modeling. These experience adjustments also include state mandates, court-ordered programs, and other program changes.

AHCCCS officials weigh the impact of emerging demand patterns and recent policy changes. For example, should DDD anticipate the expansion of developmental home services (small family homes for up to three people) to 300 additional people, these projections are taken into account in adjusting the PMPM capitation rate for the upcoming contract year. The anticipated needs are identified through the network plan and utilization trends. Conversely, should the legislature trim program benefits in order to balance the state budget, the reduced benefits are reflected in lower program capitation rates.

DDD develops most HCBS rates using independent modeling. While rate-based payments to HCBS/LTSS providers are not capitated in the same manner as ALTCS/DD payments to acute health plans, the LTSS component of the combined capitated amount DDD receives from AHCCCS is a major factor in setting HCBS rates. The DDD Rate Book outlines the methodology used in developing model rates for the following elements of HCBS: home-based services; independent living services; day treatment and training services; developmental home services; professional services (physical therapy, occupational therapy, speech therapy); support coordination services; employment support services; specialized habilitation services; and transportation services. National and local data on wages, inflation, the cost of living in the state, and other factors are taken into account in building the “benchmark” rate, and, if DDD appropriations are sufficient, the benchmark rate is updated annually for inflation. The benchmark rate constitutes the model rate, while the adopted rate is the actual rate paid based on available fiscal year appropriations.

Emphasis on HCBS. One consistent goal of the ALTCS program since its inception has been to promote the use of HCBS options. Two key features of the program offer managed care contractors incentives to emphasize HCBS. First, institutional costs are included in global capitation rates, thus providing

contractors with a strong incentive to serve enrollees in HCBS settings rather than in more costly nursing homes or facilities for people with intellectual disabilities and related conditions. Second, AHCCCS establishes a yearly target percentage of total member months spent in HCB settings for each contractor. At the end of the year, contractors that exceed the percentage target share in the savings achieved by AHCCCS, while the state recoups a portion of payments from contractors that fall short of the target percentage. As a result of the consistent application of these policies over the years and a continuing emphasis on intervening early before support needs escalate, today three-quarters of ALTCS/EPD recipients and 99 percent of ALTCS/DD recipients receive LTSS in HCB settings.

Sources:

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Principle #14. Continuous Innovation

The Federal Government and the states should actively promote innovation in LTSS for people with disabilities.

The U.S. health care system is undergoing substantial changes as policymakers seek to ensure that all citizens gain access to affordable health care. There is no shortage of proposals for improving the quality and cost-effectiveness of services to Medicare and Medicaid beneficiaries with chronic disabilities. But the vast majority of these proposals are aimed at improving the organization and delivery of preventive, primary, and acute health care services, while giving little attention to gaps and discontinuities in the nation's LTSS system.

The United States expends far more per capita on health care than any other advanced, industrialized nation, and yet, by most measures, health outcomes for its citizens are no better—and are sometimes worse—than those achieved in other developed countries.¹²¹ One of the central aims of the ACA is to improve the quality and cost-effectiveness of health care services nationwide. In pursuit of this goal, the act includes a variety of provisions designed to identify, test, and disseminate information concerning new, more effective and efficient service delivery and payment models.

Section 3021 of the ACA directs the secretary of HHS to create an Innovation Center within CMS. The purpose of this center, inaugurated in the fall of 2010, is to spearhead improvements in the delivery of Medicare, Medicaid, and CHIP services. During its first year of operations, the center launched 16 initiatives focused on improving patient safety, promoting the coordination of care across health care settings, investing in the transformation of primary care services, supporting bundled payment experiments, and addressing the complex health care and long-term support needs of people who are dually eligible for Medicare and Medicaid benefits.¹²² Funds set aside for these initial projects totaled more than \$2.7 billion, with an additional \$7.3 billion expected to be obligated for additional initiatives between now and FY 2019.

No doubt, some people with disabilities will benefit from the projects being funded by the Innovation Center, especially the Financial Alignment Demonstrations for Dual Eligible beneficiaries. But the projects funded to date focus almost exclusively on innovations in financing and delivering primary and acute care services, with little or no attention directed toward parallel improvements in LTSS. Early in 2012, for example, the center selected 73 innovation advisors to help refine, apply, and sustain the technical skills necessary to drive system reform for the benefit of Medicare and Medicaid beneficiaries. None of the advisors, however, is affiliated with an institution responsible for furnishing LTSS to people with disabilities.

The outlook is similar when one reviews expenditures on comparative outcome research. Congress set aside \$1.1 billion for comparative clinical effectiveness research in the ARRA of 2009, splitting responsibility for administering these funds among the National Institutes of Health (\$400 million), the Agency for Healthcare Research and Quality (\$300 million), and the secretary of HHS (\$400 million). A year later, as part of the ACA, Congress set up a trust fund to finance comparative effectiveness research and established a nonprofit corporation, called the Person-Centered Outcome Research Institute (PCORI), to administer these funds. The trust fund is to be capitalized through a \$1 to \$2 per member fee paid by public and private health plans.¹²³ These fees, which take effect in plan years after September 30, 2012, are expected to generate approximately \$2.5 billion in research funds through 2019.¹²⁴

The initial draft research agenda released by PCORI on January 23, 2012, identifies five areas where comparative effectiveness research is needed to support decision making, but does not single out specific diseases, treatments, or procedures for study.¹²⁵ There is no indication in PCORI's initial plan that research related to the comparative effectiveness of alternative long-term service intervention strategies is contemplated.

Building a strong, resilient community-based infrastructure to support people with disabilities is an essential part of creating a sustainable health care delivery system. But in the absence of a long-range, national commitment to researching and developing evidence-based service delivery and financing practices in the long-term services arena, it is difficult to envision how such an infrastructure can be created and sustained. Congress implicitly acknowledged this

weak link by including in the ACA a nonbinding Senate resolution urging Congress to “address long-term services and supports in a comprehensive way that guarantees elderly and disabled individuals the care they need.”¹²⁶ Until that promise is fulfilled, federal and state policymakers will face the challenge of instituting systemwide reforms without an adequate research foundation or sound methods of developing, testing, and evaluating the efficacy of new, potentially more effective strategies for financing and delivering LTSS.

Principle #15. Maintenance of Effort and Reinvesting Savings

CMS should rigorously enforce the ACA “maintenance of effort” provisions in granting health and long-term service reform waivers. Agency officials also should mandate that any savings achieved through reduced reliance on high-cost institutional care, reductions in unnecessary hospital admissions, and improved coordination and delivery of services be used to extend services and supports to unserved and underserved people with disabilities.

Under the ARRA provisions, Congress conditioned the receipt of temporary increases in the federal share of Medicaid spending on a state’s agreement to maintain existing Title XIX eligibility levels through December 31, 2010. This maintenance of effort (MOE) requirement remained in place after the enhanced Medicaid matching ratios were extended for an additional year in 2010. Meanwhile, Congress, as part of the ACA, had decided to retain the ARRA MOE requirement until states established fully operational health insurance exchanges.¹²⁷

States should not be permitted to use health reform waiver/demonstration programs to circumvent the statutory requirement (Section 2001(b) of the ACA) that they maintain Medicaid “eligibility standards, methodologies, and procedures” for adult beneficiaries through 2014 and for childhood beneficiaries through 2019. Congress should resist pressures to repeal the existing MOE requirement.¹²⁸ Current Medicaid law affords states a number of alternative ways of trimming program expenditures other than reducing program eligibility, including slicing provider payment rates and restricting optional state plan coverage. Indeed, during the recession, many states exercised these and other cost-containment strategies to

hold down Medicaid spending in the face of tumbling revenue projections. There are better alternatives than dropping low-income beneficiaries from the Medicaid rolls.

Excess Service Demand and Waiting List

One approach being used by a growing number of states to improve the overall cost-effectiveness of Medicaid service delivery is to employ managed care techniques. As efficiencies are achieved, the resulting savings should be used to fill gaps in the Medicaid safety net. For example, hundreds of thousands of people with disabilities lack access to the high-quality health care and long-term supports they need, as evidenced by the long waiting lists for services in many jurisdictions. In 2009, 39 states reported that a total of 365,553 people were waiting to be enrolled in Medicaid HCB waiver services. Waiver programs targeted to people with I/DD had the longest waiting lists, totaling 221,898, followed by programs serving senior citizens and nonelderly adults with physical disabilities (107,563).¹²⁹ One research group concluded that states would have to increase service capacity by an average of 25 percent to meet current demand for I/DD waiver services.¹³⁰

These figures significantly understate the demand for LTSS, since eligibility for HCBS waiver services is limited to people who meet Medicaid financial eligibility and institutional need criteria. Moreover, HCBS waiver waiting list data mask the large gap in unmet demands for public mental health services because such a small number of nonelderly adults qualify for HCB waiver services due to the so-called IMD exclusion.¹³¹ Testimony before a Texas legislative panel suggests the magnitude of the gap. An official of the Mental Health and Substance Abuse Division of the state Department of Health Services told Texas lawmakers that the number of people on waiting lists for mental health treatment increased by 642 percent between 2004 and 2010 and now exceeds 10,000 people statewide.¹³²

It is imperative, therefore, that savings achieved through improved delivery of services and supports be redirected to assisting people who currently are denied access to essential health care and long-term supports. These efforts should be combined with other strategies, such as service delivery innovations and improved outreach and enrollment efforts, as part of a broader plan to close the service access gap.

Principle #16. Coordination of Services and Supports

Within a well-balanced service system, the delivery of primary and specialty health services must be effectively coordinated with any LTSS that an individual might require.

The most appropriate organizational arrangement for coordinating health care and long-term supports will vary according to the needs of the individual as well as the population being served. Managed care enrollees with complex chronic health conditions should be assigned a health care coordinator with specialized knowledge and experience in assisting people with disabilities. The designation of a health care coordinator, however, does not preclude the need for a knowledgeable individual to assist in planning and monitoring a beneficiary's long-term, community-based services and supports. Where health services and long-term supports are administered by a single MCO, enrollees receiving LTSS should be assigned an independent LTSS coordinator.

Medical oversight of the treatment process is essential when the need for ongoing social or other supports is a direct consequence of untreated or ineffectively managed chronic health conditions, as often is the case for many older and chronically ill people. By contrast, the most pressing needs among the vast majority of younger people with physical, developmental, behavioral, and sensory disabilities is for assistance in establishing and maintaining a productive, rewarding life in the community, and gaining access to the services and supports that will enable them to stay healthy and engaged. The composition of MCO care teams should reflect these differences in enrollee need profiles.

In recent years, various effective strategies have been developed to coordinate and integrate the delivery of physical and behavioral health services, including the colocation of acute health care and behavioral health services; the use of enhanced health homes; the integrated use of health IT (see also the discussion under Principle #12); disease management models; and unified primary care and behavioral health models.¹³³ These efforts are fueled by studies indicating that on average, recipients of public mental health services die 25 years earlier than other Americans.¹³⁴

Case management has played a key role in the provision of Medicaid-funded HCBS since the program first began financing such services in the 1970s. In recent years, however, the functions performed by case managers have diversified as LTSS options expanded and the concept of self-directed services gained popularity. These changes are reflected in the proliferation of terms used to describe traditional and new activities falling under the general “case management” rubric—care manager, counselor, options counselor, caseworker, care coordinator, support coordinator, systems navigator, and community living specialist. The growing emphasis on self-direction within LTSS systems also has led to the introduction of new terms to describe a constellation of supports to people who choose to self-direct their services and supports—consultant, advisor, monitor, decision assistant, support team member, circle of support member, care guide, community guide, support broker, and resource manager.¹³⁵

In addition, some states have chosen to assign case managers specialized roles. The decision to do so often is influenced by the type and level of reimbursement associated with a particular initiative. For example, some states claim Medicaid reimbursement for “transitional case management (or service/support coordination) services” in conjunction with their Money-Follows-the-Person demonstration program or State Balancing Incentive Program (SBIP). In such instances, the state’s aim is to ensure that people slated to move from a long-term care institution to a community setting receive more intensive guidance and support during the critical months preceding and following community placement. New Jersey, for example, covers “transitional case management services” under its Global Options waiver program for seniors and adults with disabilities.¹³⁶ A similar function also is built into the state’s Community Care waiver program for people with developmental disabilities to assist in transitioning residents of state-run developmental centers to the community as part of New Jersey’s *Olmstead* initiative.

