

**Adults with Disabilities in
Medi-Cal Managed Care:
Lessons from Other States**

*Prepared by
Center for Health Care Strategies*

September 2003

Report

The Medi-Cal Policy Institute, established in 1997 by the California HealthCare Foundation, is an independent source of information on the Medi-Cal and Healthy Families programs. The Institute seeks to facilitate and enhance the development of effective policy solutions guided by the interests of the programs' consumers. The Institute conducts and commissions research, distributes information about the programs and the people they serve, highlights the programs' successes, and identifies the challenges ahead. It collaborates with a broad spectrum of policymakers, researchers, providers, consumer representatives, and other stakeholders who are working to create higher-quality, more efficient Medi-Cal and Healthy Families programs.

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The California HealthCare Foundation (CHCF), based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. CHCF's Medi-Cal Policy Institute seeks to facilitate and enhance the development of effective policy solutions for Medi-Cal and Healthy Families with a particular interest in identifying and understanding options for improving enrollment and retention, access to care, and the quality of care provided to people served by these public programs.

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Executive Summary

Background

Across the country, states are exploring how to provide more cost-effective care for people with chronic illnesses and disabilities. Increasing demand for Medicaid services, combined with a drop in state revenues available to pay for them, has led some to pursue the option of enrollment in managed care. Those who have embraced Medicaid managed care for this population believe it can deliver better access and better quality at a more predictable cost.^{1,2} Managed care can also provide an accountable infrastructure to support more sophisticated quality monitoring and improvement, which is almost entirely absent in the traditional fee-for-service (FFS) system. One national Medicaid expert asserts that states have developed standards of performance and monitoring capacity under managed care that far exceed what is possible under traditional Medicaid FFS.³

To help policymakers determine whether such an approach might be appropriate for California, the Medi-Cal Policy Institute commissioned the Center for Health Care Strategies (CHCS) to study how well managed care for people with chronic illnesses and disabilities has functioned in four other states: Massachusetts, New Jersey, Oregon, and Pennsylvania. CHCS conducted interviews with senior state Medicaid officials, health plan executives, and leaders from consumer organizations. Interviews were also conducted with executives of several specialty plans providing consumer-centered managed care programs for people with disabilities. All interviewees demonstrated the capacity to look back on their experiences, both positive and negative, in order to improve future performance. The study also weaves in both successful and not-so-successful experiences of other states that CHCS has worked with to develop programs in this area.

Currently, California serves approximately 161,000 adults with disabilities through three different models of managed care. State policymakers and key stakeholders will need to decide how and whether to expand mandatory enrollment of Medi-Cal beneficiaries with chronic illnesses and disabilities. The ability to learn from the experiences of others offers the opportunity to avoid potential pitfalls; however, any program that California builds will have to reflect both its own health care marketplace and its unique political landscape.

The perspectives from the interviews in this study provide valuable insights for consideration in six priority areas of managed care for people with disabilities. These include model design; beneficiary enrollment and consumer engagement; financing, rate setting, and cost containment; network adequacy; care coordination and carve-outs; and quality monitoring and improvement.

Findings

Following are key findings in each priority area:

- *Managed Care Model Design.* Conducting a thorough analysis of service utilization, disabling conditions, and patterns of care will assist states in understanding the complexity and heterogeneity of the population of people with chronic illnesses and disabilities. Good utilization and cost data can help states plan for appropriate enrollment strategies, networks, care coordination, quality measures, rates, and budget projections. Building a comprehensive and responsive model takes time but offers greater opportunities for care coordination.
- *Beneficiary Enrollment and Consumer Engagement.* States can maximize consumer choice in the enrollment process by systematically engaging disability organizations, individual consumers, and family members. States with an attitude of “we know what’s best for you” will automatically lose consumer buy-in and trust.
- *Financing, Rate Setting, and Cost Containment.* A high tolerance for deferred gratification with respect to cost savings is critical. Short-term savings are difficult to achieve due to high initial utilization (due to pent-up demand and improved care coordination), difficulty in setting accurate capitation rates, and up front administrative costs. Longer-term savings are achievable through more effective clinical management and care coordination programs. Risk-adjusted capitation, the preferred vehicle for financing, provides incentives for prevention, flexibility, specialized programs, and care coordination.
- *Network Adequacy.* Traditional network adequacy standards offer little guidance for disability care; therefore, states need to give plans flexibility to develop network capacity and standards to better serve people with disabilities. Health

plans should create broad networks of providers that can meet the specialty, ancillary, and rehabilitative care needs of members. Specialty plans can often provide more customized services to respond to unique needs of the population.

- *Care Coordination and Carve-Outs.* Care coordination, effectively implemented, goes beyond the medical models of case management and disease management. Successful programs address the medical and psychosocial needs of beneficiaries, focus on wellness and prevention, and manage both covered and noncovered services. Carve-outs can be problematic, creating challenges for care coordinators and consumers—particularly in the area of behavioral health.
- *Quality Monitoring and Improvement.* Managed care provides greater capacity to measure performance. Traditional quality measurement systems must be modified to reflect the complexity of chronic conditions common among people with disabilities. An early warning program can be used to systematically flag problems and improve deficiencies.

These findings provide direction for states in designing managed care options for beneficiaries with disabilities. While this study was conducted for California, the lessons herein have broader application for states across the country considering managed care options for people with disabilities. Given rising costs, more states are laying the groundwork now for more comprehensive ways of managing the complex array of services used by people with disabilities. The firm consensus among the states and health plans interviewed for this study is that some form of managed care is the best path to take for meeting the needs of this population. Consumers, while less sure, also agreed that managed care offers the potential for better access and increased quality at a more predictable cost.

If California ultimately decides to design and implement a more widespread managed care program for people with disabilities, it should consider the following: (1) the development of a comprehensive program must occur at a reasoned pace; (2) quick fiscal relief is not a realistic expectation, but long-term fiscal gains may be feasible; and (3) the fundamental motivation needs to come from the belief that enrollees will benefit from more prevention-oriented, coordinated care that is monitored through an accountable infrastructure. To recast a political maxim from the recent past, “It’s the quality, stupid.”

I. Introduction

Background

Policymakers in California have raised the question: Should the state consider expanding mandatory enrollment of Medi-Cal beneficiaries with chronic illnesses and disabilities in managed care? In response, the Medi-Cal Policy Institute (MCPI) commissioned the Center for Health Care Strategies to examine the experiences of other states that have attempted to embrace managed care for this population: Massachusetts, New Jersey, Oregon, and Pennsylvania. This report outlines findings from these four states on designing and implementing effective managed care strategies for enrollees with chronic illnesses and disabilities. While this study was conducted for California, the lessons herein have broader application for states across the country considering managed care options for beneficiaries with disabilities and chronic illnesses.

Most national Medicaid experts readily acknowledge the theoretical appeal of expanding managed care to adults with disabilities. They agree that flexible, prepaid financing gives managed care the incentive to improve access to a primary care provider, to enhance preventive care services, and to provide continuity and coordination of complex care needs. Thus, managed care holds promise for slowing the progression of illness, assisting people with disabilities in maintaining function, and reducing the use of unnecessary and duplicative services.

California has many years of managed care experience upon which to draw. As of January 2003, approximately 6.3 million people were enrolled in Medi-Cal, of which roughly 767,000 individuals were nonelderly people with disabilities. Medi-Cal offers managed care programs in 22 of 58 counties and enrolls approximately 3.2 million beneficiaries in one of its three managed care models. For people with disabilities, enrollment is mandatory in the County Organized Health Systems (eight counties) and voluntary in the Two-Plan Model (twelve counties) and the Geographic Managed Care model (two counties). Overall, approximately 161,000 individuals with disabilities are enrolled in managed care.⁴

What Managed Care Can Offer People with Disabilities

For consumers, managed care offers the opportunity for:

- Access to a medical home;
- Prevention-focused primary care; and
- Coordination of services.

For states, managed care creates a vehicle for:

- Purchasing systems of care based on value;
- Greater accountability; and
- Budget predictability and cost containment over time.

For health plans, the business case for entering Medicaid may include:

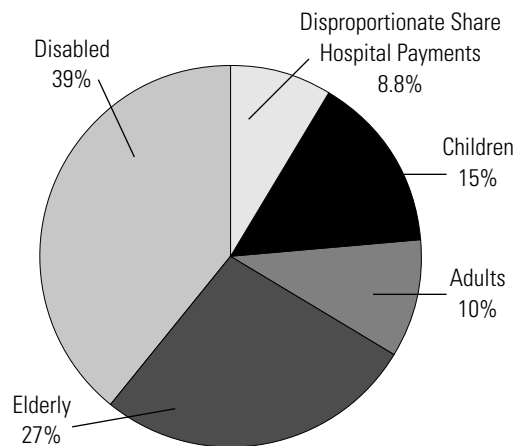
- Additional covered lives;
- Predictable costs;
- Opportunity to use clinical management capacity to generate return on investment; and
- Mission to care for underserved populations.

For providers, the business case for joining managed care may include:

- Assistance with care coordination for complex populations;
- Better disease management;
- Steadier or higher reimbursement; and
- Avoidance of bureaucratic administrative procedures in fee-for-service Medicaid.

