

# **REPORT TO CONGRESS**

## ***SAFEGUARDS FOR INDIVIDUALS WITH SPECIAL HEALTH CARE NEEDS ENROLLED IN MEDICAID MANAGED CARE***

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November 6, 2000

## ACKNOWLEDGMENTS

This report was produced by a team of individuals within the Department of Health and Human Services (DHHS), under the direction of the Health Care Financing Administration's (HCFA's) Center for Medicaid and State Operations (CMSO). A 36-member work group oversaw the design and conduct of the study. We are very grateful to members of this team, who generously shared their time, talent and expertise. CMSO staff included: Kathleen Blume, Peggy Clark, Burt Cowgill, Alissa DeBoy, Tanya Ehrmann, Saul Goldberg, Frederick Harris, Pat Hufford, Patricia Kurtz, Barbara Marmion, Ann Page, Kathy Rama, and Tim Roe of HCFA's Central Office; Jack Allen and Bill Brooks of the Dallas Regional Office; Elena Byrne of the Boston Regional Office; Mark McMullen and Cindy Smith of the Denver Regional Office; Sharon Patterson of the Kansas City Regional Office; Robert Reed of the Seattle Regional Office; and Robin Strimling of the San Francisco Regional Office. Members from HCFA's Office of Strategic Planning were Linda Frisch and Donna Ronsaville. Vic Santoro represented HCFA's Center for Beneficiary Services.

Work group members from the Health Resources and Services Administration (HRSA) were: Lauren Deigh of the HIV/AIDS Bureau; Jean Hochron of the Bureau of Primary Health Care's Health Care for the Homeless Branch; Merle McPherson, MD, from the Division of Children with Special Health Care Needs; and Alexander Ross of the Center for Managed Care. Other DHHS work group members were: Eric Gopelrud of the Substance Abuse and Mental Health Services Administration (SAMHSA); Kate-Louise Gottfried and Paul Stange of the Centers for Disease Control and Prevention; Jim Harrell of the Administration for Children, Youth and Families; Fred Hellinger of the Agency for Healthcare Research and Quality (AHRQ); Gavin Kennedy and Hunter McKay of the Office of the Assistant Secretary for Planning and Evaluation (ASPE); and Sunday Mezurashi of the Administration on Aging.

Special recognition is due Burt Cowgill, Tanya Ehrmann, Linda Frisch and her colleagues at the Office of Strategic Planning, Patricia Kurtz, Mark McMullen, Ann Page, and Cindy Smith for their research, analysis and writing that underpins this report. We also thank Barbara Altman, PhD, Senior Research Fellow, AHRQ, for her consultation and guidance on disability; and Jennifer Tolbert and Claudia Williams, ASPE, for their sound policy advice and assistance in producing this report.

We also thank AHRQ for facilitating the efforts of the National Academy for State Health Policy (NASHP) to bring together representatives of beneficiaries with special health care needs and other stakeholders in order for us to fulfill our statutory requirement to consult with external parties in the conduct of this study. In particular, we thank Marcia Clark of

AHRQ; Patricia Riley and Maureen Booth of NASHP; Cheryl Barnes, AMERICORP member at the National Coalition for the Homeless; Ellen Battistelli of the Child Welfare League of America; Julie Becket and Heather McCabe of Family Voices; Miriam Brewer of the District of Columbia Alzheimer's Association; Barbara Coleman of the American Association of Retired Persons; Kathleen Cota of the Minnesota Department of Human Services; Jeffrey Crowley of the National Association of People with AIDS; Randolph DeSonia of the National Governor's Association; Mary Dewane of CalOPTIMA; Harry Gill of the Iowa Department of Human Services; Mary Graham of the National Mental Health Association; Jan Hart, Arizona Health Care Cost Containment System; Loretta Jennings, Wayne State University Health Center; Ann Clemency-Kohler, New York Department of Health; Frank McCorry, New York Office of Alcoholism and Substance Abuse; Kathleen McGinley, The ARC of the United States; Susan Neibacher, Care for the Homeless; Lee Partridge, American Public Human Services Association; Estelle Richmond, Philadelphia Department of Public Health; Patsy Riley, Allina Health System; E. Clarke Ross of the National Alliance for the Mentally Ill; Candace Schaller of the American Association of Health Plans; Marina Weiss of the March of Dimes; Linda Wertz of the Texas Health and Human Services Commission; Diane Wimmer of Arizona Physicians IPA/United Health Care; and Joel Young of the Oregon Office of Medical Assistance Programs.

We also are grateful to MSI, Inc. of New York for assistance in editing this report.

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## *Executive Summary*

One of the Federal government's goals in administering its health care programs is to assure that beneficiaries receive the care to which they are entitled under Federal law. This includes establishing safeguards for all Medicaid beneficiaries, and in particular for beneficiaries with special health care needs, in all settings of care, including managed care. The Balanced Budget Act of 1997 (BBA) enacted the first major revision in over a decade of the statutes governing Medicaid managed care. The BBA established new beneficiary protections in such areas as beneficiary information, quality assurance, and enrollee rights. It also provided States with greater flexibility in the design of their managed care initiatives by eliminating certain requirements such as those pertaining to the composition of enrollment in Medicaid-contracting Managed Care Organizations (MCOs), and allowing enrollees to disenroll without cause at any time. The BBA also allowed States to use a simpler mechanism to receive Federal permission to require certain populations to enroll in MCOs. However, the BBA prevents States from using this mechanism for other populations, including children with special health care needs, children in foster care, and Medicaid beneficiaries who also are Medicare beneficiaries. The BBA also directed the Secretary of the Department of Health and Human Service to:

*“conduct a study concerning the safeguards (if any) that may be needed to ensure that the health care needs of individuals with special health care needs and chronic conditions who are enrolled with Medicaid managed care organizations are adequately met.”*

*(Section 4705(c)(2) of the Balanced Budget Act of 1997).*

This report responds to that directive.

Individuals with special health care needs and chronic conditions (collectively referred to in this report as individuals with special health care needs) are adults and children who daily face physical, mental, or environmental challenges that place at risk their health and ability to fully function in society. They include, for example, individuals with mental retardation or related conditions; individuals with serious chronic illnesses such as Human Immunodeficiency Virus (HIV), schizophrenia, or degenerative neurological disorders; individuals with disabilities resulting from many years of chronic illness such as arthritis, emphysema or diabetes; and children and adults with certain environmental risk factors such as homelessness or family problems that lead to the need for placement in foster care.

The evidence of Medicaid MCOs' success in improving access to quality health care for individuals with special health care needs is limited and mixed. Most evaluations of Medicaid managed care have focused on the Medicaid population overall, not on

populations with special health care needs. As States increasingly enroll populations with special health care needs, access and quality of care issues have been raised. This report addresses these and related issues.

### ***Study Approach***

#### **C Managed Care**

In response to the charge from Congress, during October 1998 to August 1999 HCFA conducted a study of existing research, data and other information in a variety of areas related to the needs of special populations. The study focused on capitated Medicaid managed care initiatives, rather than the fee-for-service (FFS) form of managed care known as Primary Care Case Management used by some State Medicaid programs. This focus attempts to address concerns about the use of certain managed care practices, particularly those practices used by capitated, health maintenance organization (HMO)-type organizations, for populations with special health care needs. Such practices include; for example, restrictions on enrollee use of providers to those within a MCO's own network and the financial incentives inherent in capitation to provide less, rather than more, care.

#### **C Targeted Populations**

The study focuses on six populations identified as having special health care needs. These groups have in common the presence or increased risk of disability. They are:

- |  |  |
|--|--|
| ~ children with special health care needs                                    | ~ children in foster care                                    |
| ~ individuals with serious and persistent mental illness/<br>substance abuse | ~ non-aged adults with disabilities<br>or chronic conditions |
| ~ older adults with disabilities   | ~ individuals who are homeless                               |

#### **C Beneficiary Focused**

The study *first* identified the special requirements of beneficiaries with special health care needs, and then analyzed the interaction of these requirements with the characteristics of Medicaid managed care. The work plan for the study sought to identify: 1) the special health care needs of Medicaid beneficiaries; 2) attributes of managed care that might deter these needs from being addressed appropriately; 3) existing strategies in use by States and



MCOs to address these attributes; 4) situations in which special health care needs are not adequately addressed; and 5) safeguards that could be implemented to protect beneficiaries with special health care needs from the attributes of managed care that could deter appropriate care.