One of the key issues that must be resolved when a state chooses to cover LTSS as part of its managed care program is the methods to be used to ensure the provision of an appropriate, person-centered array of services and supports when care coordinators are employed by the MCO. Because care coordinators typically are employed by an MCO, which in turn receives fixed capitated service payments from the state, there are built-in incentives

to limit the range and intensity of services made available to plan enrollees. A 2009 report by the CMS Workgroup on Managed HCBS pointed out that a state can minimize incentives to underserved enrollees through carefully crafted contract language requiring MCOs to report detailed quality data for use in pinpointing and rectifying such problems.¹³⁷

The ACA language authorizing the SBIP, however, mandates “conflict-free case management services” in states that choose to implement this new Medicaid authority.¹³⁸ It also requires states to use a standardized assessment instrument and institute a No Wrong Door/Single Entry Point intake system. In its announcement concerning the availability of the SBIP, CMS pointed out that—

The design of services, rate establishment, payment methodologies, and methods of administration...may all contribute to potential conflicts of interest. These contributing factors can include obvious conflicts such as incentives for either over- or under-utilization of services; subtle problems such as interest in retaining the individual as a client rather than promoting independence; or issues focused on the convenience of the agent or service provider rather than being person-centered.¹³⁹

“To mitigate any explicit or implicit conflicts of interest,” CMS states, “the independent agent [case manager] should not be influenced by variations in available funding, either locally or from the State.” Although not explicitly reflected in current policy, it seems likely that the concept of conflict-free case management services will migrate to other Medicaid HCBS funding authorities in the near future.

As pointed out in Massachusetts’ dual eligibles demonstration project application, “community services are critical supports that enable people [with disabilities] to live independently and remain in their homes and communities.”¹⁴⁰ Addressing the need for an independent LTSS coordinator, the proposal goes on to state—

It is essential that the care team has a designated resource with expertise in understanding the different kinds of LTSS needs and the resources available in the community to address them. Each care team will have access to an independent, qualified LTSS Coordinator from a community-based organization (CBO) such as an Independent Living Center (ILC), a Recovery

Learning Community (RLC), an Aging Services Access Point (ASAP), [a] Deaf and Hard of Hearing Independent Living Services program, an Arc, or other key organizations expert in working with people with disabilities. ICOs [Massachusetts' equivalent to an MCO] will contract with these CBOs to provide staff specifically trained to serve as independent LTSS Coordinators.¹⁴¹

The assessment process should fully engage the enrollee and explore various factors bearing on the individual's needs for both health care and LTSS, including the person's living situation and vocational goals. Steeped in the culture of health care, MCO staff and network health providers may lack the cultural competency to provide person-centered care to people with complex behavioral, physical, sensory, intellectual, and developmental disabilities. That is why it is so important that a qualified, independent long-term services coordinator be involved in the assessment and service coordination process for people with disabilities.

Managed Care Operating Components

Certain components of Medicaid-funded services are especially important to beneficiaries with disabilities, including the availability of assistive technology and durable medical equipment, as well as the design and operation of a quality management system.

Principle #17. Assistive Technology and Durable Medical Equipment

Participants in managed care plans must have access to the durable medical equipment and assistive technology they need to function independently and live in the least restrictive setting.

A state's managed care plan must afford people with disabilities access to the durable medical equipment (DME) and assistive technology that they require to live the most independent, inclusive, and healthy lives feasible in their community of choice. Covered services must include professional assessments of a beneficiary's need for such equipment as well as setup, maintenance, and user training.

DME, including such items as wheelchairs, walkers, oxygen tanks, and related supplies, is a covered part of the Medicaid home health benefit (42 CFR 440.70(b)(3)) and also may be provided as part of other Medicaid-covered benefits, such as rehabilitative services (42 CFR 440.130(d)). Unlike Medicare, state Medicaid agencies are required by federal regulations to provide all medically necessary, nonexperimental DME and may not categorically exclude items without first individually assessing whether the item has a medical purpose.¹⁴² Medicare limits DME coverage to items for use only in the beneficiary's home—a policy that is out of step with the country's independent, community living movement. In contrast, Medicaid is authorized to purchase equipment and supplies necessary to assist recipients to function at home or in the community. Thus, for example, Medicaid is more likely to approve the purchase of heavy-duty wheelchairs that can be used both at home and to navigate around the community.

As payers of last resort (42 CFR 433.139), state Medicaid agencies are obligated to “cost avoid” claims that may be reimbursed by a third party, such as a private health insurance plan or Medicare. As a result, beneficiaries who are eligible for both programs, or have third party insurance coverage, often experience lengthy delays in receiving equipment because Medicaid does not pay until after a written denial of payment has been received from Medicare or the private insurance plan. This is just one of several inconsistencies between Medicare and Medicaid policies that should be reconciled in order to create a seamless, integrated service system for dual eligibles. Other cross-program glitches include the following:

- The tendency to purchase unnecessarily expensive or even inappropriate equipment by relying on self-interested DME suppliers to navigate the complexities of Medicare and Medicaid procurement policies.
- The disruptions in DME supplier networks and purchasing routines that frequently occur when a Medicaid beneficiary becomes dually eligible for Medicare benefits and must shift to new Medicare-approved suppliers.

To address these problems, (a) states should adopt streamlined procedures for co-managing Medicare and Medicaid DME benefits, similar to policies already adopted by

New York and Connecticut; (b) Medicaid beneficiaries newly qualified for Medicare benefits should be granted transition rights that guarantee continued access to all Medicaid-reimbursed goods and services for a reasonable period of time; (c) CMS should revise Medicare coverage criteria to make DME coverage more consistent with the goal of promoting HCB living options; (d) CMS and the states should collaborate in creating straightforward fact sheets explaining coverage criteria for items where overlapping program policies create confusion; and (e) Congress should consider transferring all DME coverage for dual eligibles either to the Medicare program or the Medicaid program, while eliminating the Medicare in-home restrictions.¹⁴³

Principle #18. Quality Management

The state must have in place a comprehensive quality management system that not only ensures the health and safety of vulnerable beneficiaries but also measures the effectiveness of services in assisting people to achieve personal goals.

In designing managed care systems for people with disabilities—especially for people requiring both acute health care services and long-term supports—CMS and the states should build upon improvements in quality managed practices reflected in policies governing Medicaid HCB waiver programs. This approach, developed over the past decade, is based on an ongoing, cyclical process of discovery, remediation, and improvements in seven major focus areas, with a strong emphasis on performance measurement and continuous quality improvement.¹⁴⁴

A state's quality management (QM) system, at a minimum, should address the following:

- **System Capabilities.** A state's QM system must be capable of (a) continuously monitoring the performance of all managed care contractors and subcontractors and ensuring that prompt remedial actions are taken when deficiencies are identified; (b) reporting, tracking, investigating, and analyzing incident patterns and trends in order to pinpoint and promptly remediate threats to the health and safety

of managed care beneficiaries (see discussion below); (c) assessing the quality of services and supports provided on an individualized basis using valid and reliable clinical and quality of life measures, such as morbidity, mortality, health-related incidents and deaths, reduced use of emergency care and high-cost inpatient services, quality of life, and individual and family satisfaction; and (d) preparing and issuing periodic statistical reports on personal outcomes and system performance, analyzing trends, and managing quality improvement initiatives.

- **Person-Centeredness.** Monitoring strategies must be developed to ensure that (a) assessments and plans are person-centered; (b) services are delivered in accordance with the provisions of the plan; (c) services are tailored to achieve outcomes desired by the individual, meet the individual’s needs, and are modified as the individual’s needs change; and (d) people with disabilities are free of abuse, neglect, discrimination, and exploitation.
- **Stakeholder Responsive.** A state’s quality management design should be shaped by the views of service participants and other key stakeholders (family members, program staff, regulators, and funders) if the system is to “balance quality assurance activities with consumer-centered quality improvement.”¹⁴⁵
- **Qualified Personnel.** A state must retain a sufficient number of qualified personnel to carry out the monitoring and enforcement activities spelled out in its QM plan efficiently and effectively.
- **Information Technology.** State-of-the-art information management systems should be employed to assist state officials, MCOs, and individual service providers in monitoring the quality of services and supports provided to managed care beneficiaries.

Incident Management

Massachusetts has created, by statute, an independent state agency that is responsible for investigating alleged incidents of abuse involving adults with disabilities between the ages of

18 and 59. Called the Disabled Persons Protection Commission (DPPC), this agency screens all incident reports involving adults with disabilities, and decides whether to launch its own investigation or refer the case to another state agency for follow-up action under DPPC's supervision. DPPC also is responsible for ensuring that adults with disabilities have access to protective services when they need it. In Massachusetts, the state Department of Children and Families has parallel responsibilities for investigating child abuse cases, while the Department of Elder Affairs performs a similar function for adults 60 years of age or older.¹⁴⁶

In Illinois, the state Department of Children and Family Services (DCFS) is responsible for investigating all cases of alleged child abuse. The investigative team may ask a child welfare nurse specialist to complete a health assessment and a health environmental safety assessment and make recommendations when the incident involves a child with special health care needs. In addition, the agency responsible for operating the state's Medicaid HCB waiver program for medically fragile and technology-dependent children, the Division of Specialized Care for Children (DSCC) at the University of Illinois/Chicago, shares information with DCFS investigators on the unique vulnerabilities of children with special health care needs and coordinates hot line incident reporting and, when deemed necessary, places nurses caring for children with special health care needs on a state-maintained "watch list."¹⁴⁷

Performance and Outcome Measures

In a recent report, the Kaiser Commission on Medicaid and the Uninsured (KCMU) emphasized the need for disability-specific measures of access and quality in order to ensure access to and coordination of the full range of services and supports needed by people with disabilities. "Widely used quality measure sets, such as the Healthcare Effectiveness Data Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS)," the commission noted, "do not take into account, or include targeted measures that reflect, the special needs of people with disabilities. Nor have standard quality measures for LTSS been developed, a problematic gap in the context of efforts to integrate management of LTSS and acute health care."¹⁴⁸

In early 2012, CMS released a set of core quality indicators for adult Medicaid beneficiaries, as mandated under the ACA. In doing so, however, CMS acknowledged the absence of measures related to chronic care management and coordination as well as HCB services and supports, indicating that existing measures in these areas do not meet scientific soundness criteria. CMS promised to assign priority to the development of such measures,¹⁴⁹ a step that will require a major reorientation in the agency's current activities and funding patterns.

The need for more and better measurement tools was reinforced in the recent report of the Quality Measurement Workgroup of the Long Term Quality Alliance. The authors of the report noted that "further development of measures is necessary to assess aspects that contribute to quality for individuals and their families that are broader than clinical outcomes, including the measurement of outcomes such as quality of life, autonomy, relationships, compassion, social supports, and emotional well-being."¹⁵⁰

Creating such measures will not be a simple undertaking, given the diversity of needs among people with severe, chronic illnesses and disabilities (see discussion under Principle #6). The types of measures used to monitor pressure sores and falls and fractures among people with severe physical disabilities will be different from those used to assess the recovery rate of young adults with schizophrenia or the social adjustment of middle-aged people with profound intellectual disabilities. Clearly, as the authors of the recent KCMU report noted, access and quality measures need to be tailored to outcomes of greatest importance to people with specific medical conditions or types of disability. And, until a national consensus is forged around the measures to be used to monitor health and long-term service outcomes for defined groups of people with disabilities, assessing the quality and appropriateness of services will remain a major challenge for all system stakeholders.

Beneficiary Rights and Protections

A beneficiary-centered managed care plan can provide a pathway to improved health care, lower hospital admissions, more cost-effective use of available resources, and, for people with disabilities, a reduced reliance on long-term care institutions and other

24-hour congregate care settings.¹⁵¹ But when cost savings and administrative efficiencies are the primary goal, managed care can erect new barriers to care and offer perverse financial incentives that limit the care and support options available to high-need, vulnerable beneficiaries. It is critical, therefore, that a state's managed care plan include strong beneficiary protections and that these protections be rigorously enforced.

Principle #19. Civil Rights Compliance

All health care services and supports must be furnished in ADA-compliant facilities and programs.

Managed care enrollees with disabilities must have ready access to all services and sites where Medicaid services are provided. Such services and sites must fully comply with the requirements of the ADA and the Rehabilitation Act, including physical, cognitive, and sensory accessibility standards. Physical accessibility includes features such as accessible entry doors; accessible parking and pathways to the building; clear floor space and turning space in exam and activity rooms; positioning and transferring space in exam and activity rooms; accessible exam tables; patient lifts; staff assistance with transfers; accessible medical equipment; and health IT. In addition, all vehicles used to convey beneficiaries to and from service sites must meet ADA transportation accessibility standards.

Wide accessibility gaps were found in a recent survey of primary health care facilities serving Medicaid beneficiaries in California. Mudrick and colleagues discovered that only 3.6 percent of the 2,389 primary provider facilities visited by the survey team had accessible weight scales and only 8.4 percent had adjustable examination tables. High rates of barriers were also found in bathrooms and examination rooms. Parking, exterior access, building access, and interior public spaces generally met access criteria, except for van-accessible parking.¹⁵²

MCO policies and procedures must promote ADA-compliant program accessibility, including modifications in program design features intended to accommodate populations with particular disabilities. Such modifications should include accessible equipment, information provided in alternative formats, appropriately trained personnel,

and operational policies, recognizing that additional time may be required to interact with people with severe physical, behavioral, and intellectual disabilities.