Many experts also would point out that, even though approximately 1.6 million Supplemental Security Income (SSI) beneficiaries were enrolled in Medicaid managed care as of December 1998, there is limited quantitative evidence of improved access, health care quality, and cost savings at the national level.^{5,6} However, a handful of recently published reports from selected health plans and/or states are beginning to show improvements.^{7,8} Further study to demonstrate cost savings for the SSI population, which accounts for more than two-thirds of all Medicaid expenditures, is essential (see Figure 1).⁹

Figure 1. Medicaid Expenditures, 1998



Source: Urban Institute estimates, 2000.

Managed care can help states achieve budget predictability and some measure of cost containment over time. Yet, a complicating factor in the ability to achieve cost savings for people with disabilities is that 20 percent of the SSI population is dually eligible for Medicare and Medicaid.¹⁰ Savings achieved by reducing inpatient utilization for this population through greater use of preventive and community-based services would be realized by Medicare.

Medicaid managed care has seen less turmoil than both the commercial sector and the Medicare+Choice program. States have accepted some of the trade-offs inherent in managed care (such as network restrictions) to achieve a better benefit package at a better cost.¹¹ States also work with a more limited, but committed, cadre of health plans that are investing in the knowledge and infrastructure needed to serve populations with special needs.^{12,13} Furthermore, in marketplaces that cannot sustain managed care, creative alternatives to full risk-based managed care are being offered by enhanced primary care case management (PCCM) programs, disease and clinical management vendors, and Medicaid's version of administrative service organizations (ASOs). Three keys to success in purchasing all forms of managed care for the SSI population are (1) to build partnerships with all stakeholders; (2) to take time to understand the population of people with disabilities; and (3) to focus on improving quality of care, rather than solely on containing costs.

Medicaid Managed Care Enrollment Nationwide

- 20.7 million people, or 56.8 percent of the Medicaid population, were enrolled in Medicaid managed care in 1998.
- 1.6 million, or approximately 25 percent of the nonelderly SSI population, were enrolled in Medicaid managed care in 1998.

Source: Kaiser Commission on Medicaid and the Uninsured, March 2001.

Note: Most recent data available, as of December 1998.

Key Facts on State Managed Care Programs for People with Disabilities

- 36 states enroll some people with disabilities into managed care.
- 16 states use both capitated and primary care case management programs.
- 14 states use only capitated plans.
- 6 states use only primary care case management programs.
- 6 states (Arizona, Maryland, New Mexico, Oregon, South Dakota, and Tennessee) enroll more than three quarters of their beneficiaries with disabilities in managed care.
- The majority of the 1.6 million adults with disabilities in managed care are enrolled in mandatory, capitated plans.

Sources: Centers for Medicare and Medicaid Services, June 2001 and Kaiser Commission on Medicaid and the Uninsured, March 2001.

Understanding the Population

Most of the growing numbers of people with disabilities in this country face highly fragmented systems of care. Though they are the heaviest users of health and health-related services, their care remains uncoordinated and unfocused on wellness, function, and preventing exacerbation of their primary illnesses. Some 61 percent of adult Medicaid beneficiaries have a chronic or disabling condition, and nearly half of these beneficiaries live with multiple chronic illnesses and disabilities. Children have a lower rate and a different mix of diagnoses.¹⁴ Table 1 identifies the top ten chronic or disabling conditions for adults in Medicaid based on a study examining data from four states: California, Georgia, Kansas, and New Jersey.

Table 1. States' Diagnoses of Chronic or Disabling Conditions among Adult Medicaid Beneficiaries, 1994

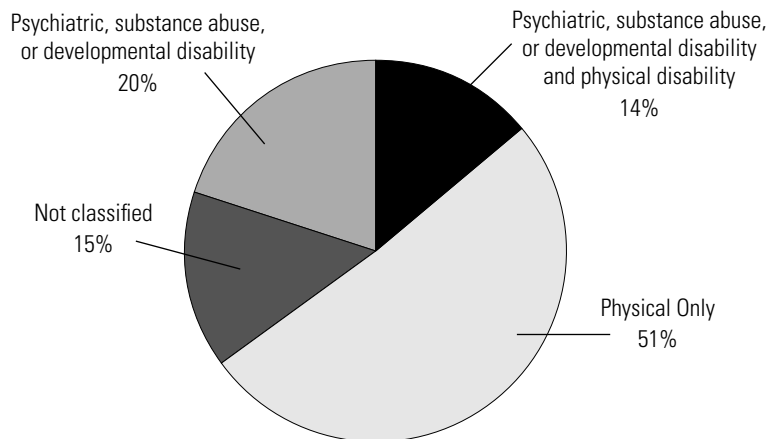
Diagnosis	Number of States (Out of Four) Reporting Condition as a "Top Ten" Diagnosis for Medicaid Beneficiaries
Hypertension	4
Psychoses	4
Asthma	4
Diabetes Mellitus	4
Other diseases of the central nervous system (such as multiple sclerosis or epilepsy)	4
Arthropathies and related disorders (such as rheumatoid arthritis)	4
Chronic Depression	4
Substance Abuse	3
Mycoses (such as fungal infection)	3
Disease of the esophagus, stomach, and/or duodenum (such as gastric ulcer)	2
Anxiety disorders (such as obsessive-compulsive disorders or agoraphobia)	2
Mental Retardation	1

Source: *The Faces of Medicaid: The Complexities of Caring for People with Chronic Illnesses and Disabilities*. Center for Health Care Strategies. November 2000.

Note: Based on data from California, Georgia, Kansas, and New Jersey.

Figure 2 shows that many of the individuals identified have both a chronic or disabling physical illness and a psychiatric, substance abuse, or developmental disability diagnosis. This chart underscores the complexity and heterogeneity of the illnesses. People with chronic illnesses and disabilities have a variety of physical impairments and limitations (such as quadriplegia and blindness), mental health conditions (such as schizophrenia and bipolarism), developmental conditions (such as autism and mental retardation), and other disabling conditions (such as cerebral palsy, muscular dystrophy, spina bifida, and HIV/AIDS).

Figure 2. Diagnosis of Adult Medicaid Beneficiaries with Special Needs



Source: *The Faces of Medicaid: The Complexities of Caring for People with Chronic Illnesses and Disabilities*. Center for Health Care Strategies. November 2000.

Note: Based on data from California, Georgia, Kansas, and New Jersey.

The major Medicaid eligibility pathway for adults with chronic illnesses and disabilities is through the SSI program, whereas children become eligible for Medicaid primarily through the Temporary Assistance for Needy Families (TANF) program.¹⁵ Once eligible for Medicaid, people within the SSI population typically need a wide range of health and nonmedical supportive services, including specialty and behavioral health services, prescription drugs, durable medical equipment, rehabilitation therapies, and home health and long-term care services. They also must be linked to supportive services, such as housing and nonemergency transportation. The fragmented fee-for-service delivery system is ill designed to meet these continuum-of-care needs and has little ability and few leverage points for inducing improvements in care for these beneficiaries.

Methodology

The Center for Health Care Strategies conducted interviews with senior state Medicaid officials, health plan executives, and leaders from consumer organizations in Massachusetts, New Jersey, Oregon, and Pennsylvania. These states were chosen because of the scope and duration of their Medicaid program expansion, the size and sophistication of their underlying managed care programs, and the diverse approaches they took in designing their programs. This study considers both the successes and failures that occurred during the implementation and on-going management of these state programs.

Research for this study focused on managed care alternatives for nonelderly adults with disabilities. Although children with special health care needs are frequently enrolled in managed care (for example, all of the states in this study currently enroll this population in managed care), the specialized California Children Services (CCS) program would make this approach

substantially more difficult to undertake in California. Another key consideration for this study was carve-out programs for special populations and diseases—especially for mental health and substance abuse, which constitute a complicating factor. Given California’s current approach to behavioral health, the study concentrated on the inherent difficulties in coordination between a physical health plan and FFS behavioral health services.

In addition to state interviews, evidence was gathered from specialty plans, including Community Medical Alliance in Massachusetts, AXIS Healthcare in Minnesota, the Community Living Alliance in Wisconsin, and Children’s Choice in Michigan, because of their perceived status at the leading edge of high quality, consumer-centered managed care for adults with disabilities.¹⁶ Specialty plans often focus on subsets of this population (such as people with HIV/AIDS or severe physical disabilities, or children with special needs) and may evolve from academic centers of excellence, specialty clinics, or even community-based organizations. They are characterized by strong commitments to consumer engagement and to a community-based, rehabilitation-oriented continuum of services. Some of these plans have even successfully taken on risk for managing long-term care services.

Finally, CHCS has previously studied and worked with other states, including both those with programs that have succeeded and those whose programs for the SSI population were, at times, derailed. Lessons from the former (Maryland, New Mexico, and Oklahoma) and the latter (Indiana and Washington) are reflected in the reported findings.

State Profiles

Each of the states selected for this study implemented different program models based on the state’s experience and readiness for extending managed care to people with disabilities. Detailed overviews of the selected states and health plans are included in Appendix A and Appendix B.

Massachusetts—MassHealth

MassHealth, the state of Massachusetts’s managed care program, was started in the early 1990s to serve both the TANF and SSI populations. Roughly 88,000 members with disabilities (as of December 2002) choose from a capitated health plan or from the state’s primary care case management program, the Primary Care Plan (PCP). SSI members who do not select from among these options are auto-assigned to the PCP. Plans are paid on a full-risk, capitated basis for physical and behavioral health services. MassHealth contracts with a mix of health plans that are predominantly Medicaid or safety net hospital-sponsored plans. Primary care physicians under the PCP plan are paid an enhanced payment rate based on specific primary care and preventive services. Finally, all beneficiaries in the PCP plan receive behavioral health services through a carve-out to a fully capitated behavioral health organization.