To address these issues, staff identified, evaluated, and analyzed information from a variety of sources, including evaluations of State Medicaid managed care initiatives; HCFA experiences in approving and overseeing these initiatives; State experiences in implementing safeguards for populations with special health care needs; articles in the professional literature; and consensus opinions of experts and advocates knowledgeable about the populations and the managed care initiatives that serve them. The analysis revealed a number of findings that led to a series of recommendations.

### ***Key Findings***

Study findings and the evidence cited in this report provide the framework for recommendations that address important elements of Medicaid managed care initiatives for enrollees with special health care needs. Many activities directed at addressing the unique needs of special populations are already underway, both in the States and at the Federal level. However, more work needs to be done. This Report is intended to identify and discuss a comprehensive set of recommendations to further this goal. While the Report should be considered in its full context, there are several key elements that must be present in order to ensure that the needs of populations with special health care needs are being met and services are being provided appropriately. While no single solution was identified that will ensure that beneficiaries with special health care needs will receive care that best meets their needs, two sets of activities are identified as essential ingredients, or “first tier” priorities in ensuring a successful implementation of the recommendations in this Report. These are the first two findings below: *Identification of Enrollees with Special Needs*, and *Educating and Involving Beneficiaries and Stakeholders*.

#### **C Identification of Enrollees with Special Needs**

Research tells us that individuals with special health care needs such as those included in this study typically require ongoing and specific care and services. Consequently, upon enrollment in Medicaid managed care, it is imperative that enrollees with special needs be identified as quickly as possible. States should use available data and other information to identify these enrollees. Once identified, the MCO should contact the enrollee and schedule an assessment to determine how his or her special health care needs should be addressed. (Recommendations 1 & 2)

#### **C Beneficiary and Stakeholder Education and Involvement**

A key strategy to ensure that beneficiaries receive appropriate and high quality care is to provide beneficiaries and other stakeholders the opportunity to participate in the development of managed care initiatives and to be educated about managed care. This includes education about: an enrollee’s particular MCO; the managed care delivery system in general and the differences from the FFS system; and enrollee rights and responsibilities. In addition, States and MCOs are responsible for ensuring that informational materials are comprehensive and accommodate impairments that may limit the use of the materials. States should also utilize consumer advocacy approaches (e.g. ombudsman programs, beneficiary information hotlines) to directly assist populations with special health care needs. (Recommendations 3, 4, and 5)

### **C Services that Match Needs**

As noted above, the purpose of identifying and assessing enrollees with special health care needs is to determine what services are needed to adequately serve them. The first step is for States to address the term “medical necessity” in their contracts with MCOs and to ensure compliance with medical necessity specifications. Further, States should ensure that care is provided in the most integrated setting possible and that appropriate parties are involved in the development of treatment plans. Finally, these structures and policies need to be accompanied by the necessary services and supports that correspond with each enrollee’s condition. (Recommendations 6 - 11)

### **C Access to Experienced Providers**

Individuals with special health care needs have a wide variety of health conditions and can face difficulties in finding providers with expertise in treating particular health conditions. Therefore, in developing managed care contracts, States should include provisions to ensure that providers who are experienced in delivering the appropriate care are available and accessible. To this end, States should consider allowing enrollees to see an out-of-network provider in the event that a provider experienced in treating the enrollee’s condition is not available. In addition, MCOs should permit either a standing referral or an adequate number of direct access visits to specialists as appropriate, and consider the use of specialists as primary care providers in certain circumstances. (Recommendations 12, 13 and 14)

### **C Coordinated and Continuous Care**

Another particular need of enrollees with special health care needs is coordination

of care. Beginning in June 1999, States are required to address case management services for children with special health care needs in their section 1915(b) and 1115 managed care waivers. States should also require coordination and continuity of care (including transition planning) in their contracts with MCOs. In keeping with the Consumer Bill of Rights, in the event that an enrollee is required to change MCOs or their provider is terminated by the MCO without good cause, the enrollee should have the opportunity (under certain circumstances) to continue seeing that provider for up to 90 days to allow time for transition of care and transfer of medical records. (Recommendations 15, 16, 17)

## **C Quality Monitoring**

A key focus of the proposed Medicaid managed care regulation implementing the BBA was to strengthen mechanisms for assessing and improving quality of care. In order for HCFA, the States, and the managed care industry to be held accountable for ensuring these beneficiary protections, there must be processes in place for measuring their collective performance. Further, States should require mechanisms to be in place for filing grievance and appeals that accommodate all enrollees, including those with special health care needs. States should monitor MCOs' execution of these processes with special emphasis on how they meet the unique needs of populations with special health care needs. (Recommendations 18, 19, and 20)

## **C Payment Methods**

In order to avoid the disincentives that can result from the costs of serving populations with special health care needs, it is important that these costs be taken into consideration when setting payment rates for MCOs. States should use reimbursement mechanisms to ensure that MCOs are paid rates that reflect the costs of the populations they enroll. This Report recommends further study and development of risk-adjusted payment methodologies. (Recommendations 21 and 22)

## **C Targeted Research**

As noted in the beginning of this Report, data and information about populations with special health care needs in Medicaid managed care are relatively sparse. Therefore, another important conclusion of this report is that more research needs to be done, in all areas related to managed care, and specifically concerning populations with special health care needs. The Department of Health and Human Services will promote and pursue both a long and a short term research and

demonstration agenda to further the goals of this Report. This will include developing additional screening tools for use in identifying individuals with special needs, developing and testing quality standards and performance measures, and pursuing methods for coordinating funding streams to achieve appropriate payment and more effective delivery of services to enrollees with special health care needs. (Recommendations 23 and 24)

### ***Implementation Authority***

#### **All but One Recommendation Can be Implemented Under Existing Authority**

For all but one of the recommendations, implementation can be achieved through existing DHHS regulatory or administrative authority and technical assistance and training for State Medicaid agencies and MCOs.

HCFA has already taken steps to address many of these recommendations through: 1) the rulemaking process to implement the Medicaid managed care provisions of the Balanced Budget Act of 1997 (BBA); 2) revisions to the 1915(b) waiver process; and, 3) technical assistance and training activities to States.

In its September 1998 proposed rule to implement the BBA Medicaid managed care provisions, HCFA included content addressing: timely assessment of MCO enrollees to determine the need for health care; provision of information on managed care to Medicaid beneficiaries; medical necessity; MCO provider networks, coordination and continuity of care; and Medicaid managed care grievance and appeal systems. HCFA's final rule will address these issues again in light of the comments received on the proposed rule; HCFA's analysis of the comments is informed by this report.

In addition, in June of 1999, HCFA developed draft interim criteria by which to evaluate 1915(b) and 1115 waiver requests for children with special health care needs. The draft interim waiver criteria also were informed by this report and address: identification of children with special health care needs; experienced providers; assessment of needs and coordination of care; quality of care; and payment methodologies. Additional HCFA technical assistance and training of States have addressed: use of encounter data to identify enrollees with special health care needs; effective models of stakeholder involvement in designing, implementing, and evaluating Medicaid managed care programs; and best practice approaches for assessing provider network adequacy.

However, recommendation number 17 would require new statutory authority if it is desired that it be a requirement as opposed to a recommendation. This recommendation proposes to allow enrollees in certain circumstances to continue seeing a specific out-of-network

health care provider for a specified period of time to allow for transition care.

### **Resource Implications**

All of the policy recommendations (both those requiring and those not requiring additional statutory authority) have resource implications for HCFA, States, and MCOs. The extent of resources needed to fully implement these policy recommendations will depend upon the approach to and timetable for implementation and will vary by the current status of individual States with respect to each of the following recommendations. Additionally, the recommendations for research and demonstrations also require funding.

The findings of this study, along with: 1) a description of HCFA's and States' current status with respect to the findings; 2) identification of further action to be taken by HCFA; and 3) recommendations for action to be taken by States, MCOs and others, are presented in the Compilation of Recommendations.

# Compilation of Recommendations

## *Finding 1: Enrollees with special health care needs need to be identified.*

**Current Status:** HCFA has taken administrative action to require identification of children with special health care needs as specified in the BBA for section 1915(b) and 1115 waivers. Further, in the proposed rule to implement the BBA's Medicaid managed care provisions, HCFA has proposed that MCOs screen Medicaid enrollees to timely identify their health care needs. In addition, a number of States already use strategies to quickly identify Medicaid managed care enrollees in need of care management or specialized care. To promote this practice on a more widespread basis, HCFA training conferences for State Medicaid agencies have included sessions on identifying enrollees with special health care needs. Further, in September 2000 HCFA awarded a contract to the Foundation for Accountability (Facct) to develop a screening tool to identify adults with special health care needs and to include this as part of a compendium of screening tools for use in Medicaid managed care to identify enrollees of all ages with special health care needs.