Services must be physically accessible and culturally and linguistically appropriate. Medicaid beneficiaries have a right to receive services, plus notices of eligibility and service denials, in a manner appropriate to their race, ethnicity, language, sex, disability status, sexual orientation, and gender identity, whether such services (and eligibility/service notices) are provided directly or through a contractor. Managed care contractors also must be held accountable for gathering necessary data on the race, ethnicity, and language of plan enrollees.

In accordance with the provisions of Title VI of the Civil Rights Act and other federal and state laws, Medicaid MCOs should be required to prepare a language access plan spelling out requirements for their internal operations as well as for provider network agencies and practitioners. The plan should include provisions governing (a) specific training and certification requirements for interpreters, (b) the availability of “I speak” cards in provider offices, (c) training for providers in language access procedures and cultural competency, (d) procedures to ensure that callers on customer service lines with limited English proficiency receive interpreter services, and (f) identification of documents and correspondence that are subject to translation requirements.¹⁵³

MCOs also must develop and maintain systems for communicating with people who are—

- **Deaf or hard of hearing.** These systems may include the use of qualified interpreters, note takers, communications Access Real Time transcription services, written materials, telephone handset amplifiers, assistive listening systems, telephones compatible with hearing aids, closed caption decoders, open and closed captioning, Text Telephone (TTY), video displays, and exchange of notes.
- **Blind or visually impaired.** MCOs and network providers should be required to comply with the ADA accessible route requirements, including Braille and raised character signage. Providers should also use one or more of the following systems to make information accessible: electronic documents; qualified readers;

taped texts; audio recordings; Braille materials; large print materials; and assistance in locating items. Systems to communicate with people with speech impediments also should be available, including TTY, computer terminals, speech synthesizers, and communication boards.

Principle #20. Continuity of Care

Enrollees should be permitted to retain existing physicians, other health practitioners, personal care workers, and support agencies that are willing to adhere to plan rules and payment schedules.

Continuity of health care and personal support arrangements are important, as is the sanctity of the relationships underlying such arrangements. Consequently, plan participants should be afforded opportunities to retain existing health practitioners and support personnel whenever possible; switch health practitioners, support staff, and health care coordinators when they are dissatisfied; and change managed care plans at periodic intervals. Beneficiaries should also be allowed to select a new primary care physician (PCP) at any time they are dissatisfied with their current physician and to have a medical specialist serve as their PCP when circumstances warrant.

Voluntary or Mandatory Enrollment

One of the key decisions a state must make in designing a comprehensive, risk-based managed care plan is whether to make plan enrollment voluntary or mandatory. Beneficiaries are offered more choices if enrollment is voluntary, but if too few people enroll then a managed health plan may be unable to spread the financial risks of high-cost health events and systemwide administrative costs across enough enrollees to sustain its operations. Some states have attempted to address this problem by (a) carving selected populations out of the plan or allowing them to enroll on a voluntary basis; (b) creating specialty health plans with provider networks capable of serving selected groups of high-need beneficiaries who cannot be effectively served through a general-purpose managed care plan; (c) mandating enrollment while allowing participants to opt out of a selected plan (or be auto-assigned to a plan) during an initial period (e.g., up to 90 days following initial

enrollment) and at established intervals thereafter; (c) phasing in enrollments over an extended period to ensure a more orderly enrollment process; or (d) some combination of the preceding approaches. Various aspects of the enrollment and plan selection process are governed by federal managed care rules. For example, states electing to mandatorily enroll beneficiaries in comprehensive, risk-based plans are required to offer beneficiaries a choice between two or more competing health plans, except in rural areas where the Medicaid agency has received a federal waiver of this requirement (42 CFR 438.52).

Another factor that states must take into account in designing their enrollment policies is continuity of services as people transition from FFS providers to managed care plans. States are required under federal managed care rules to try to preserve existing provider/enrollee relationships by attempting to enroll existing FFS providers in their provider networks (42 CFR 438.50). Often states attempt to facilitate the transition by requiring plans to reimburse FFS providers during a defined period or until a designated course of treatment is completed. Such provisions offer the managed care plan time to enroll these providers in its network or identify and enroll other qualified providers. Regardless of the strategies a state chooses, experience shows that ensuring continuity of care is a vital ingredient in successfully transitioning people with disabilities to at-risk, capitated managed care plans.

Principle #21. Due Process

Enrollees with disabilities should be fully informed of their rights and obligations under the plan as well as the steps necessary to access needed services, in accordance with the provision of Section 1932(b)(5) of the Social Security Act and 42 CFR 438.207.

States should develop and implement an aggressive education and outreach strategy to ensure that all managed care plan enrollees (and potential enrollees) have accessible information concerning the services and supports available under the plan and how they may be accessed. The state's strategy should include enlisting community-based disability organizations in developing and implementing the outreach plan. Accessible multimedia educational materials and training sessions should be geared to the various learning styles

and comprehension levels of plan enrollees, and such sessions should be held across the state. Plan participants must receive accessible, meaningful, and clear notices about programs, services, and their rights, including enrollment rights and options, plan benefits and rules, coverage denials, appeal rights and options, and potential conflicts that may arise from relationships among providers, suppliers, and others.

In the absence of meaningful notifications, important protections such as service and provider choices and appeals and grievance rights are far less effective. To be meaningful, a notice must be written at the comprehension level of the typical plan enrollee. The requirements for Minnesota's Senior Health Options and Senior Care Plus programs, for example, specify that all notices must be understandable to a person who reads at a seventh-grade level. Clear written materials are particularly important in a coordinated care environment or where a close financial relationship exists between the provider of service and the entity responsible for paying for the services. In such situations, the provider may recommend care and support strategies based on the likelihood of coverage or the financial benefits it may derive instead of describing all of the options available to the enrollee. Procedures should be in place to ensure that enrollees are informed of all available service options so they can ask their care/support team to explore a particular option. Opportunities to seek second opinions or appeal service decisions also should be available to enrollees.¹⁵⁴

Principle #22. Grievances and Appeals

Grievance and appeal procedures should be established that take into account physical, intellectual, behavioral, and sensory barriers to safeguarding individual rights under the provisions of the managed care plan, as well as all applicable federal and state statutes.

The plan should include procedures for ensuring the timely resolution of enrollee complaints and mechanisms to prevent people from being placed in jeopardy while disputes are being resolved. Appeals should comply with all existing Medicaid requirements, except in the case of plans serving dual-eligible beneficiaries, when Medicare provisions afford stronger protections to enrollees than Medicaid rules.

Given the nearly 60 million people who rely on Medicaid for health care and long-term supports and the constant fiscal pressures to hold down costs, mistakes and unjustified service denials are inevitable. Consequently, resolving such situations “fairly and expeditiously is critical to the Medicaid program’s ability to achieve its coverage goals.”¹⁵⁵ Medicaid applicants and beneficiaries are entitled to adequate notice of state agency actions and a meaningful opportunity to have unfavorable administrative decisions reviewed with reasonable promptness.

Medicaid applicants and recipients have a right to request a “fair hearing” on eligibility determinations and coverage issues. The same notice and hearing rights apply to disputes concerning whether an applicant is eligible for Medicaid services or an enrollee has a medical need for a particular Medicaid service, regardless of whether benefits are administered on an FFS basis or through an MCO. The fair hearing process must be accessible to applicants/enrollees with limited English proficiency and people with physical, intellectual, behavioral, and sensory disabilities. The Federal Government reimburses states for 50 percent of the costs of holding fair hearings. Appeal costs, however, are borne by the applicant, the beneficiary, or his/her advocates. All fair hearing decisions must be presented in writing, and applicants/beneficiaries must be notified of their right to file a judicial appeal in state court.

In addition to the fair hearing process, Medicaid MCOs are required to establish a grievance process and an internal appeals process for enrollees who wish to challenge denials of service and payment for medical assistance services. Because payments are capitated and often participants are mandatorily enrolled, MCOs have built-in economic incentives to underserve enrollees. For this reason, a fair and effective appeals mechanism is especially important in a capitated managed care environment.

An MCO is afforded flexibility in designing its internal appeals process as long as enrollees are given a reasonable opportunity to present evidence, allegations, and legal arguments in person as well as in writing. During the appeals process, federal regulations extend certain rights to enrollees governing timing, the content of required notices, and the time frames within which MCOs must resolve appeals. MCOs also are required under federal rules to maintain an expedited appeals review process.

Furthermore, for appeals that are not resolved wholly in the enrollee's favor, the MCO's written notice of the appeal resolution must advise the enrollee of his/her right to request a state fair hearing. It is up to the state to determine whether enrollees are required to exhaust their internal avenues of appeal before requesting a state fair hearing. The standards for acting on state fair hearing requests are spelled out in federal regulations.

Enrollee appeal rights should encompass the following transactions:

- Enrollment in an MCO.
- Assignment to a particular service provider, services/support coordinator, or care team.
- Decisions regarding the provision of a particular service(s).
- The inclusion, or absence, of specified provisions in a plan of care.
- Requesting a second opinion or evaluation regarding eligibility for a service (to support an appeal).
- The denial of coverage of a service.
- Filing a grievance or complaint about the MCO or any of its contractual providers.

The following safeguards should be built into the design of the appeals process: due process protections; clear notices in a language the enrollee understands; coverage of care pending resolution of the appeal; opportunities for expedited review; an established pathway to a review by an independent decision maker; and the right to appeal to an administrative law judge and, if necessary, a federal court. Regardless of the procedures governing the filing and prosecuting of appeals, the first step should be a meaningful notice informing the plan enrollee that he/she has been denied a service and providing the enrollee with sufficient information to form the basis of an appeal.¹⁵⁶

CHAPTER 4. **Recommendations to Federal and State Policymakers**

Introduction

Chapter 3 articulated a set of principles to guide the organization and delivery of services to people with disabilities who are enrolled in Medicaid managed health care and long-term support plans. Drawing upon those principles, this chapter contains advice to federal and state policymakers to ensure that people with disabilities gain access to the full array of health care and long-term supports they need while enrolled in a Medicaid managed care program. The advice to federal policymakers is directed to both members of Congress and executive branch officials, primarily HHS officials. The advice to state policymakers is directed to state legislators, governors, budget officials, state Medicaid officials, and officials of other state agencies responsible for overseeing the delivery of Medicaid-funded services to people with disabilities.

Recommendations to Federal Policymakers

Reviewing State Managed Care Requests

ISSUE #1

Given the growing interest in applying managed care principles to the organization and delivery of LTSS, CMS should develop a separate protocol for reviewing managed LTSS waiver/demonstration requests.

RECOMMENDATION #1: CMS should prepare and disseminate a written protocol outlining the criteria it intends to use in reviewing state demonstration/waiver requests to operate LTSS under a managed care format. This protocol should take into account the 22 principles set forth in chapter 3 of

this report and be used for proposals under all waiver authorities, including stand-alone LTSS requests, as well as requests to integrate the management of health care and LTSS for Medicaid-only recipients and dual-eligible beneficiaries.

The states, collectively, have had limited experience in administering Medicaid managed LTSS. All interested parties have a right to know in advance the criteria CMS officials will use in deciding whether to approve such requests. The proposed protocol will contribute to the transparency of the review and approval process by setting forth CMS's expectations in advance.

ISSUE #2

At present, responsibility for reviewing state managed care proposals involving the provision of LTSS rests almost exclusively with CMS. As a result, HHS does not take full advantage of the disability expertise that exists in other departmental units.

RECOMMENDATION #2: In reviewing state waiver/demonstration requests involving the provision of LTSS, CMS should enlist the assistance of disability experts from other components of HHS.

Several major HHS units are responsible for serving people with disabilities, including the recently established Administration on Community Living (ACL), which has extensive staff expertise in serving frail seniors and people with physical and developmental disabilities; the Substance Abuse and Mental Health Services Administration, the focal point for services to people with chronic mental illnesses and substance abusers; and the Health Resources & Services Administration, which has staff with extensive expertise in serving children with chronic illnesses and disabilities. Better decisions are likely to result from marshaling the full resources of HHS in reviewing state waiver/demonstration applications involving the provision of LTSS to selected populations of Medicaid beneficiaries with disabilities.

ISSUE #3

A number of states have elected to exclude institutional services from their Medicaid LTSS proposals, thus offering MCOs weak incentives to develop HCB alternatives to institutional care.

RECOMMENDATION #3: CMS should require states that are planning to deliver LTSS through managed care contracts to include in their LTSS coverage for both institutional and HCB services. This requirement should be built into the “terms and conditions” governing the operation of the state’s approved waiver/demonstration program.