New Jersey—New Jersey Care

New Jersey began a voluntary managed care program for the SSI population approximately six years before the state adopted a plan, in late 2000, to require mandatory enrollment for people with disabilities. With approximately 50,000 SSI beneficiaries enrolled at the end of 2002, New Jersey is slowly phasing in the mandatory program by region. The state contracts with five health plans, including a mix of commercial plans and plans that exclusively serve Medicaid. Health plans are paid on a full-risk, capitated basis. Except for those behavioral health services provided to people with developmental disabilities, which are provided through the health plans, behavioral health services are carved out from the capitation and paid FFS rate.

Oregon—Oregon Health Plan

The Oregon Health Plan (OHP) began mandatory enrollment for people with disabilities in 1995, which was one year after mandatory enrollment for the TANF population. OHP is a statewide, mandatory managed care program with nearly 54,000 SSI enrollees as of October 2002. The state contracts with 14 health plans, including commercial plans and Medicaid-only health plans. The plans are paid on a full-risk, capitated basis. The state of Oregon also runs a county-based, capitated behavioral health program. Finally, the state has a small primary care case management program in several rural counties.

Pennsylvania—HealthChoices

Mandatory enrollment in HealthChoices, the state of Pennsylvania's managed care program, for the TANF and SSI populations began in the southeast region of Pennsylvania in 1997. The state is rolling out HealthChoices for all populations through a regionalized approach, and three of the seven regions representing the vast majority of the population have implemented the program. Nearly 300,000 SSI beneficiaries were enrolled by September 2002. The state of Pennsylvania contracts with six health plans, the majority of which are Medicaid-only and are fully capitated. The state also runs a county-based, capitated behavioral health program.

II. Findings: Priority Areas for Consideration

The findings of this study are organized into the critical areas of consideration in designing and implementing a managed care program for people with disabilities. Making the decision about whether or not to extend managed care to adults with disabilities should be fully explored with a broad group of stakeholders before launching into discussions of how to design and implement the program. A first critical step for states is to clearly define their primary goals for the program. These goals will ultimately drive the program design.

Managed Care Model and Design

Lesson 1: A thorough analysis of service utilization, disabling conditions, and patterns of care for adults with disabilities is essential early in the design process. All stakeholders need to understand the complexity of the population and what providers and services are used by enrollees with disabilities. Good utilization and cost data are critical for developing appropriate enrollment strategies, networks, care coordination, quality measures, rates, and budget projections.

- A state cannot effectively rationalize and improve its care delivery system for enrollees with disabilities unless it understands the care patterns experienced under the FFS model. Reductions in inappropriate utilization and costs can help fund improved care coordination and more appropriate services. For example, Massachusetts identified extremely high rates of inpatient utilization and institutionalization for people with behavioral health problems; consequently, the state capitated behavioral health services to redirect care to outpatient and community providers.
- A state's potential health plan partners should see relevant data before designing a managed care model for people with chronic illnesses and disabilities.

“Without sound rates based on solid data,” one health plan CEO noted, “we cannot participate.”

- Sharing utilization and cost data with health plans can facilitate health plan interest in bidding on state contracts for people with disabilities and can greatly enhance health plans’ development of adequate provider networks. States that did not fully analyze cost and utilization data, and share it with health plans beforehand, encountered significant difficulties during the enrollment process.

Lesson 2: Building managed care for people with disabilities takes time. States can opt to expand managed care to different geographic regions, populations, or services in stages. This gives stakeholders the opportunity to learn from prior efforts and to build capacity and understanding of the population’s service and care coordination needs in less experienced markets.

- Pennsylvania has used a regional phase-in, starting in urban areas and moving into more rural areas over time. This method has allowed the state to work closely with key constituencies in each region to build the necessary support and infrastructure. After an initially rocky rollout of managed care in South-eastern Pennsylvania, the state improved its enrollment process and stakeholder involvement in other regions of the state.
- Given a realistic implementation schedule, “states should stick to it,” lamented a health plan CEO. Unexpected delays are detrimental to sound partnerships and are extremely costly when plans have to hire additional staff (such as care coordinators) in advance. Enrollment delays for people with disabilities in managed care in New Jersey have frustrated both health plans and consumer organizations because of the uncertainty of the enrollment timeframe (particularly for auto-enrollment) and of the commitment, or lack thereof, from the state in pursuing mandatory statewide enrollment.

Lesson 3: States benefit from truly meaningful efforts to involve disability organizations, individual consumers, and family members in the design of their programs. As one Medicaid official noted, this level of involvement is easier said than done, but it is imperative for building trust and credibility in the program.

- Oregon Medicaid officials engaged consumers in several ways, including: identifying a broad group of stakeholders; asking them to accept the reality of managed care while helping the state build the best program possible; noting that everyone would get something but not everyone would get everything; and keeping all stakeholders at the table even through periods of disagreement.
- One consumer advocate noted that, if states come to the table with an attitude that “we know what’s best for you,” they will lose consumer buy-in and trust.

States might consider contracting with cross-disability organizations to provide guidance on key policy and operational strategies.

- In several states, direct communication among consumer organizations, health plans, and enrollment brokers was critical to timely and honest discussion of key concerns. One advocate noted, “The state should not be the only vehicle for communication.”

Lesson 4: It is beneficial to design the most comprehensive managed care program possible for adults with disabilities. The majority of interviewees underscored the goal of having capitation with appropriate risk corridors and mandatory enrollment for the maximum number of subpopulations (including those dually eligible for Medicare and Medicaid), the maximum number of services (including acute, behavioral, and long-term care services), and the broadest geographic area (including as many regional markets as possible).

- Broad-based programs create more opportunities for integration of care, economies of scale, and cost containment for the state. Such all-encompassing programs also provide important leverage for the purchaser with the health plan market and for the health plans with specialty providers.
- In the state of Pennsylvania, serving “everyone, everywhere in the state” is a priority in order to create the most comprehensive program possible. According to state officials, mandatory enrollment in HealthChoices is “absolutely essential” for establishing accurate and predictable rates, redirecting savings appropriately, decreasing administrative complexities, reducing programmatic confusion for consumers, and ensuring equal and high quality care for all enrollees.
- Health plan leadership consistently advocated for an all-inclusive approach to managed care with as few exceptions as possible. One health plan CEO declared that “comprehensive care is the best care” and states should build models to support full integration of services. Being able to manage the maximum amount of services for an individual, from physical and behavioral services to long-term care services, creates better opportunities for true care coordination.
- Voluntary managed care programs were generally deemed unworkable because of potential selection bias and insufficient enrollment to assure economies of scale. Both Indiana and Washington experienced such problems in their early experimentation with managed care for disabilities.
- Consumer reaction to comprehensive programs was mixed, ranging from negative experiences in areas like access to specialty services to an appreciation of the opportunities for better clinical and care management with flexibility within well-designed programs.

Lesson 5: Given the political and operational complexities of comprehensive managed care programs, states are also experimenting with a broad range of alternative managed care options, including enhanced primary care case management programs, administrative service organizations, and disease management strategies. These models can incorporate elements of managed care without full risk. However, additional administrative capacity may be needed, particularly if a state decides to run simultaneous programs (like Massachusetts) or to develop in-house management, as opposed to contracting out such programs.

- Massachusetts operates a statewide PCCM program and a full-risk managed care program throughout much of the state. The state contracts for enrollment broker services for both managed care options. It also contracts with a separate vendor for network management and quality improvement functions for the PCCM. The same vendor provides behavioral health services under a capitated model to clients enrolled in the PCCM program.
- Because the New Jersey health plans were recently financially battered by the inclusion of a “general relief” population in managed care, the state is considering an ASO arrangement in which the state would retain the risk but would use health plans to better coordinate the delivery of care.
- States not included in this study, such as Florida and Colorado, have implemented disease management initiatives focused on specific chronic conditions and pharmaceutical management strategies.¹⁷ The results of these experiments are not yet available, but their applicability to adults with disabilities could be somewhat limited by their focus on single diseases.

The Diversity of Medicaid Managed Care Options

Many options exist for enrolling Medicaid beneficiaries into some form of managed care program. These options differ from the commercial market and are defined in Medicaid statute and/or regulations. States included in this study use a variety of approaches (see Appendix A for more detail). Current statutory definitions include:¹⁸

Primary Care Case Management Program. PCCM is a program that relies on primary care case managers to locate, coordinate, and manage services for Medicaid beneficiaries. Primary care case managers can be physicians, physician group practices, and, at state option, physician assistants, nurse practitioners, or certified nurse-midwives. PCCM programs are typically not at risk, but are paid a per-member, per-month case management fee. Claims are paid on a FFS basis.

Prepaid Ambulatory Health Plan. A prepaid ambulatory health plan (PAHP) contracts with the state on the basis of prepaid capitation payments, but is not responsible for the provision of any inpatient or institutional services. PAHPs do not have comprehensive risk contracts with the state. An example would include a dental managed care vendor.

The Diversity of Medicaid Managed Care Options (continued)

Prepaid Inpatient Health Plan. A prepaid inpatient health plan (PIHP) contracts with the state on the basis of prepaid capitation payments and is responsible for the provision of any inpatient hospital or institutional services. PIHPs do have comprehensive risk contracts with the state. An example would include a behavioral health managed care vendor that is responsible for inpatient behavioral health services.