## *Actions to be taken by the Department of Health and Human Services:*

HCFA will undertake steps to obtain, on a routine and periodic basis, information from States regarding the numbers of enrollees with special health care needs in managed care initiatives by special health care needs category. This will assist in Federal and State monitoring as well as Medicaid policy and program planning. HCFA, in collaboration with other DHHS agencies (e.g., SAMHSA, HRSA, CDC) also will support and participate in developing new tools to identify beneficiaries with special care needs to assist HCFA, State Medicaid agencies and other State health agencies to effectively identify individuals with special health care needs. HCFA also will provide technical assistance to States and disseminate best practices on approaches to identifying and serving enrollees with special health care needs.

## *Recommendations for action by others:*

**Recommendation 1:** States and MCOs should undertake efforts to identify beneficiaries with special health care needs who will be or who are enrolled in MCOs. States should consider as populations with special health care needs: children with special health care needs; children in foster care; individuals with serious and persistent mental illness and/or substance abuse; individuals who are homeless; adults aged 65 or older with disabilities; and, non-elderly adults who are disabled or have chronic conditions, either physical or mental. Identification should be conducted by utilizing information sources such as: Medicaid eligibility and utilization data, information obtained at the point of enrollment in

Medicaid managed care. In addition, States should allow beneficiaries to self-identify as having a special health care need. States also may utilize (when available) data from other State and local, public and private agencies.

**Recommendation 2:** Because of the acute nature of some situations, States should require MCOs to contact as quickly as possible upon enrollment, enrollees identified by the State to the MCO as being at risk of having special health care needs to enable screening to determine the presence of special health care needs. At a minimum, this should include: children and adults receiving SSI, children in Title IV-E foster care, beneficiaries aged 65 or older, and any other beneficiary included in relevant, State-established, risk-adjusted, higher-cost payment rate categories. States should also require MCOs to implement mechanisms designed to 1) screen all other Medicaid enrollees for the presence of special health care needs and 2) identify Medicaid enrollees who develop such needs after enrollment in the MCO.

***Finding 2: Stakeholders need to be educated and involved.***

***Current Status:*** Ongoing efforts such as regularly scheduled meetings with advocacy organizations convened by HCFA, provide a vehicle for involving beneficiaries and other stakeholders in policy and program issues at the Federal level. In addition, existing Federal Medicaid regulations already require consumer involvement in States' Medicaid program policies and operations. Further, HCFA has established requirements for stakeholder involvement for section 1915(b) and 1115 waiver programs for children with special health care needs. HCFA also provides technical assistance regarding effective stakeholder involvement at the State level.

On their own authority, States are increasingly using various mechanisms to assist enrollees. For example, the number of States that operate ombudsman or advocacy programs more than doubled from 1996 (10) to 1998 (25). HCFA encourages States to provide these types of assistance programs during the review and approval process for section 1915(b) and 1115 waivers.

***Actions to be taken by the Department of Health and Human Services:***

HCFA will continue to work with States to establish and implement mechanisms for involving beneficiaries, their families (as appropriate), and other stakeholders in the design, implementation, and evaluation of managed care initiatives for beneficiaries with special health care needs. In doing so, HCFA will work with other Departmental agencies such as the Health Resources and Services Administration and the Substance Abuse and Mental Health Services Administration to facilitate the involvement of families, advocacy

organizations and other stakeholders.

***Recommendations for action by others:***

**Recommendation 3:** States and MCOs should establish and implement mechanisms for involving beneficiaries, their families (as appropriate), health and social service agencies (as appropriate), and other stakeholders in the design, implementation, and evaluation of managed care initiatives for beneficiaries with special health care needs.

**Recommendation 4:** States should educate beneficiaries with special health care needs, their families (as appropriate), and other stakeholders during the transition to managed care and during enrollment in their MCO. Beneficiary education should promote understanding of: 1) how managed care works; 2) MCO provider network provisions; 3) Medicaid benefits provided by the MCO; 4) State's responsibilities to provide access to Medicaid State Plan services not included in the MCOs' contract, and the mechanisms enrollees can use to obtain these; 5) beneficiary rights and responsibilities as MCO enrollees; 6) MCO responsibilities for care coordination, 7) MCO grievance and appeals mechanisms; and 8) the State fair-hearing process. This should include development and distribution of consumer information materials that accommodate impairments that may limit the use of such information. MCO and provider education should address the clinical and nonclinical service needs of enrollees with special health care needs.

**Recommendation 5:** States should use mechanisms such as ombudsman programs, beneficiary information hotlines, or other consumer advocacy approaches to provide direct assistance to enrollees with special health care needs in understanding and navigating both the State's managed care initiative and the MCO in which they are enrolled.

***Finding 3: Enrollees with special health care needs require services that match their needs.***

**Current Status:** HCFA requires States to address the assessment of the needs of each child with special health care needs and the development of a treatment plan based on that assessment for section 1915(b) and 1115 waivers. In addition, many States take advantage of the benefit options available in Medicaid law through the use of section 1915(b) and section 1115 waivers.

***Action to be taken by the Department of Health and Human Services:***

HCFA will evaluate State efforts to: 1) address medical necessity in their MCO contracts, consistent with the State's fee-for-service Medicaid approach; and, 2) ensure MCO



compliance with contract specifications.

DHHS will continue to play a leadership role in the assessment and dissemination of new technologies in health care.

***Recommendations for action to be taken by others:***

**Recommendation 6:** States should develop policies and procedures for their managed care initiatives that are designed to provide care to enrollees with special health care needs in the “most integrated setting” appropriate to the needs of qualified individuals with disabilities.

**Recommendation 7:** States should require MCOs to perform a comprehensive assessment and periodic reassessment of the needs of each enrollee with special health care needs. MCOs should involve each beneficiary and (as appropriate) his or her family in the development of his or her treatment plan.

**Recommendation 8:** States should ensure that necessary services and supports, including therapies and adaptive equipment, are reasonably available to enrollees who depend on them in order to function. Key mechanisms for ensuring the appropriate delivery of needed supports and services include the use of drug formularies and purchasing lists for durable medical equipment.

**Recommendation 9:** State contracts with MCOs should contain clear language regarding the extent of the MCO’s responsibilities to provide services necessary to provide health care, diagnostic services, treatment and other Medicaid-covered services to correct a health condition discovered through the early and periodic screening, diagnostic, and treatment (EPSDT) Medicaid benefit. State Medicaid agencies should clearly inform beneficiaries about this EPSDT benefit and the statutory obligation of the State to provide the service regardless of whether the needed Medicaid service is included in the MCO’s contract with the State or in a given State’s Medicaid plan.

**Recommendation 10:** States should include a requirement in their contracts that MCOs adhere to explicit State specifications for medical necessity. These specifications should provide that medical necessity determinations for enrollees with special health care needs

should not always require improvement or restoration of functioning, but may also provide services needed to maintain, or substitute for the loss of, functioning.

**Recommendation 11:** States should take advantage of the benefit flexibility within Medicaid law to maximize the ability to ensure that needed benefits are both available and

provided to Medicaid enrollees with special health care needs.

***Finding 4: Enrollees with special health care needs require access to experienced providers.***

***Current Status:*** States and HCFA routinely assess provider networks as a part of HCFA's prior approval of MCO contracts and review of section 1915 (b) and 1115 waiver applications. The BBA created new requirements for ensuring provider network adequacy. In addition, effective June 1999, HCFA requires section 1915(b) and 1115 waivers for managed care programs that include children with special health care needs to include provisions that address the need for experienced providers to serve children with special health care needs.

***Action to be taken by the Department of Health and Human Services:***

HCFA will monitor State implementation of BBA requirements for MCO provider network adequacy and access to specialists, and provide technical assistance to States in implementing practices to address the need for experienced providers. Efforts by the Department of Health and Human Service's Office of Civil Rights (OCR) to encourage more States, MCOs, and providers to seek technical assistance from OCR on Americans with Disabilities Act (ADA) requirements will continue and will be strengthened.

***Recommendations for action by others:***

**Recommendation 12:** States should require MCOs to: 1) prospectively plan for the need for certain experienced providers; and, 2) have policies and procedures in place to address unanticipated need for other experienced providers.

**Prospectively:** When a State prospectively plans to enroll beneficiaries with special health care needs in MCOs, States should require MCOs to include in their networks: 1) providers with experience in caring for pediatric and geriatric populations; 2) providers with experience in treating prospectively identified clinical conditions (e.g., HIV/AIDS); and 3) providers with experience in caring for individuals who are homeless or in foster care, to the extent these providers

exist in the MCO's service area and to the extent the applicable population is enrolled.