The inclusion of institutional services makes sense on two levels. First, the co-management of institutional and HCB services makes it easier to transition beneficiaries and dollars from nursing facilities, ICFs/MR, and IMD to community-based service settings. Second, experience demonstrates that states usually achieve aggregate savings when people are shifted from institutions to home and community settings. Thus, two primary objectives of managed care are achieved—improving systemwide cost-effectiveness and honoring core disability values, as summarized in the first four principles in chapter 3. When institutional services are carved out of the LTSS array, MCOs and their subcontractors have little incentive to deflect people—especially people with extensive service needs—from institutional placements or to assist in transitioning current institutional residents to the community.

ISSUE #4

Waiting lists for HCBS are growing in many states as a result of continued, recession-induced budget pressures. Therefore, it is important that CMS strictly enforce the MOE clause in existing Medicaid law and insist that savings achieved through program efficiencies be used to expand access to HCB supports.

RECOMMENDATION #4: CMS should enforce the “maintenance of effort” requirement contained in Section 2001(b) of the Patient Protection and Affordable Care Act and require states to reinvest savings achieved by lowering institutional

admission rates and returning NF, ICF/MR, and IMD residents to the community in expanding access to, and the quality of, HCB supports.

With hundreds of thousands of Medicaid beneficiaries on waiting lists for HCB services, it would be unconscionable to divert savings to filling gaps in state budgets or increasing MCO profit margins. Decisions regarding the most effective strategies for redeploying savings should be left to the states in collaboration with their managed care contractors and disability stakeholders (see discussion under Principle #15 in chapter 3).

ISSUE #5

At present, CMS lacks the staff capacity to review, approve, and oversee implementation of the growing number of state managed care waiver/demonstration programs.

RECOMMENDATION #5: CMS should be allotted the personnel required to review, approve, and oversee implementation of state managed care waiver/demonstration programs and carry out its other, related statutory responsibilities.

The ACA assigns to CMS broad new responsibilities for administering multiple initiatives to reform the U.S. health care system. Yet these new responsibilities have not been accompanied by an influx of additional personnel. In fact, the agency has about the same number of employees today (4,900) as it had during the Carter Administration in the late 1970s.¹⁵⁷ The staff qualifications required to administer programs falling under the agency's jurisdiction today are far more complex and varied than they were three decades ago. The recent wave of state Medicaid managed care proposals illustrates the challenges facing CMS officials. Not only do officials have to possess the technical skills to analyze complex, multifaceted state proposals, but they need a sufficient number of qualified personnel to monitor state performance against established quality benchmarks. At present, CMS lacks the resources to perform these essential functions, especially ongoing monitoring of state performance.

ISSUE #6

An appropriately designed managed care plan can serve as a comprehensive platform for aligning service delivery policies and practices with a state’s broad disability policy goals, thereby improving the quality and cost-effectiveness of services. However, managed care will not rectify basic flaws in federal statutes governing the federal-state Medicaid program.

RECOMMENDATION #6: Congress should restructure Medicaid laws governing LTSS to eliminate the bias toward institutional services and emphasize instead person-centered community supports designed to promote the inclusion of beneficiaries with disabilities in the mainstream of American society.

The principal aim of the ACA is to reform the nation’s dysfunctional health care delivery system. The act also includes a variety of incremental changes in long-term services policies, with the common aim of improving access to HCB services and supports. But the basic statutory approach to LTSS is not addressed in the 2010 law—a fact that Congress acknowledged by including in the legislation a nonbinding “sense of the Senate” commitment to “address long-term services and supports in a comprehensive way” during the 111th Congress (Sec. 2406, P. L. 111-148). As the 112th Congress winds down, however, this promise remains unfulfilled.

For years, Medicaid policy experts have argued for a top-to-bottom recodification of existing statutes in order to rationalize the program’s multiple social roles and bring statutory provisions into alignment with contemporary goals for the program’s multiple constituencies. In the area of disability policy, the focus should be shifted to home and community-centered approaches to delivering publicly financed supports, while affording beneficiaries enhanced opportunities for independence, social integration, and self-direction. The expanded use of managed care delivery systems, fundamentally framed around the delivery of acute health services, makes the need for comprehensive statutory reforms even more imperative. Among the principal aims of such legislation should be to accommodate the widely ranging support needs among people with disabilities and place LTSS on an equal footing with health care services.

Enhancing the Quality and Accessibility of Long-Term Services and Supports

ISSUE #7

The ACA recognizes the critical role advanced information management systems can and must play in operating a modern health care delivery system. But thus far, little attention has been directed toward improving information management systems within the LTSS arena.

RECOMMENDATION #7: The Federal Government should direct more time and resources to improving the information management capabilities of state/local LTSS systems for people with disabilities.

Through the leadership of HHS, major strides have been made in establishing EMR systems that allow multiple providers of health care services (hospitals, primary and specialty physicians, and other health care practitioners) to gain instantaneous access to a patient's records, thus enabling them to coordinate the delivery of person-centered care more effectively and efficiently (see discussion under Principle #12). But to date, federal IT funding initiatives have been focused almost exclusively on acute health care information systems. Few resources have been devoted to improving MISs in the long-term services arena. This situation will have to change if states are to deliver LTSS through managed care entities.

Ready access to information and data is an essential tool in a managed care system. As is the case in the health care sector, HHS should provide (a) advice and assistance to states in mapping out the system design features of an MIS for LTSS that is compatible with (or a component of) the MIS applicable to acute health care plans in which beneficiaries are enrolled; and (b) financial incentives to public and private providers of LTSS to purchase the hardware and software necessary to participate in the new or redesigned statewide MIS. All such systems should be capable of performing the functions discussed under Recommendation #19.

ISSUE #8

The lack of well-documented, evidence-based practices is a major barrier to improving the quality and cost-effectiveness of Medicaid-funded LTSS. Yet thus far, the vast majority of federal comparative effectiveness research grants have been directed toward improving the delivery of primary and specialty health services, not LTSS.

RECOMMENDATION #8: HHS should designate LTSS as a priority area for comparative effectiveness research.

The need for comparative effectiveness research in the LTSS sector is at least as great, if not greater, than it is in the preventive, primary, and acute health care sectors. Yet none of the five priority areas established by the Person-Centered Outcome Research Institute in its initial research agenda issued in January 2012 focuses on the comparative effectiveness of LTSS. The Institute, a quasi-governmental agency established under the provisions of Section 6301 of the ACA, is expected to expend \$2.5 billion on comparative effectiveness research through 2019, and it seems reasonable to expect that a portion of these funds will be used to uncover more effective ways of delivering HCB services to people with long-term support needs.

ISSUE #9

Medicare and Medicaid statutes governing the purchase of DME are poorly aligned, and as a result, dually eligible beneficiaries often do not receive the equipment they need to function as fully participating members of society.

RECOMMENDATION #9: Congress should eliminate inconsistencies between Medicare and Medicaid statutes governing DME, possibly by assigning sole responsibility for purchasing such equipment to one program.

Until Congress enacts such legislation, CMS and the states should collaborate by (a) adopting streamlined procedures for co-managing Medicare and Medicaid DME benefits; (b) granting Medicaid recipients newly qualified for Medicare benefits transition rights that guarantee continued access to all Medicaid-reimbursed goods and services

for a reasonable period; and (c) creating straightforward fact sheets explaining coverage criteria for items where overlapping program policies create confusion.

Improving Outcomes for People with Disabilities

ISSUE #10

As pointed out in the Federal Government’s Healthy People 2020 plan, people with disabilities have substandard access to health and wellness services compared with nondisabled Americans.

RECOMMENDATION #10: CMS should encourage states that intend to enroll people with disabilities in Medicaid managed care plans to develop explicit strategies for eliminating existing disparities in access to health services between people with and without disabilities and promote wellness initiatives targeted to people with disabilities.

The HHS Office of Disease Prevention and Health Promotion has indicated that, compared with nondisabled persons, people with disabilities are more likely to—¹⁵⁸

- Experience difficulties and delays in getting the health care they need.
- Not have had an annual dental visit.
- Not have had a mammogram in the past two years.
- Not have had a Pap test in the past three years.
- Not engage in fitness activities.
- Use tobacco.
- Be overweight or obese.
- Have high blood pressure.
- Experience symptoms of psychological distress.

- Receive less social-emotional support.
- Have lower employment rates.

As states transition Medicaid beneficiaries with disabilities to managed care plans, there will be opportunities to address the disparities in access to, and the quality of, health and wellness services. Working with other HHS units, CMS should spearhead efforts to (a) formulate and disseminate clinical guidelines and best practice protocols related to health promotion, disease prevention, and treatment among discrete portions of the population with disabilities (e.g., children and adults with physical disabilities, mental disabilities, and intellectual and developmental disabilities or traumatic brain injuries); (b) work with the HHS Office of Minority Health to gain recognition of discrete subgroups of people with disabilities as “medically underserved populations,” with all of the benefits attendant to this designation; and (c) recognize adult developmental medicine as a discrete area of medical knowledge, expertise, and training in medical schools and other health care settings.

ISSUE #11

One aim of the ACA is to foster the development of improved health outcome measures for use in assessing the quality and appropriateness of care. Outcome measures specific to the health and long-term support needs of people with disabilities, however, have received little attention thus far.

RECOMMENDATION #11: The HHS Administration on Community Living, in collaboration with CMS, the Agency for Healthcare Research and Quality (AHRQ), the Long-Term Quality Alliance, and leaders of the aging and disability communities, should spearhead efforts to develop disability-specific outcomes standards to measure access to, and the quality of, health care and long-term supports for people with disabilities.

As pointed out in the discussion under Principle #18 in chapter 3, to date the Federal Government has devoted little attention to developing and field testing outcome measures normed on various subpopulations of people with disabilities (e.g., people with physical

disabilities, psychiatric disabilities, intellectual and developmental disabilities, and traumatic brain injuries). This gap is particularly wide in the area of standardized measures of quality of life, autonomy, relationships, social supports, and emotional well-being. Until this gap is closed, efforts to assess the quality and cost-effectiveness of LTSS for people with disabilities will be severely hampered. And there is little likelihood that such measures will be developed and widely adopted without strong backing and financial support from the Federal Government.

Recommendations to State Policymakers

Forging a Global, Beneficiary-Centered Managed Care Strategy

ISSUE #12

Too often, the chief factor motivating states to enroll people with disabilities in Medicaid managed care plans is a desire to curb the growth in program outlays. Little thought or attention is given to achieving beneficiary-centered outcomes.

RECOMMENDATION #12: Each state planning to enroll people with disabilities in Medicaid managed care plans should prepare a long-range strategic plan to guide the transformation of Medicaid-funded health care and LTSS for low-income people with disabilities. A state's strategic plan should be built around a core set of disability values, and those values—*independence, community integration, productivity, and personal choice and control*—should be reflected in the day-to-day service delivery policies and practices adopted by the state, as well as by all managed care and related contractors the state retains to administer the service system.

The principal aim of this strategic planning document should be to lay out the steps the state intends to take over a multiyear period to improve the quality and cost-effectiveness of health care and LTSS for eligible beneficiaries with disabilities within the framework of the principles articulated in chapter 3 of this report. Some states are in a much better position than others to restructure the delivery of health and LTSS along

managed care lines, but the reform process will take years to complete, even in states with extensive experience in operating Medicaid services under risk-based managed care contracts. In the absence of a global strategy, reforms are likely to proceed in a disjointed manner, thus leading to inequitable access to services and support. For example, health care delivery reforms may be poorly synchronized with changes in the delivery of LTSS. Or, people who are dually eligible for Medicare and Medicaid services may receive a more robust set of benefits—or be served through different health or LTSS plans—than Medicaid-only beneficiaries with similar needs.

ISSUE #13

Disability stakeholders can make important contributions to designing and operating a managed care system. Consequently, their assistance should be sought by responsible state officials in developing and administering a managed care program for people with disabilities.

RECOMMENDATION #13: States should actively enlist the assistance of nongovernmental stakeholders in designing and operating a managed care system targeted to Medicaid-eligible people with disabilities.

As pointed out in chapter 3, state officials can obtain valuable insights into the strengths and weaknesses of existing payment and service delivery policies from beneficiaries and disability service providers. They also can enlist outside stakeholders as valuable allies in hammering out the details of system operating policies and practices so the end product is a service delivery system in which the interests of enrollees with disabilities are the preeminent consideration.

The involvement of disability stakeholders, however, should not end with federal approval of a state's managed care request. Instead, disability stakeholders should be asked to participate in monitoring the implementation process and provide ongoing feedback on system performance and needed plan modifications.

ISSUE #14

Expertise in serving people with disabilities can be found in various agencies of state and local government, as well as in the private sector. Given the complexities of designing and implementing a Medicaid managed care plan, states should seek the assistance of a wide range of experts in disability policy and practice.