Managed Care Organization. A managed care organization (MCO) has a comprehensive risk contract with the state. MCOs are paid on a prepaid capitated basis and provide comprehensive services, including inpatient services. Both states and health plans can carve out certain classes of beneficiaries (such as people who are institutionalized or people dually eligible for Medicare and Medicaid) and/or services (such as behavioral health services or pharmacy benefits), making each state program and each MCO program unique.

Emerging Models

Several emerging models, described below, are developing within states as alternative forms of managed care. Although not defined in statute, these programs use existing managed care and Medicaid regulations as the basis of discussions with the Centers for Medicare and Medicaid Services.

Administrative Service Organization. States are exploring ways to contract with MCOs and PCCM vendors to coordinate a comprehensive array of managed care services on a non-risk basis. States may pay contractors an administrative fee, which could have enhanced payments linked to performance. ASOs would not assume risk or payment for the medical costs of the populations covered. Provider payment rates are based on fee-for-service rates included in the state plan.

Disease Management Programs. Disease management (DM) programs can operate within a PCCM or FFS program. The goals of DM programs are to contain cost while managing the care of people with chronic illnesses through different patient management and physician education approaches. Disease management programs implemented by states have differed in the specific diseases targeted (such as asthma, diabetes, or congestive heart failure) and in how the programs are administered (either operated in-house or contracted out for services). States pay contractors an administrative fee. Some states have developed guaranteed savings arrangements with their contractors as well.

Beneficiary Enrollment and Consumer Engagement

Lesson 6: Balance mandatory enrollment with the promotion of active consumer choice. Consumer choice can be promoted through educational campaigns, training of enrollment counselors, longer enrollment periods, and “exceptions” policies. Consumer involvement in the design phase should ideally be carried over to this first stage of implementation and beyond. Enrollment brokers can bring experience and specialization to the process, but they must have access to timely and accurate eligibility and utilization information to counsel beneficiaries effectively.

- Most states planned for a six-month enrollment process, in any given region, before resorting to the auto-assignment of members who had not selected a health plan.
- Consumer organizations in Massachusetts initially assisted in the design and distribution of culturally and disability-sensitive enrollment materials for MassHealth, and they trained enrollment broker staff about the unique needs of beneficiaries with disabilities.
- Oregon uses county caseworkers to provide choice counseling to adults with disabilities under the Oregon Health Plan. It chose to use the caseworkers in this role, as opposed to an outside vendor, but noted their competing job demands and a tendency by some to rely on the “exceptions” option for those not wishing to be enrolled in managed care. Allowing consumer “exceptions” to mandatory enrollment, as in Oregon, is viewed as a very important “safety-valve” for those concerned about the transition. Naturally, tensions will arise between the state and consumers about how tightly drawn such policies should be.

Training Counselors to Respond to Consumers’ Needs

Ray Morrison was enrolled in the Pennsylvania Medicaid program for four years—spending half the time in Medicaid FFS and half in HealthChoices, which is the Pennsylvania Medicaid managed care program. Mr. Morrison said that enrollment counselors can be very helpful to consumers when selecting health plans. He recommended that counselors be proficient in two key areas.

1. Counselors should have a well-established working knowledge of the service and support needs of people with different disabilities.
2. Counselors should understand the different health plan networks that offer appropriate services and be able to link networks and supports that are in close proximity to the consumer.

Lesson 7: Ensuring continuity of care for people with disabilities is a high priority during enrollment. Continuity of care is especially important for those with complex conditions who have established successful relationships with primary care and specialty providers through years of trial and error.

- Some individuals have learned how to be their own care coordinators and have found providers with particular knowledge, expertise, and compassion in serving adults with chronic illnesses and disabilities. These individuals merit special consideration to assure that neither the enrollment broker nor the health plan usurp this vital role.

- When assigning individuals who did not voluntarily select a health plan into a managed care option, enrollment brokers in Massachusetts used the state's comprehensive utilization analysis for enrollees with disabilities to identify existing connections with primary and specialty providers, as well as provider expertise in serving particular disability groups.
- The anticipation of disruptions in provider relationships is a major cause of consumer opposition to managed care. Partnering with consumer organizations, providers, and enrollment broker staff to identify existing relationships will help initiate managed care for enrollees with disabilities in a more positive manner. States and health plans will need to make additional efforts to contract with and retain disability-competent providers. (More information on this issue is provided in Lesson 13.)

Lesson 8: The initial enrollment process is an opportune time to gather vital information about people with disabilities—data upon which future care coordination plans can be based. Early case findings can trigger early outreach to high-risk individuals. With appropriate beneficiary safeguards and protections (see both the Medicaid statute and the Health Insurance Portability and Accountability Act, or HIPAA), states should provide information to plans on demographics (name, address, and phone number), health status (diagnosis, illness, utilization trend information, and medication regime), care network (providers and members), and the involvement of other state health and social services agencies.¹⁹

- Three Rivers Health Plan and others in Pennsylvania are given information about individuals involved with other state agencies (such as those dealing with mental health and mental retardation) so that they can identify members with special needs, facilitate care coordination, and link various care systems.
- Enrollment staff in several states gather initial information on members' self-identified special needs, which health plans can use to jump-start their own risk-assessment protocols.
- Plans must first reach those who are at highest risk and have the greatest need for clinical management. The early transmission of vital data from the state can prevent exacerbations of illnesses and save lives.

Involving Consumers in Enrollment and Access Discussions

Robert Restuccia, who has been the long-time executive director of Health Care for All in Massachusetts, has worked with consumers to shape managed care in Massachusetts to better serve people with special needs. In involving consumers, Mr. Restuccia recommends that states:

- Work with advocacy organizations to ensure adequate consumer input;
- Monitor health plans' provider networks to see that they are culturally appropriate and experienced in serving people with special needs; and
- Take every step possible to achieve the highest choice rate before auto-assignment is necessary.

Another significant consumer role can be in governance with health plans, provider groups, and the state. Contributing consumers should be supported by transportation reimbursement, stipends for attendance, convenient scheduling of meetings, accessible meeting sites, and so on.

Financing, Rate Setting, and Cost Containment

Lesson 9: All stakeholders consistently underscored how ill advised it is to pursue managed care to achieve short-term cost savings. Interviewees noted that cost savings took longer to achieve for the SSI population than for the TANF population but that, over time, savings were attainable through better clinical management and care coordination.

- “Promoting managed care for people with disabilities principally as a vehicle to save money is a recipe for political disaster,” said one Oregon Medicaid official.
- Massachusetts officials noted, “Principles underlying managed care savings assumptions for the TANF population (such as reducing emergency room use) cannot necessarily be applied to the SSI population.” Savings associated with the SSI population must come from better managing prescription drug use and more advanced clinical management and care coordination programs that generate more appropriate patterns of care over time. In particular, prevention of secondary medical complications can significantly reduce hospital utilization.
- Not a single state or health plan official foresaw the possibility of savings in the early years, particularly in a state, like California, with low hospitalization and physician payment rates; however, they all agreed that Medicaid managed care can reduce expenditure volatility, thereby improving budgetary predictability.

- Short-term savings are often reliant upon provider pricing discounts, which are highly dependent on baseline FFS rates and local market conditions. They may lead to provider “push back” or withdrawal from networks, which would not be conducive to building the broader provider networks needed for the SSI population.
- One health plan CEO with multistate experience believes strongly that, by virtue of their heavy service utilization, enrollees with disabilities can represent “a significant opportunity for savings.” However, achieving such savings is highly dependent on accurate rate setting by the state and on each health plan’s capacity to manage complex, chronic diseases.

Key Reasons Why Savings Are Difficult to Obtain Early On

- Increased utilization due to better access (pent up demand).
- Increased utilization due to improved care coordination.
- Increased up front administrative costs for both the state and health plans.

Note: It should not be overlooked that these first two cost drivers—increased access and improved care coordination—can immediately improve quality for beneficiaries.

Lesson 10: Full capitation with appropriate risk-sharing opportunities creates incentives for achieving better care and cost containment in serving adults with disabilities. Capitation provides an appropriate financing vehicle for health plans to invest in more flexible and creative service delivery, specialized programs, and care coordination infrastructure. The cost of care coordination services should be accounted for in the administrative or medical portion of the capitation rate. If necessary, states can look to alternative financing options, including partial capitation, provider incentives, and ASO arrangements associated with PCCM programs.

- The states included in the study have designed models that rely heavily on full-risk capitation for their managed care programs. Health plan CEOs asserted that capitation allows health plans the flexibility to provide services that are not otherwise covered by Medicaid, but which can help a member maintain or improve a health and functional status.
- States are also using other financing models in their managed care programs. In its PCCM program, Massachusetts uses a \$10-enhanced payment rate per visit, based on specified primary care services. Both Massachusetts and New Jersey have considered greater reliance on ASOs to capitalize on managed care’s added value in coordinating, monitoring, and improving care without requiring plans to take risk.

- States not included in this study offer other financing arrangements to consider. Oklahoma uses partial capitation in its PCCM program, wherein primary care physicians are financially responsible only for regular office visits and associated lab and x-ray services. Maine financially rewards primary care physicians who provide high-quality care on measures related to access, prevention, quality, and emergency room utilization.²⁰
- Although state officials noted the difficulty of pricing such services, Oregon built costs for its health plans' exceptional needs care coordinators into the capitation rates.