**Unanticipated need:** Because States will not be able to prospectively identify all clinical conditions affecting enrollees, and because of obstacles to prospectively

including all needed experienced providers in an MCO's network, States should require MCOs to have policies and practices in place to address the unanticipated need for, or limitations in the availability of, certain experienced providers within their service area. States should consider requiring that these policies include provisions to allow an enrollee to use an out-of-network provider if a provider experienced in treating the enrollee's health condition is not readily available within the MCO network.

**Recommendation 13:** States should require MCOs to take into account the unique needs of enrollees with special health care needs when implementing utilization management policies; including when authorizing an adequate number of direct access visits to specialists when required under an approved treatment plan. This should include considering standing referrals to specialists and use of specialists as primary care providers in appropriate situations.

**Recommendation 14:** States developing managed care initiatives for beneficiaries with special health care needs should ensure that MCOs and providers are as physically accessible as possible to populations they will serve, consistent with the Americans with Disabilities Act. If all providers or MCOs are not accessible, the State should assist enrollees with disabilities to locate providers or MCOs capable of meeting their unique needs.

***Finding 5: Enrollees with special health care needs require coordinated and continuous care.***

**Current Status:** Effective June 1999, HCFA requires section 1915(b) and 1115 waiver applications for managed care programs that include children with special health care needs to include provisions that address case management services for these children. Also in June 1999, HCFA sent a letter to all State Medicaid Directors advising them of the proven benefits of a special type of case management (Assertive Community Treatment (ACT) and Assertive Case Management (ACM)) for individuals with schizophrenia. The letter clarified that programs based on ACT principles can be supported under existing Medicaid policies. A number of States also have included

provisions to address transition care (i.e., care during transition from FFS to managed care) in their Medicaid managed care initiatives.

**Recommendation 15:** In contracts with MCOs, States should: 1) explicitly require MCOs to coordinate the care of Medicaid enrollees with special health care needs; and, 2) clearly delineate the scope of MCO responsibilities for care coordination (including coordination

with any other Medicaid Prepaid Health Plans (PHPs) or MCOs in which individuals are enrolled). States should also share this information with local public and private sector organizations that also serve Medicaid enrollees with special health care needs.

**Recommendation 16:** Federal, State and local agencies that provide services to populations with special health care needs should work together to increase efforts to coordinate care across different service systems.

**Recommendation 17:** States should have mechanisms to promote continuity of care in their managed care initiatives. These should include requiring MCOs to allow enrollees undergoing a course of treatment for a disabling or chronic condition at the time they involuntarily change MCOs, or when their provider is terminated by a MCO for other than cause, to continue seeing that provider for up to 90 days to allow for the transition of care. In order for this to be implemented, the provider must agree to: 1) accept the MCO's regular payment rate as payment in full; 2) provide all necessary information to the MCO; and, 3) promptly transfer all medical records with patient authorization during the transition period.

***Finding 6: Quality of care needs to be monitored.***

***Current Status:*** DHHS agencies, including HCFA, AHRQ, HRSA, and SAMHSA have undertaken initiatives to strengthen performance measures and quality standards for populations with special health care needs. In addition, HCFA has scheduled a major training conference for State Medicaid agencies on quality monitoring for the year 2000. Further, HCFA currently requires section 1915(b) and 1115 waivers that include children with special health care needs to address the use of: 1) performance measures, 2) performance improvement projects, and 3) procedures for identifying the number and types of complaints and grievances specific to children with special health care needs.

***Actions to be taken by the Department of Health and Human Services:***

DHHS, in partnership with States, advocacy organizations, MCOs and other stakeholders, will play a leadership role in developing and/or adapting performance measures, quality standards, and clinical practice guidelines that are necessary for monitoring and improving the quality of care provided to populations with special health care needs. Further, HCFA will monitor implementation of State quality assessment and improvement strategies, States' fair-hearing systems, and State oversight of internal MCO grievance and appeal systems, with specific attention to how well they address the needs of enrollees with special health care needs.

***Recommendations for action by others:***

**Recommendation 18:** States should require MCOs to undertake, as part of their internal quality assessment and performance improvement programs, initiatives that assess and improve the quality of care specific to populations with special health care needs.

**Recommendation 19:** States, as part of their quality assessment and improvement strategies required by the BBA, should monitor, and take action to improve, care specific to populations with special health care needs.

**Recommendation 20:** States should monitor MCOs' internal grievance and appeal systems for access and timeliness, and ensure that all aspects of the State fair-hearing system, including notice to enrollees, access to records, and continuation of benefits until the impartial hearing is held, are provided to enrollees with special health care needs in an accessible and timely manner.

***Finding 7: Payment methods need to reflect the service needs of populations with special health care needs.***

***Current Status:*** Many States already use reimbursement mechanisms such as risk-adjusted capitation and risk-sharing arrangements. In addition, HCFA currently requires all 1115 waiver programs to collect encounter data. HCFA has already requested contract funds to provide States with technical support in developing risk adjustment approaches.

***Action to be taken by DHHS:***

HCFA will commit resources to procure technical support to States in developing risk-adjusted payment methodologies related to populations with special health care needs.

***Action to be taken by others:***

**Recommendation 21:** States should use reimbursement mechanisms that reflect the costs of the beneficiaries they enroll. Such mechanisms include risk-adjusted capitation and risk-sharing arrangements.

**Recommendation 22:** States should collect and validate MCO encounter data to assist in the management of their Medicaid managed care initiatives. These data can be used, for

example, to assist in the identification of enrollees with special health care needs, in matching services to enrollees' needs, and in developing payment rates, as appropriate.

***Finding 8: Targeted research and demonstrations are needed.***

The analysis conducted for the report identified the need for further research and demonstrations. The conclusions are aggregated here in separate recommendations for research and demonstrations. The bases for these recommendations are found in the chapters indicated next to each recommendation below.

**Recommendation 23:** DHHS will promote and pursue a research agenda to:

- C develop additional screening tools for use in identifying individuals with special health care needs (Chapter Two);
- C develop evidence-based clinical practice guidelines to promote the delivery of quality health care to populations with special health care needs (Chapter Seven); and,
- C undertake longitudinal studies that examine the effect of alternative models of care delivery, care coordination, and benefits on the health outcomes of populations with special health care needs (Chapters Four and Six).

**Recommendation 24:** DHHS will promote demonstrations to develop and test:

- C performance measures and quality standards for use in measuring and improving the quality of care delivered to populations with special health care needs (Chapter Seven);
- C approaches to health-based risk-adjusted payment (Chapter Eight); and,
- C coordination of different funding streams, especially Medicare and Medicaid, to achieve more effective delivery of services to beneficiaries with special health care needs (Chapter Six).

# CHAPTER ONE

## Introduction

### Origins of Report

The State and Federal government-funded health insurance program known as Medicaid is a major payer of health care for individuals with special health care needs and chronic conditions. In 1997, more than six million children and adults were eligible for Medicaid on the basis of a physical, mental, or cognitive disability. The Medicaid program also insures more than half of people with AIDS in this country and up to 90% of children with AIDS (HCFA, 1997).

The elderly comprise another group of individuals with special health care needs, particularly elderly in frail health or with functional limitations. In 1997, nearly 4 million Medicaid beneficiaries were age 65 or older. Medicaid also is a significant source of health care coverage for individuals with mental health or substance abuse problems, accounting for an estimated 18.2 percent of all spending on mental health and substance abuse services in 1996. This ranked third following private insurance coverage and other state and local government payments at 26.3 percent and 18.7 percent, respectively. Medicare and out-of-pocket payments by consumers accounted for 13.4 percent and 16 percent, respectively (McKusick, 1998). Medicaid also is the primary insurer of children in foster care (Schneider and Fennel, 1999) and a significant source of health care coverage for individuals who are homeless.

Like purchasers in the private sector, State Medicaid agencies increasingly are providing health care coverage through the use of prepaid, capitated managed care organizations (MCOs)<sup>1</sup>. Contracting with such “accountable entities” for the delivery and coordination of health care offers States the potential to practice stronger “value-based purchasing,” (i.e., purchasing based on both price and quality considerations), a goal public and private sector purchasers are encouraged to pursue (The President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998). As a result, States increasingly are enrolling Medicaid beneficiaries with special health care needs into MCOs.