RECOMMENDATION #14: Disability policy experts—both within and outside of state government—should be involved in designing and implementing Medicaid managed care plans involving beneficiaries with disabilities, especially when LTSS are covered under the plan.

State mental health, developmental disabilities, and A/D officials should be involved in designing and carrying out a Medicaid managed care plan that includes the delivery of health care and long-term supports to people served by these agencies. These officials have intimate knowledge of the target populations and can offer valuable insights into the barriers that are likely to be encountered in transitioning Medicaid services to such people from an FFS to a capitated payment approach. Furthermore, when the state's managed care plan encompasses the provision of LTSS to beneficiaries with disabilities, these agencies should play key roles in overseeing the delivery of such services and supports.

In addition, state Medicaid agencies should draw upon the knowledge of local providers of disability services and supports (e.g., community mental health centers, independent living centers, area agencies on aging, A/D resource centers, and community I/DD provider and single-point-of-entry agencies). Often, these local agencies have decades of firsthand experience in working with the people they serve and can speak with great authority on factors that need to be taken into account in serving them.

ISSUE #15

States are accelerating the enrollment of people with disabilities in Medicaid managed care plans at a time when many state agencies are experiencing budget-related staff reductions and early retirements. As a result, it is not clear that states will have the personnel resources necessary to effectively oversee the operations of managed care contractors and their subcontractors.

RECOMMENDATION #15: State policymakers should grant the state Medicaid agency the authority and resources necessary to hire and retain an adequate number of qualified personnel to effectively administer its contracts with managed care and/or administrative service organizations in collaboration with relevant disability-specific state agencies.

As pointed out in the discussion under Principle #10 in chapter 3, overseeing the performance of managed care contractors requires a different set of skills than administering an FFS system. State Medicaid agencies need personnel experienced in designing and operating state-of-the-art MISs, developing a sound methodology for calculating PMPM capitation rates, and monitoring the performance of managed care contractors and their subcontractors against a comprehensive set of quality and outcome measures. In the absence of in-house capacity to perform such tasks, the state, in effect, cedes its responsibilities to private contractors, thereby relinquishing its accountability to the public.

ISSUE #16

Medicaid beneficiaries with disabilities have wide-ranging health and long-term support needs, and the current capacity of states to address these needs varies enormously from population group to population group, as well as within various geographic areas of the states. It is vitally important, therefore, that a state carefully assess its readiness to enroll targeted groups in managed care plans, identify any preparatory steps required prior to enrollment, and develop a phase-in schedule that takes such factors into account.

RECOMMENDATION #16: Any state planning to enroll beneficiaries with disabilities in a Medicaid managed care program should complete a readiness assessment to determine the barriers to enrolling various subpopulations of people with disabilities and use the results of this assessment to establish a population-specific phase-in plan.

As discussed under Principle #6 in chapter 3, the needs of various subpopulations of people with disabilities vary widely—as does the state’s capacity to meet the needs of any given subpopulation. People with disabilities frequently have complex health care and support needs, and consequently, extreme care needs to be taken in transitioning their services from an FFS to a capitated payment system. The purpose of the proposed assessment is to pinpoint obstacles to transitioning various subpopulations of Medicaid beneficiaries to a managed health and/or LTSS system. Among the more prominent factors to be taken into account in conducting the assessment are the following:

- The strengths and weaknesses of the state’s HCBS network, specific to each subpopulation with disabilities.
- The availability of valid and reliable instruments to assess the service/support needs of specific subpopulations with disabilities *and* predict the resources required to address those needs.
- The state’s capacity to transition institutional residents to HCBS settings.
- The availability of community housing to meet the varied needs of people with disabilities who are transitioning from institutions to the community or being diverted from institutional placements.
- Plans for ensuring that managed care enrollees receive timely and complete information on obtaining needed services and the rights, privileges, and obligations that accompany participation in the state’s managed care program.

- A comprehensive state quality management strategy capable of assessing quality outcomes and ensuring the accessibility of services and health and welfare safeguards.

The readiness assessment should be carried out in partnership with officials from state disability agencies and other disability stakeholders (see discussion under Principle #7 in chapter 3).

Establishing the Components of an Effective Managed Care Delivery System

ISSUE #17

Among the key aims of a state's managed care plan should be to prevent unnecessary admissions to long-term care institutions and facilitate the transition of people with disabilities from long-term care institutions to HCB settings. To accomplish these objectives, states should offer MCOs incentives to serve people with disabilities in HCBS settings.

RECOMMENDATION #17: States intending to enroll people with substantial disabilities in a risk-based Medicaid managed LTSS program should develop capitated payment methodologies that include incentives for providing such services in HCB settings (see related Recommendation #3 above). The strategies that states should consider include the following:

- Use an all-inclusive capitation rate that factors in the cost of both institutional and HCB service, thus providing MCOs with a strong financial incentive to opt in favor of less expensive and more inclusive HCB services.
- Use partially capitated rates for institutional care in situations where state officials conclude that MCOs are financially unable to bear the full risk of institutional placements.

- Establish special add-on payments to the base capitation rate when people with intensive support needs are served in HCB settings.
- Enter into a shared savings arrangement with at-risk MCOs whereby plans that exceed state-established, plan-specific target ratios of people served in HCBS settings vs. institutions are rewarded with extra payments and plans that underperform have their payments reduced through a reconciliation process.

States also should incorporate into their LTSS plans services designed to deflect unnecessary or premature institutional placements. A state's services network should include providers of crisis stabilization services, with interdisciplinary teams skilled in dealing with medical and psychiatric emergencies, and therapeutic homes where people can stay while recovering from a medical or psychiatric episode. These and other services should be part of a comprehensive strategy for preventing avoidable admissions to medical and psychiatric treatment facilities (for details, see the discussion under Principle #9 in chapter 3).

ISSUE #18

If managed care is to improve the quality and cost-effectiveness of services to people with disabilities, it is vitally important that MCOs assemble provider networks capable of offering the full range of services and supports required by groups targeted for enrollment.

RECOMMENDATION #18: States planning to enroll Medicaid beneficiaries in managed long-term services should carefully analyze the diverse support needs among people targeted for enrollment and require MCOs to include skilled providers of such services and supports within their provider networks, as mandated under 42 CFR 438.207.

Special attention should be focused on ensuring that the service network has the capacity and expertise to serve non-English speakers, people who are blind or deaf, racial and ethnic minorities, homeless people, and other historically underserved groups. In addition, people with disabilities should have a voice in the selection of network providers, through a consumer

advisory panel or by other means, and enrollees with disabilities should have the option of receiving services through out-of-network providers that will abide by MCO qualification standards, reporting requirements, and payment schedules. Moreover, traditional providers of community-based services to people with physical, sensory, behavioral, and developmental disabilities and traumatic brain injuries should be encouraged to enroll as network providers in order to enlist their extensive expertise and promote continuity of service delivery.

ISSUE #19

State-of-the art IT is an essential tool in administering a system of managed health care and/or LTSS for people with disabilities.

RECOMMENDATION #19: States should institute a comprehensive MIS to support effective, real-time administration of managed health and LTSS at both the state and MCO levels.

A state's MIS should be fully compatible with the MIS systems used by managed care contractors and subcontractors and should include the following:

- An electronic recordkeeping system that allows authorized personnel to access the complete health care and, where applicable, long-term supports records of all plan enrollees instantaneously so treatment and intervention strategies can be effectively coordinated and sequenced (see discussion under Principle #12 in chapter 3).
- A system for collecting and analyzing performance data as part of a comprehensive quality monitoring and improvement system (see discussion under Principle #18).
- An electronic system for reporting, tracking, investigating, and analyzing sentinel incidents (see discussion under Principle #18).
- A system for gathering and analyzing encounter data and using such data to develop actuarially sound, capitated payment rates (see discussion under Principle #13).

Safeguarding the Rights of Managed Care Enrollees with Disabilities

ISSUE #20

People with disabilities frequently have complex health care and long-term support needs that make them especially vulnerable to receiving inappropriate, inadequate, or substandard services and supports.

RECOMMENDATION #20: States should establish a comprehensive quality management (QM) system to ensure the integrity of services to, and safeguard the health and welfare of, enrollees in managed health and long-term services plans that serve people with disabilities.

The same general principles used in designing QM systems for HCB waiver services should be applied in designing a state's QM system for managed LTSS. Monitoring and oversight activities should be conducted on an ongoing basis, emphasizing performance and outcome measures, based on a continuous quality improvement model (see discussion under Principle #18 in chapter 3).

ISSUE #21

Service coordinators (case managers) play a critical role in ensuring that Medicaid beneficiaries with disabilities receive the full range of services and supports they need. It is important, therefore, that services coordination be available to recipients of Medicaid managed LTSS and that providers of such services be administratively separate from at-risk managed care contractors.

RECOMMENDATION #21: Enrollees in Medicaid managed health care and long-term support plans should have access to conflict-free service coordination (case management) to assist them in navigating the intake, assessment, service planning, provider selection, and service monitoring processes.

Because at-risk health plans (MCOs) receive flat, all-inclusive monthly payments for services rendered, they have an inherent incentive to limit the range and intensity of

services to plan enrollees. For this reason, service coordination should be provided by an independent entity not affiliated with the MCO and, consequently, able to act in the best interest of the beneficiary. Another benefit of using government employees or private contractors, rather than health plan staff, is that it greatly increases the likelihood that recipients of LTSS will be able to retain their existing service coordinators, thus easing the transition to managed care (see discussion under Principle #16 in chapter 3).

ISSUE #22

Compliance with the requirements of the ADA is essential if Medicaid beneficiaries with disabilities are to gain access to the services and supports they need.

RECOMMENDATION #22: States should conduct or commission independent surveys of facility and program sites used by managed care network contractors and subcontractors to ensure that they comply fully with the provisions of the ADA and implementing regulations.

Managed care enrollees with disabilities must have ready access to all services and sites where Medicaid services are provided. Services must be physically accessible and culturally and linguistically appropriate, and capable of accommodating people with intellectual, cognitive, sensory, and psychiatric disabilities.

California recently mandated that on-site accessibility surveys be conducted in all facilities and programs operated by network providers enrolled in the state's 1115 managed care waiver/demonstration program for seniors and people with disabilities. Early survey results indicate that physical and programmatic barriers remain in many physicians' offices, clinics, and other health care locations more than 20 years after the enactment of the ADA (see discussion under Principle #19 in chapter 3).

ISSUE #23

Medicaid beneficiaries with disabilities frequently struggle to locate health and personal support providers capable of addressing their needs. For this reason, it is especially important that states make efforts to ensure that existing care and support arrangements for people with disabilities are retained as they transition to a managed care program.

RECOMMENDATION #23: State officials and MCO personnel should allow managed care enrollees with disabilities to maintain their relationships with physicians and other health practitioners, as well as personal support agencies and workers, wherever possible.

Continuity of health care and personal support is important—especially for people with substantial disabilities—and, consequently, managed care participants should be afforded opportunities to retain existing health and personal support providers whenever possible. They also should be permitted to change health practitioners, support staff, and health care/service coordinators when they are dissatisfied, and switch managed care plans at periodic intervals (see discussion under Principle #20 in chapter 3).

ISSUE #24

People targeted for enrollment in a Medicaid managed care program face many complex choices, and therefore, responsible state officials have an obligation to inform them fully of the available options, as well as the rights and obligations afforded them should they elect to enroll in such a plan.

RECOMMENDATION #24: States should develop and implement an aggressive education and outreach strategy to ensure that all plan enrollees (and potential enrollees) have accessible information concerning the services and supports available to them under the plan and how such services may be obtained.

States should enlist the assistance of community-based disability organizations in developing and implementing their outreach plans. Accessible multimedia educational

materials and training sessions should be geared to the various learning styles and comprehension levels of plan enrollees, and such sessions should be held across the state. Managed care plan participants must receive accessible, meaningful, and clear notices about programs, services, and their rights under the plan, including enrollment rights and options, plan benefits and rules, coverage denials, appeal rights and options, and potential conflicts that may arise from relationships among providers, suppliers and others (see discussion under Principle #22 in chapter 3).

APPENDIX A. Glossary of Terms

As service delivery and financing arrangements have multiplied within the federal-state Medicaid program in recent years, the terminology used by program officials has evolved. The purpose of this glossary is to clarify for readers the meaning of terms that are widely used to describe the diverse service delivery and financing approaches adopted by state Medicaid agencies.¹⁵⁹ Although some of the terms are used in other contexts, including private health insurance and Medicare, this glossary focuses on the meaning of terms in a Medicaid policy context, with an emphasis on managed care-related terminology.