Lesson 11: Accurate rate setting is critical to achieving health plan stability and profitability over time. In any system in which consumers are given a choice of health plans, capitation rates should be based on age, sex, categorical eligibility, Medicare status, and health and functional status. States claim that the use of relatively simple risk-sharing arrangements (such as risk corridors, reinsurance, or stop loss) is vital to the success of their programs, particularly in the initial years. Many states are also implementing sophisticated risk-adjustment methodologies for beneficiaries with disabilities that incorporate health and functional status to develop more accurate capitation rates. Under these arrangements, funding for disproportionate share hospital (DSH) payments is not related to the plan's member profile and, thus, should be financed separately from the capitation rate.

- New Jersey, Oregon, and Pennsylvania are using the Chronic Illness and Disability Payment System (CDPS) to risk adjust rates based on health and functional status.²¹ Because the methodology for risk adjustment is better established now than in the mid and late 1990s, states implementing managed care for people with disabilities now have access to off-the-shelf products that are easier to implement.
- Although none of the states interviewed for this study did so, all recommend in retrospect that states implement risk adjustment at the outset of their program, since payment fluctuations among health plans during later transitions between payment systems can be problematic. Maryland was able to illustrate that the risk-adjustment methodology more appropriately compensated plans by moving substantial funds from plans with lower-risk members to plans with high-risk memberships.²²
- States should use risk sharing in circumstances where risk is seen as excessive or costs are viewed as unmanageable. For example, one health plan reported costs of \$1.7 million in 2002 for one patient with hemophilia. Pennsylvania uses risk corridors or risk pools for populations known to be high-cost users of care and for which pricing has been extremely volatile (for example, people with HIV/AIDS).

Oklahoma SSI: Costs Decrease and Patient Satisfaction Rises in Managed Care

A majority of aged, blind, and disabled people enrolled in an Oklahoma managed care plan are receiving more cost-effective care and are more satisfied with the overall quality of health care services provided under managed care versus traditional Medicaid FFS, according to a recent CHCS-funded study.²³

The study examined 538 individuals covered under the Heartland Health Plan of Oklahoma and compared costs, quality of care, and member satisfaction levels prior to managed care enrollment and one year following enrollment. Schaller Anderson, the administrator of Heartland Health Plan, oversaw the study, which revealed that managed care resulted in a 4 percent savings in total medical and administrative costs. Even more significantly, when the ten costliest enrollees are excluded from the data, the overall net cost savings are 17 percent compared to the FFS program. When enrollees were asked about their satisfaction with health services, 61 percent noted that their care was better under managed care than it was under FFS. In addition, 60 percent said it was easier to obtain a prescription through the health plan than it was under FFS.

Lynn Mitchell, who is Medicaid director for the Oklahoma Health Care Authority, notes, "We worked very closely with our contracted health plans to design a fully capitated managed care program that addresses the diverse health care requirements of individuals with special needs."

Network Adequacy

Lesson 12: People with disabilities use a broader and different array of services than the TANF population. Services include specialty care, behavioral health, prescription drugs, durable medical equipment, rehabilitation therapies, home health and long-term care, and wheelchair-accessible, nonemergency transportation. It takes time to build provider networks to meet these service needs.

- Both Keystone Mercy Health Plan and Three Rivers Health Plan in Pennsylvania suggested that six months are needed for network development (after health plan selection under the state's RFP process) before the enrollment process for adults with disabilities should begin.
- AmeriGroup of New Jersey reaches out to consumer organizations, Centers of Excellence, and state social services agencies (such as departments of mental health, developmental disabilities, aging, and child welfare) to find providers with significant experience in serving adults with chronic illnesses and disabilities. Historically, these providers have had limited relationships with health plans and might require persuasion and reassurance that managed care can be

helpful to both their patients and their practices. Also, health plans might need to modify typical provider contract standards to recruit traditional providers serving people with disabilities.

- If its provider network is not fully developed, a health plan will need to consider out-of-network approval of services.

Lesson 13: Building a competent and accessible provider network is an art, not a science.

Traditional network adequacy standards used for the TANF or commercial population (such as numbers, types, and ratios of primary and specialty providers, time and distance standards, and appointment availability) offer only limited guidance. States can use such standards (including those outlined in the 1997 Balanced Budget Act final regulations), but must also give health plans flexibility to customize in order to meet patient needs.

- “There is no board certification in disability care,” observed one health plan CEO. “States often have a vision of an ideal network of credentialed specialists that does not exist.” Questions about credentialing or whether a specialty provider can serve as a primary care physician may be less important than assuring provider commitment to appropriate disease management and care coordination practices.
- Health plans must build their own disability competence and educate their providers regarding the “culture of disability,” including how to accommodate lifestyle differences and communicate respect (such as addressing the person versus their caregiver and asking a person about his or her needs rather than making assumptions).
- Centers of Excellence in academic health centers and children’s hospitals can add unique specialty providers to a health plan’s network. Some plans may try to bypass such providers in order to avoid higher provider payment demands or higher-risk patients. As such, states must monitor health plan networks and use risk adjustment to assure that funding follows the beneficiaries needing the high-cost services.

Lesson 14: Health plans can contract with “specialty plans” or care management organizations to provide more customized services for high-need populations.

Health plans may wish to extend risk and autonomy to organizations that have expertise in serving beneficiaries with disabilities. These organizations may be better positioned to create customized programs than their parent health plans, which often focus on standardizing products for economic efficiencies.

- AXIS Healthcare in Minnesota and a small number of specialty plans across the country have subcapitation arrangements with parent health plans to provide highly individualized, consumer-focused care coordination programs for adults with disabilities.
- Subcapitation provides the flexibility needed to create customized approaches to care coordination and provides organizations and care coordinators the ability to pay for services both in and outside the standard benefits package.
- However, the different culture of the specialty plan, with its devotion to specialized consumer-centered care planning, and the larger health plan pressures to standardize processes may make it difficult to sustain a long-lasting relationship.

Care Coordination and Carve-Outs

Lesson 15: Care coordination for people with disabilities goes beyond the medical models of case management and disease management. It is critical that care coordination not be seen as gatekeeping. Also, care coordination must address the medical and psychosocial needs of beneficiaries and focus on wellness and prevention (particularly of secondary conditions). Care coordinators manage covered and noncovered services (such as carved-out mental health and substance abuse treatment) and help consumers navigate complex networks of specialty, ancillary, and supportive services.

- Sophisticated care coordination programs given sufficient resources can develop an individualized health care plan (IHCP) with a care planning team that includes the consumer, family members, and key providers. IHCPs often exist to care for children with special needs but could be adapted and modified for adults with disabilities. Health plans also need to understand that people with disabilities often have a distrust of the medical model of care and, as a result, expand the care planning team to include peer supports and nonmedical staff.
- Innovative care coordination programs often allow the consumer to select the members of their care planning team and to identify services and supports needed.
- The CEO of AXIS Healthcare, a special-needs plan for adults with chronic illnesses and disabilities in Minnesota, notes, “If we avert just one hospitalization, care coordination is paid for and the member has improved quality of life.”

Bob Dutcher, AXIS Healthcare Member

Bob Dutcher provides a classic example of what happens when an unmanaged chronic condition goes out of control due to poor self-management and lack of formal care coordination in the FFS system. Mr. Dutcher, who had insulin-dependent diabetes, hypothyroidism, and undiagnosed depression, entered the AXIS Healthcare care coordination program after suffering a stroke that left him in a nursing home.

Mr. Dutcher's AXIS care coordinator tailored a package that met his individual needs. She helped him get Social Security Disability Insurance, housing assistance, physical and occupational therapy, and mental health services for depression and his anger over his illness. Mr. Dutcher left the nursing home and moved into an apartment with donated furniture. Today, he lives independently, has a nurse visit him once a week, and receives independent living skills training, rehabilitation services, and vocational training. Had Mr. Dutcher been placed in a traditional disease management program, the sole emphasis would have been on his diabetes. The broader care coordination and individualized approach for someone with serious comorbidities improved his quality of life immeasurably. Mr. Dutcher has had no hospitalizations or emergency room visits since becoming an AXIS Healthcare member more than two years ago.

- It makes sense to health plans to concentrate scarce care coordination resources on those at the highest risk at any point in time. BMC Health Net in Boston has 15 to 20 percent of its SSI population in active care coordination, compared to only 3 percent of its TANF population.
- The exceptional need care coordinators in Oregon and the special needs units in Pennsylvania are both nationally recognized. Yet, consumer organizations still see uneven access, program operating criteria, performance, and monitoring of the care coordination process and want states to develop standardized criteria for care coordination programs. One Pennsylvania consumer representative also argued that care coordination must be individualized and in-person rather than a virtual or paper transaction.

Lesson 16: Health plans use multiple approaches to designing their care coordination programs, ranging from a centralized headquarters team to a regionalized model.²⁴ Probably more important than the model is for health plans to hire individuals with creativity and understanding of other state-funded services, as well as problem-solving skills and community-based connections. Further, a plan must place care coordination staff appropriately within its organization to assure impact.

- “Managing care for the SSI population versus the TANF population requires extremely hands-on contact, high levels of communication, and strong clinical management,” noted an Oregon health plan official. Care coordinators should

report to medical officers or quality assurance directors rather than to more administratively oriented units of a health plan.