Managed care organizations provide, or arrange for the provision of, all services included in

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<sup>1</sup>In this report, Managed Care Organizations (MCOs) refer to organizations that are capitated for either a comprehensive set of Medicaid benefits or for less comprehensive services; e.g., managed behavioral health plans and prepaid dental plans.

a benefit package specified by the State Medicaid agency in return for a monthly capitation payment for each enrollee. Therefore, an MCO, like an indemnity insurance company, is financially at risk for the costs of providing care. In MCOs, this risk may be transferred to health care providers through different types of payment arrangements. Therefore, concerns exist that these payment arrangements can create financial incentives that could result in failure to provide needed care to enrollees with higher than average costs. Administrative procedures used by MCOs also have been cited as potentially restricting access to care. Reports of problems encountered by populations with special health care needs in accessing and receiving care under Medicaid managed care have increased these concerns (See Chapters 5 and 7.).

In response, the Special Committee on Aging of the United States Senate held four forums in 1997 entitled, “*Medicaid Managed Care: the Elderly and Others with Special Needs.*” The Committee heard testimony from beneficiary groups, State Medicaid directors, HCFA, physicians and health policy experts. The forums found that Medicaid managed care can lead to improved coordination of care and enhanced benefits, but also presents the risk that vulnerable Medicaid beneficiaries may experience significant barriers in accessing health care services (Special Committee on Aging, 1997).

As an outgrowth of the Congressional concern, the Balanced Budget Act of 1997 (BBA) included the following language:

*“The Secretary of Health and Human Services, in consultation with States, managed care organizations, the National Academy of State Health Policy, representatives of beneficiaries with special health care needs, experts in specialized health care, and others, shall conduct a study concerning the safeguards (if any) that may be needed to ensure that the health care needs of individuals with special health care needs and chronic conditions who are enrolled with Medicaid managed care organizations are adequately met.” (Section 4705(c)(2) of the Balanced Budget Act of 1997)*

This report is the response to the BBA mandate.

## **Approach to Study**

In undertaking this study, HCFA pursued a strategy designed to produce reliable and representative information to guide public policy. This approach included: 1) collaborating with stakeholders; 2) establishing clear report parameters; and, 3) employing a report methodology that was beneficiary-focused, evidence-based and targeted. In pursuing this approach, HCFA received the assistance of many other agencies within the Department of



Health and Human Services (DHHS) which are responsible for promoting better health care for populations with special health care needs. This report was reviewed by these agencies as part of the DHHS clearance process and incorporates their comments. The study was conducted during the period from October 1998 to August 1999.

**Collaboration with stakeholders.** Soon after enactment of the BBA, HCFA engaged in discussions with a wide variety of stakeholder groups. In the Fall of 1997, HCFA met with representatives of advocacy organizations and States. Throughout 1998 HCFA also met with numerous other groups, both at their request and at meetings HCFA convened. At these meetings, HCFA shared its thinking about the topic areas for study and modified the topic list based on group comments and input.

In early 1998, HCFA began a collaborative project with the Center for Health Care Strategies (CHCS) to convene a broad group of stakeholders to comment on “Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs,” (the “Key Approaches” document) (HCFA, 1998d). HCFA developed this document to provide technical assistance to States about issues related to enrolling populations with special health care needs in Medicaid MCOs. The group included representatives from State Medicaid agencies, advocacy organizations, provider membership organizations, and MCOs. HCFA asked the group to identify areas that would benefit from new or additional efforts to develop technical assistance tools for States to consider using when addressing safeguards for populations with special health care needs enrolled in managed care. As a result of that meeting, the CHCS funded two more groups to examine the identified areas. One group addressed issues related to appropriate financing of managed care; the other began work related to performance measures for populations with special health care needs. HCFA was an active participant in both projects.

Finally, HCFA entered into an inter-agency agreement with the Agency for Health Care Policy and Research (AHCPR) ( now the Agency for Healthcare Research and Quality (AHRQ))<sup>2</sup> to modify an existing contract with the National Academy for State Health Policy (NASHP) to have NASHP coordinate and chair two special meetings with another group of stakeholders to advise on the study. These participants corresponded to the categories of stakeholders specified in the BBA mandate (see page 1). The group met in March of 1999 to review and comment on proposed content areas for the study and to

identify the most critical areas for consideration. The group met again in July 1999 to comment on the draft study report and recommendations.

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<sup>2</sup>The Healthcare Research and Quality Act of 1999 reauthorized the Agency for Health Care Policy and Research and changed its name to the Agency for Healthcare Research and Quality.

**Establishing report parameters.** In consultation with Congressional staff and stakeholders, HCFA identified the following report parameters:

- C Focus on capitated managed care initiatives.** The statute called for the study to address care delivered by Medicaid MCOs. These organizations are defined in statute as MCOs at financial risk for services provided; that is, those paid on a capitation basis. In addition, where concerns about Medicaid managed care have been expressed, the concerns most often pertain to capitated forms of Medicaid managed care. Thus, the study addresses Medicaid managed care initiatives that predominantly employ capitation payment arrangements. The study does not address FFS forms of Medicaid managed care; that is, Primary Care Case Management (PCCM).
  
- C Focus on specific populations.** The statute called for the study to address safeguards needed for “individuals with special health care needs and chronic conditions.” While “chronic conditions” was easily understood, “special health care needs” was less clear. In order to clarify the populations to be addressed, HCFA consulted with staff of the Senate Special Committee on Aging, States, representatives of advocacy organizations, providers of speciality care, and other Department of Health and Human Services (DHHS) agencies. Based on their collective guidance, the study focuses on: 1) children with special health care needs; 2) children in foster care; 3) individuals with serious and persistent mental illness and/or substance abuse; 4) individuals who are homeless; 5) older adults (individuals age 65 and older) with disabilities; and, 6) non-elderly adults who are disabled or have a chronic condition, whether physical or mental. In this report, these individuals are collectively referred to as “individuals with special health care needs.” Individuals in these groups either already have functional disabilities or they live with health or social conditions that place them at risk to develop functional disabilities. Further, because these individuals are in populations with the potential for higher service needs and costs, concerns about the effects on health care of financial incentives inherent in managed care are more pertinent.

The study does not address rural populations, racial or ethnic minorities, or women. These are also populations with special health care needs, but concerns have not been raised about their increased risk as enrollees in managed care as opposed to fee-for-service. This report also did not identify beneficiaries who are dually eligible for Medicaid and Medicare as a separate category of “individuals with special health care needs.” To the extent that dually eligible beneficiaries possess the characteristics of one or more of the six targeted populations, the safeguards identified in this report will apply to them.

- C **Distinguish between safeguards and best practices.** Also consistent with the statute, the study focuses on processes that should be in place to prevent an adverse event (i.e., serve as a safeguard) as opposed to desirable practices to best serve an individual with special health care needs. Although differences between a “safeguard” and a “desirable practice” might not always be easy to distinguish, the study recommends safeguards that should be in place because the health of a beneficiary could be affected adversely without them. The study does not recommend best practices; because although desirable, they might not always be necessary.
- C **Excluded topics.** This report focuses on issues more likely to be found in, or affected by, managed care arrangements. Issues present in the health care system overall, such as culturally competent health care, confidentiality of health care information, and reducing errors in health care are not unique to managed care and thus were not the focus of this report. Similarly, the weakness of existing health care information systems is acknowledged briefly in the chapter on monitoring quality, but is not substantially addressed in this report.

**Report methodology.** Although a number of different approaches could have been used to conduct this study, HCFA chose an approach designed to produce reliable, valid, and representative information in a timely manner. The study methodology is:

- C **Beneficiary-focused.** The study focuses on the implications of the needs of beneficiaries with special health care needs when they are enrolled in Medicaid managed care. The line of inquiry sought to identify: 1) the needs of beneficiaries with special health care conditions; 2) attributes of Medicaid managed care that could adversely affect these needs; 3) strategies currently in use by States and MCOs to address these attributes; 4) situations in which needs are not well addressed; and, 5) the safeguards that should be implemented to protect beneficiaries relative to these attributes of Medicaid managed care.
- C **Evidence-based.** HCFA identified, evaluated, and analyzed existing information available from a variety of sources related to the enrollment of beneficiaries with special health care needs in Medicaid managed care. These sources included evaluations of Medicaid managed care initiatives, HCFA experiences in approving and overseeing these initiatives, articles in the professional literature, and consensus opinions of experts and advocates knowledgeable about the populations and the managed care initiatives that serve them.
- C **Targeted.** HCFA began by reviewing information on topics addressed in the *Key*

*Approaches* document. Based on this review, and on comments received from the stakeholder group that met in March 1999, HCFA identified seven areas of inquiry for the study: 1) identification of Medicaid beneficiaries with special health care needs ; 2) education and involvement of stakeholders; 3) matching services to needs; 4) access to experienced providers; 5) coordinated and continuous care; 6) quality monitoring; and, 7) aligning payment incentives. The report addresses each area in an individual chapter (see Chapters 2 through 8).