Accountable Care Organization

A uniform federal definition of this term has not emerged, and the concept continues to evolve. But generally, an accountable care organization (ACO) is a group of health care providers that agree to share responsibility for delivering health care services and achieve specific outcomes for a defined group of people. The organizational structures of ACOs vary, but in concept all ACOs include primary and specialty care physicians and at least one hospital. Individual providers agree to coordinate care for shared patients in order to enhance the quality and efficiency of services, and the ACO as an entity is held accountable for the appropriateness and quality of care provided. Some states have begun developing Medicaid ACOs in conjunction with other service delivery reforms discussed below (e.g., primary care case management, medical homes, MCOs). States also may use different terminology for their Medicaid ACOs. For example, in Oregon ACOs are referred to as coordinated care organizations, while in Colorado they are called regional care collaborative organizations.

Bundled Payments

Increasingly, providers of health services, rather than being reimbursed on a per-visit or per-procedure basis, are receiving a fixed payment for care provided during a given period (e.g., a year) or for all services associated with a particular medical procedure (e.g., a knee replacement) or diagnosis (e.g., a sinus infection). These are called “bundled payments.” Medicaid agencies often differentiate between episodic bundled payments, where the provider receives a fixed amount for all procedures performed in connection with a particular episode of care (e.g., a coronary bypass graft), and global bundled payments, where the provider receives a single, pre-established payment for a wide range of services furnished over a period of time (e.g., caring for patients at high risk of hospitalization). Frequently the amount of the bundled payment is risk-adjusted to account for the demographic characteristics of the provider’s patients, such as age, gender, or general health status.

Capitation

Capitation refers to the fixed per-member, per-month (PMPM) amount that a state Medicaid agency pays to a managed care organization (MCO) for providing or arranging to provide services to enrolled beneficiaries. Because the capitation

amount is preestablished, the MCO is at financial risk if the cost of the services it provides exceeds the aggregate payments it receives from the state. Capitated payments may be risk-adjusted to take into account differences in the demographic characteristics of beneficiaries, such as age, gender, and health status.

Care Coordination

Although there is no standard definition of this term, most care coordination programs target high-risk (high-cost) beneficiaries with the goal of improving the coordination of both medical services and social supports provided by different health providers and support agencies to the same beneficiary. Care coordinators, for example, may assist beneficiaries in arranging transportation, preparing a self-directed or patient-centered plan, navigating the available care and support options, and brokering medical and social services. **Care management**, in contrast to care coordination, tends to focus primarily on the beneficiaries' health care needs. Another distinction is that care coordination programs, unlike care management programs, often facilitate the delivery of services and supports whether they are Medicaid-reimbursable or not.

Case Management

For Medicaid purposes, case management refers to services designed to assist eligible enrollees to obtain medical and other services. States have the option of seeking reimbursement for case management functions as part of a separately defined service, called targeted case management services, or they may claim such costs as part of another covered services (e.g., as a nursing facility or intermediate care facility for the mentally retarded service) or as a cost of administering the state's Medicaid program. When services are billed as targeted case management, either in a FFS or managed care context, states must specify the population group(s) eligible to receive such services. Some states, especially in Medicaid-funded disability services, may refer to case management as service coordination or support coordination.

Disease Management

In an attempt to improve the quality and cost-effectiveness of care for beneficiaries with chronic diseases, many states have organized disease management (DM) programs. The aim of DM programs is to identify chronic conditions early, treat them more effectively, and slow the progression of the disease. DM programs can be carried out by a **managed care organization** or integrated into a state's **primary care case management** program. States that provide a DM program on a FFS basis can either operate the program itself or contract with a disease management organization. While the first DM programs tended to focus narrowly on the management of specific chronic conditions (e.g., asthma, diabetes, congestive heart failure), in recent years programs have evolved toward more comprehensive management of participants' total health care needs.

Fee-for-Service

In a fee-for-service (FFS) system, the state Medicaid agency establishes fee levels for the various services covered under the state plan and pays providers for

each delivered service. Providers bear no financial risk. Medicaid beneficiaries must locate an FFS provider willing to accept Medicaid payments and to enroll new patients. Generally, there is no organized provider network similar to those found in a managed care system.

Health Home

The Medicaid health home builds on the traditional *medical home* model. Targeted to people with multiple chronic conditions, health homes are designed to be beneficiary-centered systems of care that facilitate access to and coordination of primary and acute physical health services, behavioral health services, and community-based health and social supports. Health homes develop a comprehensive care plan for each beneficiary and coordinate and integrate the provision of the beneficiary's clinical and nonclinical services.

Managed Behavioral Health Organization

A managed behavioral health organization (MBHO) is a specialty *managed care organization* that provides mental health and substance abuse treatment services. A state Medicaid agency may contract directly with one or more MBHOs to provide and manage behavioral health services to Title XIX-eligible beneficiaries, or managed care organizations may subcontract with an MBHO. Under either approach, the MBHO maintains a distinct provider network, coverage policies, and administrative services and performs other insurance functions.

Managed Care Organization

A managed care organization (MCO) is a health plan that operates under a risk-based contract with a state to provide a specific set of benefits to plan enrollees for a fixed per-member, per-month (PMPM) payment, or capitation rate. The dynamics of a capitated payment system are different than those of a FFS system because the MCO is at financial risk should total expenditures exceed total PMPM payments. Although MCOs are at financial risk in providing a comprehensive array of Medicaid benefits included in their capitation rates, most states carve out of managed care contracts certain benefits, such as prescription medications or behavioral health services. These carved-out benefits in turn are provided either on an FFS basis or through a separate contractor (e.g., with a noncomprehensive *prepaid health plan*). Medicaid MCOs are required to meet an extensive array of federal requirements plus state-specific standards covering such areas as enrollment protocols, provider network adequacy, data gathering and reporting, and access and quality benchmarks.

Managed Long-Term Services and Supports

Risk-based arrangements for the delivery of long-term services and supports (LTSS) are referred to as managed LTSS (MLTSS), or managed long-term care, plans. MLTSS plans provide an array of home and community-based services and supports designed to assist targeted groups of beneficiaries to remain in their own homes, thereby avoiding institutional placements. Some MLTSS plans include institutional care costs, while others carve such expenditures out of the plan, choosing instead to reimburse long-term institutional costs on a FFS basis.

Some MLTSS plans are limited to LTSS, while others also cover primary, acute, and specialty medical services. Program for All-Inclusive Care for the Elderly sites, for example, provide a comprehensive array of medical, social, and long-term services to frail elderly enrollees who otherwise would need nursing home care. In addition, a number of states have submitted requests to initiate integrated care demonstration projects designed to co-manage Medicare and Medicaid-funded health care and LTSS for targeted groups of seniors and people with disabilities.

Medicaid Home

The medical home concept began in the 1960s as an effort to eliminate gaps and overlaps in pediatric services due to the lack of communication and coordination. In 2002, the American Academy of Pediatrics defined a medical home as an approach that is “accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective.” Since then, the medical home model has continued to evolve and now includes the patient-centered medical home, where the personal physician leads a medical team in addressing the totality of a patient’s health needs over time, and the enhanced medical home, where the primary care provider assumes additional responsibilities for the care of people with chronic health conditions, such as providing case management services, round-the-clock access to care, nutritional interventions, and/or mental health services. With the passage of the ACA, these various approaches are considered to be part of the *health home* model.

Medical Loss Ratio

The medical loss ratio (MLR) is the share of premium revenues that an insurer or health plan spends on patient care and quality improvement activities, in contrast to administration and profits. Beginning in 2011, the ACA required insurers in the large-group market to meet an MLR standard of 85 percent annually, and insurers in the small-group market to meet an MLR of 80 percent annually. Health insurers are required to report the portion of premium dollars spent on health care and quality improvement in each state in which they operate, and those that fail to meet the applicable MLR standard are required to rebate the difference to insured individuals. The MLR requirements of the ACA do not apply to Medicaid recipients.

Pay-for-Performance

Pay-for-performance (P4P) is a health care payment model that rewards providers or MCOs financially for achieving or exceeding certain quality benchmarks. Under some P4P programs, physicians and hospitals are paid directly based on a variety of quality measures. A majority of states that contract with MCOs incorporate P4P components into their payment policies, such as withholding a portion of capitated payments, which an MCO can earn back through high performance or by offering performance-based bonuses as add-ons to the capitated payment.

Prepaid Ambulatory Health Plan

A prepaid ambulatory health plan (PAHP) is a noncomprehensive *prepaid health plan* that provides only certain outpatient services, such as dental services or

outpatient behavioral health care. PAHPs provide no inpatient services and are paid on an at-risk or capitated basis.

Prepaid Health Plan

Prepaid health plans (PHPs) provide either comprehensive or noncomprehensive benefits to Medicaid enrollees through risk-based contracts with the state Medicaid agency. **Medicaid managed care organizations** are comprehensive PHPs, while **prepaid inpatient health plans** (PIHPs) and **prepaid ambulatory health plans** (PAHPs) are noncomprehensive PHPs. PAHP and PIHP contractors frequently offer services that are carved out of the responsibilities of MCO contractors.

Prepaid Inpatient Health Plan

A prepaid inpatient health plan (PIHP) is a noncomprehensive **prepaid health plan** that offers only inpatient or institutional services, such as inpatient behavioral health care. PIHPs received fixed PMPM payments and are at risk of financial overruns.

Primary Care Case Management

In a primary care case management (PCCM) program, the state Medicaid agency contracts with primary care providers to provide, locate, coordinate, and/or monitor care for Medicaid beneficiaries who select them or are assigned to them. Providers of PCCM, in effect, serve as a **medical home** for their enrollees and are considered managed care providers. States generally require PCCM providers to meet certain requirements such as minimum hours of operation at each location, credentialing and training, and referrals to specialists. State agency staff perform, or sometimes contract out, administrative functions such as network development and credentialing. States pay PCCMs a small monthly fee for providing case management services, but all other services furnished by the provider are billed on a FFS basis. PCCMs that assume additional responsibilities or furnish other services are referred to as enhanced primary care case management programs.

APPENDIX B. A Brief History of Managed Care

The origins of managed care can be traced back to at least 1929, when Michael Shadid, a physician in Elk City, Oklahoma, established a health cooperative for farmers in a small community without medical specialists or a nearby general hospital. He sold shares to raise money to establish a local hospital and created an annual fee schedule to cover the costs of providing care. By 1934, 600 family memberships were supporting a staff that included Dr. Shadid, four newly recruited specialists, and a dentist. That same year, two Los Angeles physicians, Donald Ross and Clifford Loos, entered into a prepaid contract to provide comprehensive health services to 2,000 employees of a local water company.¹⁶⁰

Development of Prepaid Health Plans

Other major prepaid group practice plans were initiated between 1930 and 1960, including the Group Health Association in Washington, DC, in 1937, the Kaiser-Permanente Medical Program in 1942, the Health Cooperative of Puget Sound in Seattle in 1947, the Health Insurance Plan of Greater New York in New York City in 1947, and the Group Health Plan of Minneapolis in 1957. These plans encountered strong opposition from the medical establishment, but they also attracted a large number of enrollees.

Today, such prepaid health plans are commonly referred to as health maintenance organizations (HMOs). The term “health maintenance organization,” however, was not coined until 1970, with the aim of highlighting the importance that prepaid health plans assign to health promotion and prevention of illness. HMOs are what most Americans think of when the term “managed care” is used, even though other managed care models have emerged over the past 40 years.

Public Managed Care Plans

The enactment of the Health Maintenance Organization Act of 1973 (P. L. 93-222) provided a major impetus to the expansion of managed health care. The legislation was proposed by the Nixon Administration in an attempt to restrain the growth of health care costs and also to preempt efforts by congressional Democrats to enact a universal health care plan. P. L. 93-222 authorized \$375 million to assist in establishing and expanding HMOs, overrode state laws restricting the establishment of prepaid health plans, and required employers with 25 or more employees to offer an HMO option if they furnished health insurance coverage to their workers. The purpose of the legislation was to stimulate greater competition within health care markets by developing outpatient alternatives to expensive hospital-based treatment. Passage of this legislation also marked an important turning point in the U.S. health care industry because it introduced the concept of for-profit health care corporations to an industry long dominated by a not-for-profit business model.¹⁶¹

In the decade following the passage of P. L. 93-222, enrollment in HMOs grew slowly. Stiff opposition from the medical profession led to the imposition of regulatory restrictions on HMO operations. But the continued, rapid growth in health care outlays forced government officials to look for new solutions. National health expenditures grew as a proportion of the overall gross national product (GNP) from 5.3 percent in 1960 to 9.5 percent in 1980.¹⁶² In response, Congress in 1972 authorized Medicare payments to free-standing ambulatory care clinics providing kidney dialysis to beneficiaries with end-stage renal disease. Over the following decade, the Federal Government authorized payments for more than 2,400 Medicare procedures performed on an outpatient basis.¹⁶³

Responding to the relaxed regulatory environment, physicians began to form group practices and open outpatient centers specializing in diagnostic imaging, wellness and fitness, rehabilitation, surgery, birthing, and other services previously provided exclusively in hospital settings. As a result, the number of outpatient clinics skyrocketed from 200 in 1983 to more than 1,500 in 1991,¹⁶⁴ and the percentage of surgeries performed in hospitals was halved between 1980 (83.7%) and 1992 (46.1%).¹⁶⁵

The Influence of Medicare Prospective Payments

Health care costs, however, continued to spiral upward, consuming 10.8 percent of GNP by 1983. In an attempt to slow the growth rate, Congress in 1982 capped hospital reimbursement rates under the Medicare program and directed the secretary of HHS to develop a case mix methodology for reimbursing hospitals based on diagnosis-related groups (DRGs). As an incentive to the hospital industry, the legislation (the Tax Equity and Fiscal Responsibility Act (P. L. 97-248)) included a provision allowing hospitals to avoid a Medicare spending cap by reaching an agreement with HHS on implementing a prospective payment system (PPS) to replace the existing FFS system. Following months of intense negotiations involving federal officials and representatives of the hospital industry, the Reagan Administration unveiled a Medicare PPS. Under the new system, health conditions were divided into 468 DRGs, with a fixed hospital payment rate assigned to each group.