- Another health plan CEO noted the difficulties that care coordinators face in trying to find a balance between pure financial discipline and pure patient advocacy. Care coordinators should have financial, clinical, and administrative control so that they can “feel the risk of their decisions” from both the health plan and member perspectives.
- A former state Medicaid director observed that nonmedical, long-term care services can present greater care coordination problems than behavioral carve-outs. (More information on this issue is provided in Lesson 17.) If an inexperienced, traditional plan with undisciplined care coordinators accesses these services indiscriminately, costs could shift to the state’s long-term care budget.
- Health plans must consider where to house and how to staff care coordination programs relative to other disease management or high-risk case management programs. Care coordination staff may need more autonomy and decision-making authority than a health plan has traditionally given other types of case management programs.

More information about the Oregon exceptional needs care coordinators and the Pennsylvania special needs units can be found at the following Web site addresses: www.omap.hr.state.or.us/managedcareplans and www.dpw.state.pa.us/omap.

Lesson 17: Carve-outs create incentives for cost-shifting and enormous challenges for care coordinators, particularly in the behavioral health arena. A capitated behavioral health program is much easier to work with than the traditional FFS system, which, according to a range of interviewees, tends to over-rely on individual therapeutic, inpatient, and institutional services. Although a capitated program does not guarantee integration of physical and behavioral health services, it can serve as a vehicle to enhance clinical management and care coordination and provide necessary infrastructure and systems. Such programs can also be held accountable for operating coordinated systems of care.

- CareOregon officials describe coordination with the state mental health program as most problematic because they do not know what alternative therapies or psychotropics have been prescribed. As the state mental health program experiences further reductions in funding, health plans providing physical health services see additional referrals for behavioral health issues. Confusion about which entity is responsible for managing, providing, and paying for the full range of behavioral health services continues to exist.

- Pennsylvania’s Keystone Mercy Health Plan would prefer “carving in” behavioral health services but recognizes that it would need to build support with the advocates by focusing on the benefits of continuity and integrated care.
- Massachusetts is one of the few states interviewed to have accomplished a measure of physical and behavioral health integration through its dual contracts with Value Options as a behavioral health managed care organization and as an administrative agent for the state’s PCCM program. The PCCM network management vendor produces “profile” reports that document the rates at which members with serious mental illness receive preventive care, such as mammograms and cervical cancer screening. These reports are shared with outpatient behavioral health providers. Value Options is also locating primary care providers in two mental health facilities to provide physical health services.

Lesson 18: Pharmacy services should be included in the health plan capitation payment because plans can practice more sophisticated clinical management than would occur in the traditional FFS system. A recent study comparing pharmacy drug prices, drug mix, and utilization rates for the TANF population concluded that, while health plans start at a price disadvantage because of preferential rebates given to the Medicaid agency, health plan clinical management efforts produce lower per member per month pharmacy costs relative to FFS.²⁵ Furthermore, including pharmacy in the overall benefit package could help health plans provide more integrated care to members while assuring adherence to clinical standards.

- Most health plans prefer to have pharmacy included in capitation rates because it allows them immediate access to drug data, which can be a highly effective tool for identifying high-risk patients and developing appropriate clinical management initiatives. AmeriGroup’s CEO in New Jersey stated that access to pharmacy data should be a priority, no matter how the benefit and financing systems are structured. A Massachusetts behavioral health plan official asserted that carving out pharmacy “is a lost opportunity.” Health plans’ desire for access to pharmacy data should be accommodated within patient privacy protections under Medicaid and HIPAA.
- In discussing the issue of prescribing drugs for mental illnesses, Pennsylvania Medicaid officials warned, “There will always be dragons there.” All interviewees, particularly consumers caught in the middle, noted the enormous tension around coordination with behavioral health providers—particularly when the health plan providing physical health care must pay for the drugs that behavioral providers prescribe.
- Managing appropriate standards of access, quality, and cost in prescribing behavioral health drugs is one of the hardest issues facing Medicaid because it

involves multiple state agencies, turf-conscious plans and providers, and a highly organized advocacy community (often supported by provider groups) that assists a very vulnerable population.

- States must revisit pharmacy rates annually to ensure that rate increases keep up with cost and utilization trends. The recent Balanced Budget Act regulations provide states with the additional flexibility to tie rates to actuarially equivalent standards rather than traditional FFS expenditures.

Quality Monitoring and Improvement

Lesson 19: States can develop a quality measurement and monitoring system for enrollees with disabilities that ensures accountability and builds on existing systems but recognizes that segmentation of data (by age, gender, and eligibility category) will be needed. Current systems for TANF and related populations (such as HEDIS and CAHPS) do not adequately reflect the complexity of chronic conditions and are insufficiently sensitive to broader dimensions of health (such as pain, functional status, and so on).²⁶ Therefore, states must also develop specialized utilization measures related to adults with disabilities.²⁷

- By separately analyzing HEDIS and CAHPS data for the SSI population, Oregon officials found problems with access to durable medical equipment and learned that people with disabilities were not receiving the same level of preventive care services, such as mammograms and pap smears, as the TANF population. The capacity to capture this kind of important information has been enhanced by managed care because of its greater focus on performance measurement and accountability.
- Pennsylvania supplements HEDIS and CAHPS information by monitoring 16 measures related to people with special needs, including cervical cancer screening for women who are HIV positive, dental visits for people with developmental disabilities, and appropriate pharmaceutical treatment for people newly diagnosed with depression.
- The Community Medical Alliance in Boston monitors rates of hospitalization for decubitus ulcers and falls or fractures within its membership of individuals with several physical disabilities. CD-4 counts, HARRT utilization, viral loads, and mortality are measures used for evaluating care for members with HIV/AIDS.
- The state of Minnesota developed a comprehensive evaluation to gauge the success of its Minnesota Disability Health Options project. It tracks six program principles: holistic focus, enrollee self-direction, integrated service coordination, disability competence, accessibility, and independent living.

Developing Quality Measures Specific to People with Disabilities

Recognizing the need to develop disability-specific quality indicators, the state of Minnesota established an evaluation consortium to identify key goals and measures for the Minnesota Disability Health Options (MnDHO) project. The consortium included consumers, AXIS Health-care, UCare Minnesota, Minnesota Department of Human Services, University of Minnesota, National Rehabilitation Hospital Center for Health and Disability Research, and the Centers for Medicare and Medicaid Services. The quality of care goals for which measures were created are listed below.

- Provide services that promote optimal health outcomes.
- Prevent health complications secondary to a person's disability.
- Increase the delivery of preventive services, such as screenings and immunizations.
- Improve or maintain functioning appropriate to an enrollee's health status and disability.
- Test the effectiveness of various clinical interventions.
- Meet the access needs of enrollees.
- Increase enrollee capacity for independent living.
- Foster and maintain optimal enrollee involvement in care delivery.
- Include the social and emotional needs of enrollees in the service delivery process.

Lesson 20: To overcome the limitations of existing measurement systems, states also use the external quality review organization (EQRO) process to develop more focused clinical quality review studies for enrollees with disabilities. States may select chronic illnesses for the performance improvement projects required under the Balanced Budget Act.

- Many states have focused on clinical care for diabetes and congestive heart failure as part of their EQRO process. Health plan disease management programs that identify high-risk patients, encourage patients and providers to adhere to evidence-based guidelines, and provide consumer and provider education offer enhanced ways to monitor and improve clinical quality of care.
- Accurate and complete collection of encounter data and access to selected medical records can assist EQRO vendors in reducing the burden and cost of such studies.²⁸
- Plans should heed emerging research on potential racial and ethnic disparities in access and outcomes to determine whether more culturally sensitive clinical quality improvement approaches are needed for minorities with disabilities.

Lesson 21: States should implement an “early warning program” to flag problems before they become systemic. Often with the help of ombudsman programs, states can monitor such areas

as complaints, grievances and appeals, denials of service, and disenrollment rates to detect early problems and develop solutions before they become systemic.

- By developing the ability to track problems with basic data rather than individual anecdotes, consumer organizations can be instrumental in detecting and reporting early problems in managed care programs.
- Once early warnings have been detected, states must commit to remedying deficiencies that are uncovered through a quality improvement process with health plans, enrollment brokers, and consumer representatives.
- States should also embrace the Institute of Medicine recommendations included in *Crossing the Quality Chasm* by developing standards for health plan performance, publicly disclosing performance information, and rewarding higher quality through financial and nonfinancial incentives.²⁹ A number of states and their plans are actively engaged in developing such programs.

For more information on how to develop an early warning system, see *Monitoring Managed Care Via an Early Warning Program* by Howard Dichter online at the Center for Health Care Strategies Web site: www.chcs.org/publications/purchasing.html.

III. Conclusion

The consensus among the state and health plan experts interviewed for this study is that managed care for people with disabilities is the right thing to do because of the potential for improving access and quality of care. Consumer opinion was less uniform, but most consumer representatives accepted the potential of managed care to add real value. Each constituency admitted to concerns in areas such as access to specialists and coordination with services not covered by the plans, especially prescription drugs and behavioral health care. Yet, each of the states studied remains committed to managed care for adults with disabilities. They understand that this approach:

- Requires political consensus—it takes time to design a model that fits a local and state marketplace and to build the partnerships with the governor, the legislature, health plans, consumers, and providers that are essential to sustaining a viable program;
- Promises budgetary predictability and cost containment (compared to prior trends) over time rather than quick fiscal relief; and
- Can deliver more prevention-oriented and coordinated care to beneficiaries and provide an accountable infrastructure upon which to build clinical quality improvement—the likes of which are rarely seen in traditional FFS Medicaid.