**Department-wide participation.** HCFA's Center for Medicaid and State Operations (CMSO) coordinated the study. HCFA staff served as lead analysts for the research, analysis and writing of the report, as well as sources of programmatic information and reviewers of early drafts. Other agencies within DHHS contributed significantly to the development of this study by identifying sources of information, presenting issues before the intradepartmental workgroup, writing sections of the report and reviewing drafts of this document. These agencies included: the Administration on Aging, the Administration for Children and Families, the Agency for Health Care Policy and Research, the Health Resources and Services Administration, the Office of the Assistant Secretary for Planning and Evaluation, and the Substance Abuse and Mental Health Services Administration.

### **Background Information: Four Approaches to Medicaid Managed Care Enrollment**

There are four distinct pathways through which a State can enroll Medicaid beneficiaries with special health care needs into managed care: 1) voluntary enrollment; 2) mandatory enrollment under a State Plan option; 3) mandatory enrollment through section 1915(b) waivers; and, 4) mandatory enrollment through section 1115 demonstration waivers. Federal laws and, therefore, Medicaid policies and program requirements, vary for each of these pathways. This has implications for the implementation of the safeguards recommended in this report.

**Voluntary enrollment.** States can offer enrollment in an MCO to beneficiaries on a voluntary basis at any time. Of the 18 States which offered voluntary enrollment in managed care as of August 1999, 16 offered voluntary enrollment to beneficiaries with special health care needs. The BBA includes requirements related to safeguards for Medicaid beneficiaries who enroll on a voluntary (as well as mandatory) basis in Medicaid MCOs. These safeguards address processes for disenrollment and reenrollment, provision of information to beneficiaries, specification of covered benefits, ensuring access to emergency services, protection of enrollee-provider communication, grievance procedures, adequate capacity and services of MCOs, antidiscrimination, access standards, quality monitoring procedures and MCO solvency protections. HCFA monitors compliance with these requirements by reviewing and approving all contracts between States and MCOs

in excess of \$1 million and by performing ongoing reviews of State compliance with managed care requirements on a periodic basis.

**Mandatory enrollment under a State Plan Option.** The BBA permits States, as part of an approved State plan, to require certain Medicaid beneficiaries to enroll in managed care. Some populations are excluded from this option, including: 1) children eligible for benefits under Supplemental Security Income (SSI); 2) individuals eligible for Medicaid under section 1902(e)(3) (i.e., Katie Beckett children); 3) children in foster care or other out-of-home placement; 4) children receiving foster care or adoption assistance; and 5) children receiving services through a family-centered, community-based coordinated care system that receives grant funds under section 501(a)(1)(D) of title V, and is defined by the State in terms of either program participation or special health care needs. The remaining populations with special health care needs addressed in this study may be included in managed care through the State plan option. To exercise this option, a State must submit a State plan amendment to HCFA for approval. In addition to the beneficiary protections required for voluntary enrollments enacted in the BBA (described above) that apply to all managed care initiatives in Medicaid, the statute requires that mandatory enrollees in managed care under the State plan option have a choice of at least two MCOs, except in rural areas in which a choice of primary care physicians must exist.

As of December 1, 1999 HCFA had approved one State plan amendment (for North Carolina) that requires a population with special health care needs to be enrolled in managed care. North Carolina's approved amendment mandates managed care for the adult SSI population. North Carolina previously required enrollment of this population in managed care through a waiver under section 1915(b) of the Social Security Act.

**Mandatory enrollment through section 1915(b) waivers.** States can use section 1915(b) waivers, also known as "freedom-of-choice waivers" to require beneficiaries to enroll in managed care. Waivers can be used to provide comprehensive Medicaid benefits or a limited specific set of benefits, that usually include mental health, non-emergency transportation or dental services. Section 1915(b) waivers may be approved statewide or for a defined geographic area of the State. Some States initially obtain waivers for a limited geographic area, such as a county or city, to develop and test the infrastructure before expanding to a larger area or statewide. As of 1998, eighty-six 1915(b) waivers were in effect throughout the United States. Of these 86 waivers, 57 were for capitated managed care initiatives. Forty-five of the capitated managed care waiver initiatives served populations with special health care needs (SSI-related and elderly); 15 were initiatives that solely addressed behavioral health.

HCFA reviews a State's readiness to implement a section 1915(b) waiver through a site visit. The review includes assessing the comprehensiveness of the managed care networks

and processes in place to coordinate with other programs. HCFA staff meet with stakeholder groups, including beneficiaries and advocacy organizations to receive their views on the proposed initiative. Section 1915(b) waivers are monitored for the same requirements as voluntary managed care initiatives. In addition, States must arrange for an independent evaluation or assessment (conducted by an organization external to and independent of the State Medicaid agency) of their waiver program and submit the results of the evaluation or assessment to HCFA when requesting renewal of their waiver. The independent assessment must address access to and quality of services, as well as the cost-effectiveness of the program. The independent assessment is required, at a minimum, for the first two waiver periods.

**Mandatory enrollment through section 1115 demonstration waivers.** Alternatively, States may require beneficiaries with special health care needs to enroll in Medicaid managed care under the authority provided by section 1115 of the Social Security Act. At the discretion of the Secretary of Health and Human Services (HHS), section 1115 waivers allow States to waive certain requirements of Federal law (such as freedom to choose providers of health care) when these waivers are needed to implement a demonstration project (e.g., testing an approach to comprehensive health reform). As of August 1999, seventeen States operated such mandatory managed care initiatives on a statewide basis through this type of waiver. Of these 17 States, 10 States enrolled SSI-related children; 10 States enrolled SSI-related adults; 11 States enrolled children in foster care; and 11 States enrolled individuals age 65 and older. These waivers are granted for five years and may be extended for additional one to three-year periods. Section 1115 demonstrations provide States with the flexibility to waive an array of Medicaid statutory requirements in order to improve health care delivery systems. These demonstrations must be budget-neutral by the end of the demonstration period. States may use cost savings to expand benefits or the eligible population.

Both Central and Regional Office HCFA staff review section 1115 demonstration waiver applications. Other DHHS agencies also are involved. Once a waiver is approved, HCFA staff visit a State and perform a readiness review to certify that the State is prepared to implement the Medicaid managed care initiative. States must meet and be monitored for the same requirements as voluntary managed care initiatives. In addition, States must submit to HCFA quarterly waiver reports on each section 1115 demonstration and participate in monthly telephone conferences with HCFA. HCFA has also contracted with independent research entities for evaluations of selected section 1115 demonstrations.

## CHAPTER TWO

### Identify Beneficiaries with Special Health Care Needs

**Summary:** *This study identifies six population groups with “special health care needs:” 1) children with special health care needs; 2) children in foster care; 3) individuals with serious and persistent mental illness and/or substance abuse; 4) individuals who are homeless; 5) older adults with disabilities and 6) non-elderly adults who are disabled or have chronic conditions. These groups share an increased presence or risk of disability. Thus, individually and as a group, these Medicaid managed care enrollees are likely to require a greater diversity, intensity and coordination of services than other Medicaid enrollees. In order to provide those services, MCOs and States must first identify these individuals, and the State and HCFA must have information about the individuals for monitoring, policy, and planning purposes. Historically, such identification and reporting has not occurred uniformly, in part because of past practices by HCFA, State Medicaid agencies, and MCOs; the lack of effective tools to identify such individuals; and confidentiality concerns.*

#### **Actions to be taken by the Department of Health and Human Services:**

*HCFA will undertake steps to obtain, on a routine and periodic basis, information from States regarding the numbers of enrollees with special health care needs in managed care initiatives by special health care needs category. This will assist in Federal and State monitoring as well as Medicaid policy and program planning. HCFA, in collaboration with other DHHS agencies (e.g., SAMHSA, HRSA, CDC) also will support and participate in developing new tools to identify beneficiaries with special care needs to assist HCFA, State Medicaid agencies and other State health agencies to effectively identify individuals with special health care needs. HCFA also will provide technical assistance to States and disseminate best practices on approaches to identifying and serving enrollees with special health care needs.*

#### **Recommendations for action by others:**

**Recommendation 1:** *States and MCOs should undertake efforts to identify beneficiaries with special health care needs who will be or who are enrolled in MCOs. States should consider as populations with special health care needs: children with special health care needs; children in foster care; individuals with serious and persistent mental illness and/or substance abuse; individuals who are homeless; adults aged 65 or older with disabilities; and, non-elderly adults who are disabled or have chronic conditions,*