Once the DRG system was fully phased in, Medicare payments to hospitals stabilized.¹⁶⁶ However, since DRGs applied to inpatient hospital services only, many hospitals, like many group medical practices, began to expand their outpatient services in order to offset revenues lost as a result of shorter hospital stays. Between 1983 and 1991, the percentage of hospitals with outpatient care departments grew from 50 percent to 87 percent. Hospital revenues derived from outpatient services doubled over the period, reaching 25 percent of all revenues by 1992.¹⁶⁷

Since DRGs were applied exclusively to Medicare payments, hospitals began to shift unreimbursed costs to private health insurance plans. As a result, average per employee health plan premiums doubled between 1984 and 1991, rising from \$1,645 to \$3,605.¹⁶⁸ With health insurance costs eroding profits, many employers took aggressive steps to control health care expenditures. Plan benefits were reduced. Employees were required to pay a larger share of health insurance premiums. More and more employers—especially large corporations—decided to pay employee health costs directly rather than

purchase health insurance. And a steadily increasing number of large and small businesses turned to managed health care plans in an attempt to rein in spiraling health care outlays.

Managed Long-Term Services and Supports

Arizona became the first state to apply managed care principles to the delivery and financing of Medicaid-funded LTSS in 1987, when the federal Health Care Financing Administration (later renamed the Centers for Medicare and Medicaid Services) approved the state's request to expand its existing Medicaid managed care program. Medicaid recipients with physical and developmental disabilities became eligible to participate in the Arizona Long-Term Care System as a result of this program expansion. Over the following two decades, a number of other states joined Arizona in providing managed LTSS, and by the summer of 2012, 16 states were operating Medicaid managed LTSS programs.¹⁶⁹

Growth of Commercial Managed Care Plans

During the late 1980s and early 1990s, managed care plans were credited with curtailing the runaway growth in health care costs. They achieved these efficiencies mainly by eliminating unnecessary hospitalizations and forcing participating physicians and other health care providers to offer their services at discounted rates. By 1993, a majority (51%) of Americans receiving health insurance through their employers were enrolled in managed health care plans.¹⁷⁰ Eventually, however, benefit denials and disallowances of medically necessary services led to a public outcry and the enactment of laws in many states imposing managed care standards. According to one analysis, nearly 900 state laws governing managed health practices were enacted during the 1990s.¹⁷¹ Among the measures approved were laws permitting women to visit gynecologists and obstetricians without obtaining permission from their primary care physician, establishing the right of patients to receive emergency care, and establishing the right of patients to appeal decisions made by managed care firms. Congress even got into the act in 1997 when it passed the Newborns' Mother Health Protection Act, prohibiting so-called "drive-through deliveries" (overly restrictive limits on hospital stays following the birth of a child).¹⁷²

Research studies have yielded little evidence that managed health care excesses have undermined the quality of health care services. For example, in a survey of 2,000 physicians, Remler and colleagues found that managed care insurance plans denied only about 1 percent of recommended hospitalizations, slightly more than 1 percent of recommended surgeries, and just over 2.5 percent of referrals to specialists.¹⁷³ In another study, Franks and colleagues found that medical outcomes were similar for participants in HMOs versus FFS health plans.¹⁷⁴ Franks also reported that HMO patients were hospitalized 40 percent less frequently than FFS patients, and the rate of inappropriate hospitalizations was lower among HMO patients.

Recent Developments

Over the past 15 to 20 years, the public outcry against draconian managed care practices has waned, primarily due to the expanded out-of-network options afforded to participants in HMOs, PPOs, and POS health plans. But the perception that managed care represents an overly cost-conscious, mass market approach to delivering medical services lingers among the American public, even though more than 135 million people with health insurance coverage now receive their primary, preventive, and acute health services through a managed care plan.¹⁷⁵ People with disabilities, especially high users of medical care and LTSS, share many of the same negative perceptions of managed care as the general public.

APPENDIX C. **Evolution of Managed Care Within the Medicaid Program**

Medicaid and Disability Services

The original aim of the Medicaid program was to ensure that low-income, uninsured Americans gained access to primary and acute care services. Initially eligibility for program benefits was restricted to recipients of federally subsidized cash assistance, commonly referred to as welfare payments. Since many states used highly restrictive disability and financial eligibility criteria governing the receipt of adult cash benefits (i.e., Aid to the Blind (AB), Old Age Assistance (OAA), and Aid to the Permanently and Totally Disabled (APTD)), comparatively few people with disabilities qualified for Medicaid benefits during the early years of the program.

The enactment of the Social Security Amendments of 1972 (P. L. 92-603) marked a major turning point in Medicaid eligibility for low-income Americans with disabilities. The legislation repealed federally assisted, state-administered public assistance programs for low-income adults (OAA, AB, and APTD) and replaced them with the Supplemental Security Income (SSI) program, effective January 1, 1974. In addition to shifting responsibility for administering cash assistance benefits for low-income senior citizens and persons with disabilities to the Federal Government, P. L. 92-603 extended Medicaid eligibility to virtually all SSI recipients and established a national income eligibility floor that was substantially higher than the previous financial eligibility test for APTD, OAA, and AB benefits in most states. The legislation also, for the first time, extended cash benefits and Medicaid eligibility to children with severe disabilities living in low-income families and adopted a uniform statutory definition of disability applicable to both SSI and SSDI benefits. Passage of the 1972 legislation resulted in a sharp increase in the number of Medicaid enrollees with disabilities. Over the next three decades, Congress amended the Social Security Act repeatedly to extend Medicaid eligibility and coverage to additional segments of the population with disabilities.¹⁷⁶

Section 1115 Waiver/Demonstration Authority

Even before the federal-state Medicaid program was created in 1965, Congress had established a mechanism for waiving statutory requirements under the Social Security Act. The Public Welfare Amendments of 1962 (P. L. 87-543) added Section 1115 to the Social Security Act. Under this authority, the secretary of Health, Education, and Welfare¹⁷⁷ was authorized to grant states statutory waivers to demonstrate new, more effective ways of administering and delivering federally assisted services authorized under the Social Security Act. Decades later, states began using the Section 1115 authority to circumvent statutory barriers to enrolling Medicaid beneficiaries in managed health care plans.

Federal Managed Care Rules

Following the enactment of the Health Maintenance Organization Act of 1973 (see appendix B), enrollments in Medicaid managed health care plans increased substantially. But as more and more beneficiaries were enrolled in such plans during the 1970s, concerns mounted about questionable marketing practices, inadequate service delivery, poor quality of care, and the financial instability of some plans. These concerns led Congress to enact the Health Maintenance Organization Amendments of 1976 (P. L. 94-460). This legislation mandated that Medicaid beneficiaries could constitute no more than 50 percent of the enrollees in a managed health care plan. In addition, under P. L. 94-460, (a) entities seeking risk-based Medicaid contracts were required to meet federal HMO standards; (b) the definition of an HMO under the Social Security Act was aligned with the definition in the 1973 HMO act and the term “basic health services” was defined to include all Medicaid mandatory services; and (c) payments to organizations providing inpatient hospital services or any other managed Medicaid services were limited to federally qualified HMOs.¹⁷⁸

In 1981, as part of the Omnibus Budget Reconciliation Act (P. L. 97-35), Congress increased the maximum percentage of Medicaid/Medicare enrollees in a qualified HMO from 50 percent to 75 percent and amended Title XIX of the Social Security Act to offer states opportunities to experiment with alternative service delivery methods. One of these new authorities, established under Section 1915(b) of the Social Security Act, allows states to seek “freedom of choice” waivers, thus permitting them to lock selected groups of beneficiaries into Medicaid managed care plans. Under the same waiver authority, the secretary of HHS is empowered to grant waivers permitting states to limit the provision of services to selected geographic areas (a waiver of statewideness) and target services to a limited group of recipients (a waiver of comparability). States also are permitted under the Section 1915(b) waiver authority to use managed care savings to finance services not otherwise reimbursable under their Medicaid programs.

Beginning in the late 1990s, federal officials began to allow states to combine waivers under Section 1915(b) and Section 1915(c) to apply managed care principles to the delivery of LTSS. Secretarial waivers granted under Section 1915(b) allow a state to use managed care techniques in delivering LTSS, while Section 1915(c) waiver permits states to capture federal financial participation (FFP) in the cost of a wide range of HCBS. The Texas Star-Plus program and Michigan’s Specialty Services program for people with mental illness, developmental disabilities, and substance use problems are early examples of Section 1915 (b)/(c) combination waiver programs.

By 1990, about 2.3 million Medicaid beneficiaries were enrolled in managed care plans.¹⁷⁹ Still, fewer than one in ten Medicaid recipients were participating in a managed care plan of any type.¹⁸⁰ In 1993, states began using the Section 1115 research and demonstration authority to combine eligibility expansions with mandatory managed care enrollment to reshape the delivery of health care services to low-income people and families.¹⁸¹ By employing Section 1115 waivers, states were able to create statewide managed care plans composed mainly (<75%) of Medicaid and Medicare beneficiaries.

By 1997, CMS had approved 14 statewide managed care initiatives under Section 1115 demonstration/waivers, with total enrollment of around eight million people. All of these plans involved mandatory enrollment for at least a portion of participants.¹⁸²

Enhanced Managed Care Rules

The Balanced Budget Act of 1997 (P. L. 105-33) granted states authority to enroll most Medicaid recipients in mandatory managed care plans by amending their state plans, rather than by obtaining special secretarial waivers.¹⁸³ To qualify for a state plan amendment, a state must agree to meet specific managed care program requirements, which include consumer due process protections, standards of access, and procedures for monitoring the quality and appropriateness of services. P. L. 105-33 also repealed the 75/25 rule governing the proportion of Medicare/Medicaid enrollees to private plan enrollees in qualified HMOs, thus permitting states to create Medicaid-only managed care plans.

As states expanded health insurance coverage to children and adults from lower middle-class families during the late 1990s and early 2000s, they sought to add more affordable plans with less robust coverage than was mandated under Medicaid law. In response to the states' pleas, Congress included in the Deficit Reduction Act of 2005 (P. L. 109-171) authority for states to offer narrower coverage to selected groups of Medicaid recipients and impose cost-sharing requirements for such recipients. These so-called "benchmark" plans are similar to the major medical coverage offered under many commercial plans, with the aim of expanding coverage to comparatively healthy children and adults at an affordable cost.

Recent Development

Finally, the Patient Protection and Affordable Care Act of 2010 (P. L. 111-148) made a number of changes in federal statutes governing Medicaid managed care and expanded and improved HCBS options for Title XIX-eligible people with disabilities. In addition to authorizing several new and revised HCBS coverage options, Congress instructed HHS to mount a series of demonstrations to test innovative payment and service delivery models for people dually eligible for Medicare and Medicaid benefits (see discussion under Principle #1, Community Living, in chapter 3).

APPENDIX D. Types of Network-Based Health Plans

As the use of managed care techniques has proliferated, several distinctive network-based models have emerged to address the needs of various sectors of the health care marketplace. The principal types of programs, as discussed below, range from more restrictive to less restrictive approaches.

A **health maintenance organization** (HMO) is a coordinated delivery system that combines within the same organization responsibility for financing and delivering services. In exchange for a monthly subscriber fee (premium), enrollees gain access to a comprehensive network of physicians, hospitals, and other health care providers and facilities. Under early versions of the HMO model, physicians and other health care providers were employed by the organization that also owned and operated many of the health care facilities where members received treatment. Today, however, there are three basic types of HMOs:

- A **staff model HMO** in which physicians and other health care professionals are salaried employees of the organization.
- A **group model HMO** in which the insuring organization contracts with a group of physicians on a per capita basis and pays the group a monthly, per enrollee fee in return for the provision of open-ended physician services to members of the enrolled population.
- A **network model HMO** in which the organization contracts with several different medical groups to furnish physician services on either a FFS or capitated basis.