For the state of California to expand enrollment for beneficiaries with disabilities in mandatory managed care programs, it will have to learn from other states. California can also learn from its own very deliberative process in building the current Medi-Cal managed care program—a program that already serves millions of beneficiaries, including 161,000 people with disabilities. Partnerships between the state, counties, consumers, traditional providers,

and health plans have created an innovative and viable program in many parts of the state that is looked to nationally for leadership in areas like cultural competency and inclusion of community-based providers. The sheer size and relative stability of the California program is testimony to the fact that Medicaid can achieve its well-wrought goals with regard to improving health care services for individuals with chronic illnesses and disabilities.

Appendix A

Table A1. Overview of State Medicaid Programs for People with Disabilities (Massachusetts, New Jersey, Oregon, and Pennsylvania)³⁰

Program Features	Massachusetts	New Jersey	Oregon	Pennsylvania
Medicaid Enrollees in Managed Care	627,272 (February 2003)	657,648 (December 2002)	363,850 (December 2002)	1,013,771 (December 2002)
TANF Managed Care Model	<ul style="list-style-type: none"> • Statewide • Mandatory • MCO or PCCM • Auto-assignment to MCO or PCCM 	<ul style="list-style-type: none"> • Statewide • Mandatory • MCO • Auto-assignment to MCO 	<ul style="list-style-type: none"> • Statewide • Mandatory • MCO • Auto-assignment to MCO 	<ul style="list-style-type: none"> • Mandatory in three regions (25 counties) • Voluntary (25 additional counties) • PCCM (42 counties) • Auto-assignment to MCO in mandatory regions
Initial TANF Enrollment	1992	1995	1994	1996
SSI Managed Care Model	<ul style="list-style-type: none"> • Statewide • Mandatory • MCO or PCCM • Auto-assignment to PCCM only 	<ul style="list-style-type: none"> • Proposed statewide • Mandatory • Auto-assignment to MCO (currently suspended) 	<ul style="list-style-type: none"> • Statewide • Mandatory • MCO • Auto-assignment to MCO 	<ul style="list-style-type: none"> • Mandatory in three regions (25 counties) • Voluntary (25 additional counties) • PCCM (42 counties) • Auto-assignment to MCO in mandatory regions
Initial SSI Enrollment	1992 (Initially mandatory)	1995 (Initially voluntary; mandatory phased in by region beginning in 2000)	1995 (Initially voluntary; mandatory in 1995)	1996 (Initially voluntary; mandatory phased in by region beginning in 1997)
SSI Enrollees In Managed Care	87,500 (February 2002)	50,226 (December 2002)	53,868 (October 2002)	298,590 (September 2002)
Enrollment Administration	Enrollment broker	Enrollment broker	State/county case workers	Enrollment broker
Behavioral Health Model	<ul style="list-style-type: none"> • Capitated, statewide behavioral health program for PCCM enrollees • Part of capitation for MCO members 	<ul style="list-style-type: none"> • Fee-for-service (except for people with developmental disabilities) 	<ul style="list-style-type: none"> • Capitated, county-based behavioral health program 	<ul style="list-style-type: none"> • Capitated, county-based behavioral health program
Care Coordination Model	<ul style="list-style-type: none"> • Intensive clinical management/care coordination for PCCM members • Care management required as part of MCO contract for members with special health care needs 	<ul style="list-style-type: none"> • Case management in MCO required 	<ul style="list-style-type: none"> • Exceptional needs care coordinators (ENCCs) in MCOs 	<ul style="list-style-type: none"> • Special needs unit in MCO required • Specialist as PCP • Special needs division in state agency • Letters of agreement on coordination required between MCO and behavioral health organization and other social service entities

Table A1. (Continued)

Program Features	Massachusetts	New Jersey	Oregon	Pennsylvania
Financing Model	<ul style="list-style-type: none"> Fully capitated MCO Use of case mix information PCCM administrative fee added to FFS rate Capitated, shared risk behavioral health carve-out for PCCM members 	<ul style="list-style-type: none"> Fully capitated CDPS risk adjustment 	<ul style="list-style-type: none"> Fully capitated CDPS risk adjustment 	<ul style="list-style-type: none"> Fully capitated PCCM administrative fee Risk corridors/sharing CDPS to enhance risk adjustment implemented in January 2003
Number Of Health Plans (2002)	4 MCOs: <ul style="list-style-type: none"> 2 commercial nonprofit (1 primarily Medicaid) 2 Medicaid only 	5 MCOs: <ul style="list-style-type: none"> 2 commercial 3 Medicaid only 	14 MCOs: <ul style="list-style-type: none"> 6 commercial 8 Medicaid only 1 PCCM	7 MCOs: <ul style="list-style-type: none"> 5 Medicaid only 2 Medicaid and Medicare+Choice
Exclusions And Carve-Outs	<p>Populations:</p> <ul style="list-style-type: none"> Institutionalized Members with other insurance Persons 65 or older <p>Services:</p> <ul style="list-style-type: none"> Long-term care (more than 100 days) Personal care Adult day health Day habilitation Private duty nursing Dental Eyeglasses Hearing aids Nonemergency transportation 	<p>Populations:</p> <ul style="list-style-type: none"> Institutionalized Members in private or Medicare HMO without Medicaid contract Medicaid demonstration programs Medically needy Home- and community-based waiver program participants Presumptively eligible QMBs, SLMBs, QDWIs, QI1&2 <p>Services:</p> <ul style="list-style-type: none"> Mental health/substance abuse (except for clients of Division of Developmental Disabilities [DDD]) Outpatient rehabilitative care (physical, occupational, and speech therapy) Long-term care Personal care Medical day care Atypical antipsychotic drugs DDD/Community Care waiver program services Nonemergency transportation Abortions Family planning (in and out of plan services) Home health for nondual eligibles Inpatient psychiatric ICF-MR 	<p>Populations:</p> <ul style="list-style-type: none"> Members with other managed care Special needs children Medically needy Medically fragile children Citizen alien waived emergency medical <p>Services:</p> <ul style="list-style-type: none"> Mental health Substance abuse (one area of state; others in MCO) Dental Some psychotropic drugs Occupational therapy 	<p>Populations:</p> <ul style="list-style-type: none"> Persons residing in nursing facilities more than 30 days Nursing facility eligibles enrolled in aging waiver Ventilator-dependent and hospitalized more than 30 days <p>Services:</p> <ul style="list-style-type: none"> Emergency Medicaid Post-30-days nursing facilities Certain waiver program services

Appendix B

Table B1. Plans Interviewed: Massachusetts, New Jersey, Oregon, and Pennsylvania

	Massachusetts			New Jersey		Oregon	Pennsylvania	
Health Plan	Boston Medical Center HealthNet Plan	Network Health	Value Options	AmeriGroup New Jersey	Developmental Disabilities Health Alliance (provider organization)	CareOregon	Keystone Mercy Health Plan	Three Rivers Health Plan
Type/Plan Model	Nonprofit, safety net hospital	Nonprofit, MCO	Privately held, behavioral health organization	For-profit, MCO	For-profit	Nonprofit, MCO	Nonprofit, MCO	Privately held for-profit, MCO
Product Lines	Medicaid only	Medicaid only	Medicaid only	Medicaid only	Primary care, mental health care, and care management services	Medicaid only	Medicaid only, physical health services	Medicaid only
Medicaid TANF Enrollment (as of 12/2002)	100,000	—	330,000	90,000	0	—	157,000	—
Medicaid SSI Enrollment (as of 12/2002)	6,000	—	70,000	5,500	1,140	—	75,000	—
Combined Medicaid Enrollment (TANF and SSI)	—	49,382	—	—	—	93,000	—	186,403
Year Plan Established	1997	1997	1998 (partnership between Value Health and Options Health Care)	1995	1997	1993	1992	1996
Year of Initial SSI Enrollments	1997	1997	1996	1996	1997	1995	1995	1996
Service Area	Boston Metropolitan	Boston Metropolitan	Statewide	Statewide (20 of 21 counties)	Statewide	Statewide	Southeast PA	Southwest PA and Lehigh County

Note: Data shown is directly from the health plans interviewed. Where possible, health plans submitted enrollment information for TANF and SSI members separately. However, some health plans submitted only aggregate membership information, as displayed in the “Combined Medicaid Enrollment” row.