*either physical or mental. Identification should be conducted by utilizing information sources such as: Medicaid eligibility and utilization data, information obtained at the point of enrollment in Medicaid managed care. In addition, States should allow beneficiaries to self-identify as having a special health care need. States also may utilize (when available) data from other State and local, public and private agencies.*

***Recommendation 2:*** *Because of the acute nature of some situations, States should require MCOs to contact as quickly as possible upon enrollment, enrollees identified by the State to the MCO as being at risk of having special health care needs to enable screening to determine the presence of special health care needs. At a minimum, this should include: children and adults receiving SSI, children in Title IV-E foster care, beneficiaries aged 65 or older, and any other beneficiary included in relevant, State-established, risk-adjusted, higher-cost payment rate categories. States should also require MCOs to implement mechanisms designed to 1) screen all other Medicaid enrollees for the presence of special health care needs and 2) identify Medicaid enrollees who develop such needs after enrollment in the MCO.*

### **Increased Risk for Disability a Shared Characteristic**

The BBA required the DHHS to report on safeguards for individuals with chronic conditions and “special health care needs.” While “chronic conditions,” was commonly understood, “special health care needs,” required further clarification to determine which groups would be addressed in this report. Two issues were considered: 1) because the words, “chronic conditions,” are linked in the statute with “special health care needs,” the two concepts should have some common characteristic; and 2) because the safeguards are to address those enrolled in managed care, staff sought to identify those populations for whom the structure and operational practices of an MCO had greater implications for their care rather than for the care of other individuals.

The following population groups were identified. NOTE: This report collectively refers to individuals within these groups as “individuals with special health care needs:”

- 1) children with special health care needs;
- 2) children in foster care;
- 3) individuals with serious and persistent mental illness and/or substance abuse;
- 4) individuals who are homeless;
- 5) older adults with disabilities; and,
- 6) non-elderly adults who are disabled or chronically ill with physical or mental disabilities.



Individually, and as a group, these Medicaid managed care enrollees are likely to require a greater diversity, intensity, and coordination of services than other Medicaid enrollees. Thus, the concerns frequently expressed about MCO financial incentives, utilization management practices, and provider networks could have greater implications for their care.

To distinguish these six groups from other groups that might have been included in this report (i.e., women, racial and ethnic minorities, and individuals living in rural areas), “the presence or increased risk of disability” was determined to be the defining characteristic of the populations with “special health care needs” addressed in the report. The increased risk of disability is common to the all six populations addressed in this report.

### *Varied Definitions of Disability Have a Common Attribute*

Several different authorities have defined disability. Although all differ somewhat in exact wording, each definition articulates a common understanding of disability. The United States government defines disability for a variety of different purposes, such as qualifying for disability benefits, determining eligibility for health insurance and establishing civil rights protections. Each of these definitions represents different aspects of disability, which results in over 40 different legislative definitions of disability and leads to conceptual confusion and policy debates (Mashaw and Reno, 1996).

- C The Social Security Administration (SSA), which administers the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs, provides one of the most commonly used definitions of disability. SSA defines disability as the inability to work due to a physical or mental impairment which is expected to last at least one year or result in death (Social Security Act, sections 216(i)(1) and 223(d)(1)(A)). For purposes of receiving SSI benefits, to be considered as having a childhood disability, a child must have a physical or mental impairment that results in marked and severe functional limitation and that can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months (Social Security Act, section 1614(a)(3)(C)). Qualifying for SSDI or SSI is frequently used as a pathway to Medicaid and/or Medicare eligibility. Individuals who qualify for SSI benefits are considered “categorically eligible” for Medicaid, meaning that all State Medicaid programs are required to enroll these individuals.
  
- C The Americans with Disabilities Act (ADA) defines individuals with disabilities as those with a physical or mental impairment that substantially limits a "major life activity," individuals with a record of such impairment, or individuals who believe that others regard them as having such an impairment (Americans with Disabilities

Act, 1990). The ADA provides civil rights protection to individuals with disabilities, ensuring access to services, programs, and activities in the most integrated setting. The disability definition associated with the ADA was created to protect civil rights and therefore intended to be encompassing rather than restrictive.

- C Most recently, in 1997 the Committee on Assessing Rehabilitation Science and Engineering (Committee) addressed the concept of disability. Formed under the auspices of the Institute of Medicine at the request of the United States Congress, the Committee was charged to define disability in the context of current knowledge and prevalent rehabilitation models and to evaluate federal programmatic efforts. The Committee produced a multidimensional model of disability that describes disability in a continuum from enabling to disabling. The model also acknowledges the importance of risk factors, such as social context or environment, in exacerbating or minimizing disability. Disability is understood as a limitation in performing certain roles and tasks expected in society. It is the gap between a person's capabilities and the demands of the environment (Brandt and Pope, 1997).
- C The National Center for Health Statistics (NCHS) classifies someone as having a disability if that person: 1) has a specific physical, functional, or mental/emotional disability or limiting condition; 2) has a lot of difficulty performing daily self-maintenance activities; 3) uses special equipment or devices such as a wheelchair or breathing aid; 4) is limited in major or other life activity due to physical, mental or emotional problems; 5) receives income or insurance based on disability; or, 6) has other indicators of disability such as poor overall health status, use of specialized programs or services, or other behavioral indicators of disability or developmental delay (Meyer and Zeller, 1999).
- C The World Health Organization (WHO) defines disability as the medical and societal limitations experienced by individuals when performing various activities. The WHO definition integrates a medical model of disability, which perceives disability as a problem directly caused by disease, trauma or health conditions that require medical treatment, with a social model of disability, which perceives disability as a problem of barriers to the integration of individuals with disabilities into society (WHO, 1998).

These definitions share a recognition that disability is not just a physical condition or impairment but a function of the interaction between an individual and his or her physical and social environment. Thus, two individuals with identical conditions can have different levels of disability as a result of the environments in which they live, work, and interact with others. As a result, measurement and identification of individuals often is achieved by assessing an individual's ability to perform age-appropriate activities such as walking,

bending or stooping (Haber, 1967; Verbrugge et al., 1991) bathing, dressing, feeding oneself, shopping, making meals, handling money, or decision making (Katz, 1963; Katz and Akpom, 1976). More broadly, disability can be defined by whether a person is able to work at a job, go to school, do housework, and participate in other social roles (Haber, 1967 and LaPlante, 1988). Defining disability in children is largely a determination of a child's ability to perform age-appropriate activities in school and at play (Newacheck and Halfon, 1998).

Estimates of the prevalence of disability in the United States population vary from seven to 21 percent according to the definition of disability used (21% is based on the NCHS definition). The prevalence increases with age. Using the NCHS definition, about 10 percent of children, 18 percent of school-aged children, 17 percent of nonelderly adults, and 51 percent of older adults are disabled. However, 70 percent of individuals with disabilities are children or working adults. Medicaid is the largest single source of health care financing - public or private - for the disabled. In 1997, Medicaid provided coverage for 6.8 million individuals who qualified for Medicaid on the basis of a disability (Meyer and Zeller, 1999).

#### *Many Different Individuals Are Either Disabled or At Risk for Disability*

In general, chronic illness and physiologic impairments are the major causes of disability in our society, although other factors such as environmental toxins, substance abuse, accidents, and violence can be initiating factors. The 10 most commonly occurring conditions associated with disability at all ages are heart disease, orthopedic impairments and disorders of the spine or back, osteoarthritis and allied disorders, orthopedic impairment of lower extremity, asthma, diabetes, mental disorders, eye disorders, learning disability, and mental retardation, and cancer (LaPlante, 1989). The most common causes of childhood disability are chronic conditions such as asthma, speech impairments, and mental retardation (Newacheck and Halfon, 1998).

Because disability has multiple causes, Medicaid beneficiaries with special health care needs also differ. To illustrate these differences, the six target populations are each described below. However, individuals do not fit neatly into these six categories. Rather, co-occurring illnesses and disabling conditions lead to substantial overlap among populations. For example, between 40 percent and 65 percent of patients who have had a myocardial infarction have a co-occurring depressive disorder. Approximately 25 percent of cancer patients, and between 10 percent and 27 percent of post-stroke patients, meet diagnostic criteria for major depressive disorders (National Institute of Mental Health, 1996). In addition, children with special health care needs can be homeless and then in foster care; adults can be disabled, elderly, chronically ill, and homeless.