Each HMO subscriber (member) is asked to choose a primary care physician (PCP). In addition to providing basic preventive and primary care services to the patient, the PCP acts as a gatekeeper for specialty services. Patients needing specialty services must be referred by their PCP before visiting a medical specialist. In addition, nonemergency hospital admissions are subject to preauthorization by the PCP. Typically, HMOs do not pay for services rendered by health professionals or facilities that are outside the plan network unless such visits are preauthorized, except in emergency situations as defined in the plan.

Prior to 1980, staff and group HMO models predominated. Most were nonprofit organizations operating clinics and other health care facilities. As the managed care concept matured during the 1980s and 1990s, however, the focus shifted toward network model HMOs and away from nonprofit to proprietary organizations. The percentage of HMO enrollees participating in network-based plans grew from 19 percent in 1980 to 58 percent in 1990. Most network HMOs operate for-profit plans and depend primarily on contracted, rather than salaried, physicians and other health care providers.¹⁸⁴ Approximately eight million Americans (about 4 percent of the U.S. population) were receiving their health services through HMOs in 1980. By 1993, 43 million participants in employer-based health plans were enrolled in an HMO.¹⁸⁵

An **independent practice association** (IPA) is a legal entity that contracts with a group of physicians to provide services to HMO members. The contract usually is nonexclusive and, therefore, the IPA is free to sign contracts with multiple HMOs. Quite frequently, physicians who participate in IPAs also serve FFS patients not affiliated with any managed care plan. Some analysts consider an IPA to be a type of HMO, rather than a freestanding network health plan.

Instead of contracting with various insurers or third party administrators, health providers may contract with a **preferred provider organization** (PPO). Unlike an HMO, a PPO does not require its members to make modest copayments every time a service is delivered. Instead, PPO members are required to meet a deductible before insurance payments kick in, with a specified share of the cost of any subsequent services paid for by the insurer. If, for example, the PPO plan requires a 20 percent copayment with a \$1,000 annual deductible, the member has to spend \$1,000 out of pocket on covered services before insurance payments begin and make a 20 percent copayment for all services received thereafter during a plan year. Because the member assumes a substantial portion of the “first dollar” costs of services and a set portion of costs thereafter, PPO plans generally are less expensive than HMO plans.

A **point-of-service** (POS) plan blends features of the approaches discussed above. POS plan members are not obligated to choose the system to be used until the point of service delivery. As the plan participant’s choices move further away from a managed care approach, his or her out-of-pocket costs increase. For example, using an out-of-network provider without a PCP referral usually results in higher participant cost share. This model has gained a degree of popularity in the commercial health sector because it offers enrollees greater flexibility and freedom of choice than a standard HMO plan.

Finally, many traditional, indemnity health insurance plans now incorporate managed care features such as prior authorization of nonemergency hospital admissions and utilization reviews. Such plans are often referred to as **managed indemnity plans**.

APPENDIX E. Characteristics of Statutory Authorities: Medicaid Managed Care

	Sec. 1932(a) State Plan	Sec. 1915(b) Waivers	Sec. 1915(b)(c) Combo Waivers	Sec. 1115 Demo/Waivers
General Authority	Exempts states from these statutory requirements: <ul style="list-style-type: none"> * Statewideness * Comparability * Freedom of choice 	Waives state plan requirements for: <ul style="list-style-type: none"> * Statewideness * Comparability * Freedom of choice <p>Allows state to provide “other” services” and limits number/types of providers</p>	Same as Sec. 1915(b), but permits reimbursement for non-Medicaid services necessary to allow people to live in home and community settings	Supports all of the waivers permitted under Sec. 1915(b) & (c) plus the waiver of other Sec. 1902 requirements. Also permits federal matching for non-Medicaid funded services
Approval Period	Indefinite	Initial 3-year period + indefinite 5-year renewals	Same as Sec. 1915(b)	Initial 5-year period, subject to renewal
Mandatory Enrollment Target Populations	All state plan populations except children with special needs, American Indians, and Medicare beneficiaries	All state plan populations	All state plan populations	All state plan populations plus designated groups not otherwise eligible for Medicaid benefits
Application Requirements	Completion of state plan amendment preprint	Completion of CMS application template	Same as Sec. 1915(b)	Submit proposal describing key program features
Fed. Budget Requirements	No budget/cost analysis required	Demonstrate cost-effectiveness	Same as Sec. 1915(b)	Demonstrate budget neutrality

	Sec. 1932(a) State Plan	Sec. 1915(b) Waivers	Sec. 1915(b)(c) Combo Waivers	Sec. 1115 Demo/Waivers
CMS Review Timeframe	Approval within 90 days unless disapproved or CMS requests additional info. Request must be approved or disapproved by CMS within 90 days of receipt of additional info.	Same as Sec. 1932(a) state plan amendments	Same as Sec. 1932(a) state plan amendments	No required timeframe for CMS review or approval
Renewal Period	No renewal required	After 3 years for initial waiver requests and after 5 years for all subsequent requests	Same as Sec. 1915(b) waiver requests	Customarily up to 3 years, but CMS may approve a 5-year period if dual eligibles are being enrolled
Program Documentation	Contained within CMS state plan preprint	Contained within CMS application template	Contained within CMS application template	Special terms and conditions negotiated between CMS and the state
Monitoring/ Evaluation	CMS monitors implementation of the State Plan Amendment to ensure that requirements are met. State required to conduct separate evaluations of managed care entities	CMS monitors implementation of waiver to ensure that requirements are met. State required to conduct separate evaluations of managed care entities	Same as for Sec. 1915(b) waivers	CMS monitors implementation of the waiver to ensure that requirements are met. Periodic external evaluations also required

Source: Adapted from Medicaid and CHIP Payment and Access Commission, *Report to Congress: The Evolution of Managed Care in Medicaid* (Washington, DC: Medicaid and CHIP Payment and Access Commission, June 2011).

APPENDIX F. **Disability-Related Medicaid Service Coverages**

The Medicaid program offers a wide array of services to people with disabilities, although service coverages vary considerably from state to state. It is important to note that the Medicaid program—unlike Medicare and the vast majority of commercial health programs—offers long-term services and support to people with chronic illnesses and disabilities.

Covered Services

Congress has acted on numerous occasions over the past 30 years to expand the types of HCB long-term services and supports available to Medicaid recipients who require assistance in activities of daily living (ADLs) as well as instrumental ADLs. These statutory provisions, along with judicial rulings and administrative initiatives, have resulted in a steady increase in the proportion of Medicaid expenditures devoted to HCB services versus institutional services, especially since the mid-1990s. As a share of overall LTSS expenditures, noninstitutional services have increased from 18 percent of total expenditures in 1995 to 44 percent in FY 2009.¹⁸⁶

Improved access to HCB services has occurred through the establishment and expanded utilization of both Medicaid state plan services and several types of waiver services. In the area of state plan services, the most commonly used HCB service options are personal care services, home health services, rehabilitative services, and clinic services. Over the past 20 years, however, states have relied heavily on secretarial waivers granted under the authority of Section 1915(c) of the Social Security Act to finance HCB services to low-income senior citizens and people with physical, intellectual, developmental, and other types of disabilities.¹⁸⁷ In addition, many states have used either the rehabilitative service option or the Section 1915(b) waiver authority, or both, to finance behavioral health services for low-income people with severe, chronic mental illnesses and substance use disorders, including offering intensive case management, assertive community treatment, crisis intervention services, peer support, and various types of residential supports.

Generally, federal laws and regulations afford states considerable latitude in determining medical necessity and establishing limits on the amount, duration, and scope of a covered service. Thus, for example, a state may choose to limit the number physical therapy sessions Medicaid will pay for per month on behalf of eligible recipients, or restrict the circumstances under which housekeeping services may be claimed as part of a personal assistance service. Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services for children under 21 years of age are an exception to the general policy. States are required to cover any service specified in federal Medicaid law (including optional services not otherwise offered under the state's Title XIX plan) if it is needed "to correct or ameliorate defects and physical and mental illnesses and

conditions.” Dental services, for example, must be made available as part of a state’s EPSDT coverage even if such services are not made available to qualified adults under the state’s Medicaid plan.

Coordination with Other Human Services Programs

There are numerous intersections between Medicaid coverage and other federal and federal-state programs to assist people with disabilities. Here are a few of many such connections:

- The federal Individuals with Disabilities Education Act requires states to ensure that all children with disabilities between the ages of 3 and 21 receive a “free, appropriate public education.” Medicaid programs in many states, however, reimburse public schools for the cost of furnishing health-related services (e.g., physical, occupational, and speech therapy) to Medicaid-eligible children with disabilities. School-based health providers, however, meet the same licensure requirements as other Title XIX providers of the same service.
- A case manager for a Medicaid beneficiary may be reimbursed under Medicaid’s Targeted Case Management state plan option for assisting beneficiaries to develop individual plans of care and helping beneficiaries to access appropriate services consistent with the plan. But the case manager also may be reimbursed for assisting the same beneficiary to access non-Medicaid-reimbursable services, such as applying for food stamps or enrolling in adult education classes.
- Under various statutory authorities, a state Medicaid agency may purchase, on behalf of eligible people with disabilities, a wide range of HCB services; but room and board expenses may not be included in the cost of such services.
- For years, state Medicaid agencies have collaborated with state and local housing authorities to ensure that Medicaid beneficiaries gain access to government-subsidized low-income housing. In fact, the U.S. Department of Housing and Urban Development recently announced that it was making \$85 million available to state housing agencies to provide affordable supportive housing for extremely low-income people with disabilities. For the first time, housing agencies will be required to partner with state health and human services agencies, including state Medicaid agencies, to qualify for funding.¹⁸⁸
- A state Medicaid agency is required by law to maintain a memorandum of agreement with the state maternal and child health agency, and often state Medicaid agencies maintain similar collaborative agreements with the state vocational rehabilitation, developmental disabilities, and mental health agencies.

This web of interagency collaborations is yet another indication of the wide-ranging service and support needs of Medicaid beneficiaries who qualify on the basis of disability.

APPENDIX G. **Employment-Related Medicaid Eligibility Categories**

Over the years, Congress has created several alternative pathways for working people with disabilities to qualify for Medicaid benefits. Under Section 1905(q) of the Social Security Act, states are required to continue Medicaid benefits to people under age 65 who (a) have not recovered from the physical or mental impairment(s) that formed the basis of their eligibility; (b) need Medicaid coverage in order to continue working; (c) would otherwise lose Medicaid and SSI benefits due to earnings in excess of the SGA test; and (d) continue to meet other SSI and Medicaid eligibility requirements. These Medicaid beneficiaries are referred to as “Qualified Severely Impaired Individuals.” They are entitled to receive Medicaid coverage after the loss of SSI eligibility until they reach an income level the Social Security Administration considers sufficient to purchase “reasonably equivalent” health insurance coverage (or buy into Medicaid coverage) and, if required, pay for attendant care services.

The Balanced Budget Act of 1997 (P. L. 105-33) gave the states the option of allowing workers with disabilities to buy Medicaid coverage. States are allowed to charge such workers monthly premiums and impose cost-sharing requirements based on the worker’s income. To qualify for buy-in benefits, a worker must (a) meet the federal SSI disability definition and be eligible for SSI benefits if earnings are not taken into account; (b) have earnings that exceed the maximum amount permitted for the retention of Medicaid benefits by a “Qualified Severely Impaired Individual”; and (c) be a member of a family with net income below 250 percent of the federal poverty level (FPL). For a family of three in 2011, the income cutoff for the Medicaid buy-in option was \$3,860 a month. States are permitted to use more restrictive methods of increasing buy-in income and resource thresholds.

The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) (P. L. 106-170) created two additional Medicaid buy-in options for working people with disabilities:

- Under Section 1902(a)(10)(A)(ii)(XV) of the Social Security Act, states may offer a buy-in option to working-age people (age 18–64) who would be eligible for SSI benefits except for their earnings. Income and asset tests, as well as the methodology for determining countable income and assets, are established by states electing this option.
- Under Section 1902(a)(10)(A)(ii)(XVI), states may elect to continue offering Medicaid coverage to working people with disabilities whose medical condition remains severe but who otherwise would lose SSI eligibility due to medical improvement as determined during a periodic continuing disability review. This option is limited to people who cease to be eligible for the first TWWIIA option due to medical improvement.

For both of the above TWWIA options, states may impose premiums or cost-sharing requirements based on a sliding income scale. They may charge 100 percent of premiums to people with income between 250 percent and 450 percent of the FPL, provided such premiums do not exceed 7.5 percent of an individual's income. States must charge TWWIA enrollees with adjusted gross incomes of \$75,000 or more 100 percent of Medicaid premiums, although a state may subsidize the premium with unmatched state dollars.

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