Table B2. Special Needs Health Plans Interviewed

	Minnesota	Michigan	Wisconsin	Massachusetts
Health Plan	AXIS (Ucare) Healthcare	Children's Choice of Michigan	Community Living Alliance	Community Medical Alliance
Type/Plan Model	Nonprofit, MCO	Nonprofit, MCO	Nonprofit, MCO,	Nonprofit, MCO
Product Lines	Medicaid Plus Medicare	Title V Program for children with special needs, Medicaid, SCHIP	Medicaid only	Adults with HIV/AIDS, children in state custody with complex medical needs, pilot program for generally disabled adults, Medicaid only
Medicaid TANF Enrollment (as of 12/2002)	0	1,500	0	0
Medicaid SSI Enrollment (as of 12/2002)	200	Data not available	122	800
Year Plan Established	2001	1998	1996	1992
Year of Initial SSI Enrollments	2001	Data not available	1996	1992
Service Area	Hennepin, Anoke, Dakota, and Ramsey Counties	Wayne, Oakland, Macomb, and St. Clair Counties	Dane County	Statewide with each program having a distinct coverage service area

Appendix C

Table C1. Interviewed State Medicaid Officials, Health Plan Executives, and Leaders from Community-Based Organizations and Specialty Plans

Massachusetts		Oregon	
Laurie Ansonge Ball	Deputy Assistant Commissioner for Program Policy, Massachusetts Division of Medical Assistance	Joseph Anderson	Chairman and Chief Executive Officer, Schaller Anderson, Inc.
Kathy Bennett	Medical Director, Boston Medical Center HealthNet Plan	Hersh Crawford	Former Director, Oregon Office of Medical Assistance Programs
Bruce Bullen	Chief Operating Officer, Harvard Pilgrim Health Care; Former Commissioner, Massachusetts Division of Medical Assistance	Maureen King	Actuarial Services Coordinator, Oregon Office of Medical Assistance Programs
Charlie Carr	Executive Director, NE Independent Living	David Labby	Medical Director, CareOregon
Ruth Ikler	Manager of Disability Policy for Office of Acute and Ambulatory Care, Massachusetts Division of Medical Assistance	Judy Mohr-Peterson	Analysis and Evaluation Manager, Oregon Office of Medical Assistance Programs
Allan Kornberg	Chief Executive Officer, Network Health	Ellen Pinney	Executive Director, Oregon Health Action Project
Michael Norton	Director of Behavioral Health, Massachusetts Division of Medical Assistance	Pennsylvania	
Phyllis Peters	Assistant Commissioner, Massachusetts Division of Medical Assistance	Gretchen Bell	Managed Care Coordinator, Liberty Resources
Rob Restuccia	Executive Director, Health Care for All/Community Catalyst	Shirley Blevins	Vice President, Medical Services, Three Rivers Health Plan
Richard Sheola	President, Public Sector Division of Value Options	Peg Dierkers	Associate, Malady & Wooten Public Affairs, Former Deputy Secretary, Pennsylvania Department of Public Welfare
Kate Willrich	Director, MCO Program, Massachusetts Division of Medical Assistance	Kit Gorton	Chief Medical Officer, Pennsylvania Department of Public Welfare
New Jersey		Karen Heim-McKean	Director, Financial Strategies, Three Rivers Health Plan
Lowell Arye	Executive Director, Alliance for the Betterment of Citizens with Disabilities	Dan Hilferty	President and Chief Executive Officer, Keystone Mercy
Ted Kastner	President, Developmental Disabilities Health Alliance	Nancy Kliman	Director, Special Needs Unit, Three Rivers Health Plan
Sandy Kelman	Chief, Bureau of Statistical Analysis, New Jersey Division of Medical Assistance	Tom Lyman	Senior Vice President, AmeriHealth Mercy Health Plan
Meg Murray	Executive Director, Association for Health Center Affiliated Health Plans; former Director, New Jersey Division of Medical Assistance	Roy Morrison	Consumer Representative Managed Care Reviewer
Bev Roberts	Program Director, The Arc of New Jersey	Carol Ranck	Director, Special Needs Division, Pennsylvania Department of Public Welfare
Jill Simone	Executive Director, New Jersey Division of Medical Assistance	Ann Torregrossa	Director, Pennsylvania Health Law Project
Norione Yukon	President and Chief Executive Officer, AMERIGROUP New Jersey	Specialty Plans	
		Bev Crider	Family Centered Care Administrator, Children's Choice of Michigan
		Chris Duff	Chief Executive Officer, AXIS Healthcare
		Sara Roberts	Director of Quality Improvement, Community Living Alliance
		Lois Simon	Vice President for Development, Community Medical Alliance

Notes

1. Regenstein, M., C. Schroer, and J. Meyer. *Medicaid Managed Care for Persons with Disabilities: A Closer Look*. Economic and Social Research Institute for the Kaiser Commission on Medicaid and the Uninsured. April 2000.
2. Schaller Anderson, Inc. *Serving the Special Program/Aged, Blind, and Disabled Population through Managed Care*. Center for Health Care Strategies. April 2002; *Maryland Health Choice Evaluation: Final Report and Recommendations*. Maryland Department of Health and Mental Hygiene. January 2002; and *Texas Star Medicaid Managed Care Report*, Second Edition, Fiscal Year 1998. Texas Department of Health. May 2000.
3. Hurley, R. *Public Sector Managed Care: A Tale of Two Trajectories*. PowerPoint presentation at the National Health Policy Forum. January 2003.
4. Medi-Cal Policy Institute. *Medi-Cal County Data Book*, 2002 Edition. Oakland, CA: January 2002.
5. Kaiser Commission on Medicaid and the Uninsured. March 2001. (Most recent data available as of December 1998.)
6. “SSI beneficiaries” is used here to represent individuals who are aged, blind, or disabled who qualify for Medicaid through their eligibility for cash assistance through the federal Supplemental Security Income program or through state 209(b) programs. Under the SSI definition of disability, an individual must have a severe medically determinable physical or mental impairment that prohibits the ability to engage in substantial gainful activity. Other pathways to Medicaid eligibility exist for people with disabilities, including the working disabled. For more information on Medicaid eligibility policy for people with disabilities, see A. Schneider, V. Strohmeier, and R. Ellberger. *Medicaid Eligibility for Individuals with Disabilities*. Kaiser Commission on Medicaid and the Uninsured. May 2000.
7. Regenstein, M., et al. (April 2000).
8. Schaller Anderson, Inc. (April 2002); Maryland Department of Health and Mental Hygiene (January 2002); and Texas Department of Health (May 2000).
9. Vladeck, B. “Where the Action Really Is: Medicaid and the Disabled.” *Health Affairs*. January/February 2003: 92.
10. Schneider, A., V. Strohmeier, and R. Ellberger. *Medicaid Eligibility for Individuals with Disabilities*. Kaiser Commission on Medicaid and the Uninsured. May 2000.
11. Hurley, R. and S. Somers. “Medicaid and Managed Care: A Lasting Relationship.” *Health Affairs*. January/February 2003: 77-87.
12. Felt-Lisk, S., R. Dodge, and M. McHugh. *Trends in Health Plans Serving Medicaid—2000 Data Update*. Kaiser Commission on Medicaid and the Uninsured. November 2001.
13. Hurley, R. and S. Somers. (January/February 2003).

14. Allen, S. and A. Croke. *The Faces of Medicaid: The Complexities of Caring for People with Chronic Illnesses and Disabilities*. Center for Health Care Strategies. November 2000: 12, 15.
15. Ibid.
16. Community Medical Alliance is forming a new nonprofit organization, Commonwealth Care Alliance, to serve people with disabilities under Medicaid and to bid to become a Senior Care Organization (SCO) in Massachusetts. SCOs will serve individuals dually eligible for Medicare and Medicaid.
17. See Connors, S., N. Highsmith, and A. Croke. *Contracting for Chronic Disease Management: The Florida Experience*. Center for Health Care Strategies. March 2001; and Bernasek, C., C. Harrington, R. Ramchand, and D. Mendelson. *The Florida Medicaid Prescription Drug Benefit: A Case Study*. Kaiser Commission on Medicaid and the Uninsured. February 2002.
18. See Code of Federal Regulations, Title 42. Public Health, Chapter IV. Centers for Medicare and Medicaid Services, Department of Health and Human Services, Sections 438.2 and 438.6(b).
19. For information about the Health Insurance Portability and Accountability Act, visit www.cms.hhs.gov/hipaa/hipaa1/default.asp.
20. For these and additional examples, see Smith, V., T. Des Jardins, and K. Peterson. *Exemplary Practices in Primary Care Case Management Programs*. Center for Health Care Strategies. June 2000.
21. Kronick, R., T. Gilmer, T. Dreyfus, and L. Lee. *Improving Health-Based Payment for Medicaid Beneficiaries: CDPS*. Health Care Financing Review. Spring 2000: 21(3).
22. Interview with Robert Hurley, Ph.D., Associate Professor. Virginia Commonwealth University. February 2, 2003.
23. Schaller Anderson, Inc. (April 2002).
24. See also Rosenbach, M. and C. Young. *Care Coordination in Medicaid Managed Care: A Primer for States, Managed Care Organizations, Providers, and Advocates*. Center for Health Care Strategies. July 2000.
25. Beronja, N., J. Menges, A. Cheng, and M. Murray. *Comparison of Medicaid Pharmacy Costs and Usage between the Fee-for-Service and Capitated Setting*. Center for Health Care Strategies. January 2003.
26. HEDIS (Health Plan Employer Data and Information Set) is a registered trademark of the National Committee for Quality Assurance. HEDIS provides a set of standardized performance measures so that purchasers and can uniformly compare the performance of managed health care plans. CAHPS (Consumer Assessment of Health Plans) is a registered trademark of the Agency for Healthcare Research and Quality. CAHPS surveys offer a standardized measurement tool to assess consumer satisfaction with and access to health care services.
27. Ireys, H., C. Thornton, and H. McKay. "Medicaid Managed Care and Working-Age Beneficiaries with Disabilities and Chronic Illnesses." *Health Care Financing Review*. Fall 2002: 24(1).
28. See also Verdier, J., R. Dodge, L. Chimento, J. Menges, and M. Forbes. *Using Data Strategically in Medicaid Managed Care*. Center for Health Care Strategies. January 2002.
29. Institute of Medicine, Committee on Quality Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy Press. 2001.
30. Gathered from state interviews and from Kaye, N. *Medicaid Managed Care: A Guide for States*, 5th edition. National Association for State Health Policy. June 2001.



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