Currently, HCFA does not collect data specifically on the numbers of beneficiaries with special health care needs enrolled in Medicaid managed care. If a target population corresponds to a Medicaid eligibility category (e.g., age, foster care) Medicaid can estimate how many beneficiaries with these special health care needs are served by the Medicaid managed care initiative. Even in these situations, Medicaid likely underestimates the number of beneficiaries with special health care needs because beneficiaries sometimes qualify for Medicaid under more than one eligibility category, but are listed under only the primary source of eligibility. Where Medicaid has estimates of the number of Medicaid beneficiaries in each special health care needs category, the number is given in each of the sections below.

**Children with special health care needs.** The DHHS Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs defines children with special health care needs as, "Those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"(McPherson, 1998). Estimates of 1994 data suggest that 12.6 million children in the United States met this definition (Newacheck et al., 1998). In 1997, Medicaid served about one million children eligible for Medicaid on the basis of a blind or disabled SSI designation (HCFA, undated).

Children with special health care needs include those with mobility, sensory, cognitive or emotional impairments; those who are dependent on medical technology; and those with high health care utilization. These children require a wide array of health-related services including: skilled primary and specialty medical care, specialized nursing and therapeutic services, rehabilitative services, family support services, equipment and supplies, and related services (McPherson, 1998). They also can require care coordination, psychosocial services, specialty hospital services, dental services, durable medical equipment, home nursing, and special nutritional support.

The BBA prohibits the mandatory enrollment of certain children with "special needs" in Medicaid MCOs except through the use of a Medicaid section 1915(b) or 1115 waiver. The BBA provision targets children in one or more of the following five categories: 1) children who are eligible for SSI; 2) children who meet the criteria of section 1902(e)(3) of Title XIX (Medicaid) of the Social Security Act pertaining, in part, to an individual requiring a level of care provided in a hospital, nursing facility or intermediate care facility but for whom it is appropriate to provide such care outside of an institution; 3) children who receive foster care or adoption assistance under part E of Title IV of the Social Security Act; or 4) children who are in foster care or otherwise in an out-of-home placement; and, 5) children who are mentioned in Title V (Maternal and Child Health Service Block Grant) of the Social Security Act in section 501(a)(1)(D) as children with special health care

needs (BBA, 1997).

**Children in foster care.** An estimated 600,000 children presently are in foster care in the United States (Lutz and Horvath, 1997). The proportion of these covered by Medicaid is unknown.

Most children are placed in foster care because of abuse or neglect in the home or the incapacity or absence of parents, although a small percentage of children are placed in foster care voluntarily by their families because of the degree of medical and/or behavioral health care needs they require. By 1996, 22 States enrolled children in foster care into Medicaid managed care; 17 States had some degree of mandatory enrollment for this population (NASHP, 1997). The BBA exempts children in foster care from mandatory enrollment in Medicaid managed care except through the use of section 1915(b) and 1115 waivers.

Children with special health care needs are found in higher proportions among children in foster care than among other groups of children (Dreyfus and Tobias, 1998). Children in foster care have disproportionately high rates of birth defects, mental illness, developmental disabilities, and chronic illnesses and disabilities (Horvath, 1997). They also might present complex medical and emotional conditions such as post-traumatic stress disorder, emotional and/or sexual abuse, exposure to alcohol and/or drugs, HIV infection, injuries from abuse, sexually transmitted diseases (STDs), and malnutrition (Lutz and Horvath, 1997; Dreyfus and Tobias, 1998). Exposure to abuse of alcohol or other drugs is implicated in at least 75 percent of foster care placements (Dreyfus and Tobias, 1998). As a result, many medical and nonmedical people are involved in the health care of these children, including social workers, foster parents, health care providers, and the courts. The large number of people involved in caring for each child in foster care requires the coordination of a broad array of social, psychological, developmental, and health care services. Every time a child is moved to a different foster home, the possibility of a new set of providers arises, further exacerbating lack of continuity of care and medical history, and potentially creating significant barriers to care as well as risk of adverse effects. For example, a child's allergy and immunization record and history of illnesses could be lost with each new foster care placement.

**Individuals with serious and persistent mental illness/substance abuse.** More than 16 million individuals (approximately 10 percent) of the adult U.S. population are estimated to have a mental or emotional problem. About half of these have more severe illness in which day-to-day activities such as work and school are affected (Willis et al., 1998). Approximately 14 percent of Medicaid beneficiaries have mental health or substance abuse disorders (Davis and O'Brien, 1996); the proportion of these who have serious and persistent mental illness is unknown.

Mental illness can be severely disabling, affecting a person's physical and social functioning. One-third of individuals with mental illness report limitations in activities of daily living. Individuals with severe and persistent mental illness or substance abuse are impaired in their ability to obtain and maintain employment (Willis et al., 1998). Mental illness and substance abuse treatment often require longer inpatient lengths of stay than other diagnoses. Inpatient care utilization rates for mental health care are 150 percent to 200 percent higher than rates for physical acute care (Larson et al., 1998).

The most common mental illness diagnoses are schizophrenia, major depression, and dual diagnosis (i.e., stress/adjustment disorders, personality disorders, childhood disorders, anxiety, and other mood disorders). Other diagnoses include manic depression or manic episodes, schizo-affective disorder, panic disorder, obsessive-compulsive disorder and Alzheimer's disease. Serious mental illness is defined as either one of the above diagnoses or as a functional impairment such as substantial interference with vocational capacity, serious interpersonal difficulties, or a suicide plan or attempt (Kessler et al., 1998).

A significant co-occurrence of severe mental illness and substance abuse exists. Up to 10 million people in the U.S. have co-occurring substance-related and mental disorders in any given year according to combined data from the National Comorbidity Study, the Epidemiological Catchment Area Studies, and estimates of homeless and institutionalized populations (Kessler, 1995; Kessler, Nelson and McGonagle, 1996). This is a reflection of the prevalence of substance abuse in the population at-large. In 1997, almost 14 million Americans used illicit drugs, most commonly marijuana and hashish. An estimated 5.5 million people used other illicit drugs (Substance Abuse and Mental Health Services Administration (SAMHSA), 1998a).

Medicaid has become increasingly important to individuals with serious and persistent mental illness and/or substance abuse. In 1996, Medicaid expenditures for mental health and substance abuse treatment exceeded \$14.4 billion (McKusick, Mark, King et al., 1998). Medicaid eligibility is tied to SSI eligibility for low-income adult disabled populations. In 1994, more than 50 percent of adults on SSI were disabled on the basis of a mental impairment. Thus, the prevalence of mental illness and substance abuse is higher in the Medicaid population than in privately insured populations. In 1996, Congress terminated SSI and Medicaid eligibility when substance abuse is the primary disabling condition, so the prevalence of substance abuse in Medicaid may decrease over time.

By February 1998, 40 States had some degree of managed care services for behavioral health and/or substance abuse services. Twenty-five States were operating managed care initiatives specific to mental health and substance abuse service needs (Bergman, 1998). Some States have chosen to carve these services out of the comprehensive managed care benefit package for medical services while other States integrate physical and mental health

care.

**Individuals who are homeless.** Individuals who are homeless are defined as those who lack a fixed, regular, and adequate night-time residence. This includes people whose primary residence either: 1) is not designed or ordinarily used as regular sleeping accommodations for humans; or, 2) is a supervised shelter designed to provide temporary living accommodations (Care for the Homeless, 1998). The number of individuals who are homeless is unknown. “Estimating the size of this population in the United States and in any particular city has been contentious and problematic, hampered by the geographic and temporal transience of homeless individuals and the logistical difficulties with sampling techniques. Numbers have ranged from 250,000 to 3 million on any specific night”(O’Connell, 1999). The number or percent of individuals who are homeless and are served by Medicaid also is unknown. However, one sample of homeless families in 10 Los Angeles shelters found that Medicaid was the primary source of insurance for 61% (O’Connell, 1999). There are no statistics on the number enrolled in Medicaid managed care.

A number of factors lead to homelessness, including: overcrowded living situations (e.g., “doubled-up” with family/friends), abusive home environments (e.g., domestic violence, unwanted youth), mental illness, addiction disorder, and unemployment/loss of income (Care for the Homeless, 1998). Individuals who are homeless have a variety of traumatic backgrounds ranging from survivors of domestic violence to disabled veterans (McMurray-Avila, 1997). Fifty percent of individuals who are homeless are estimated to be severely mentally ill (Kessler et al, 1998). An estimated 60 percent had a drug abuse or dependence problem (Kales, et al, 1995; Drake, Osher and Wallach, 1991).

The stressors involved in living on the street can contribute to, and in some cases exacerbate, health problems for those individuals who are homeless. In addition to common primary care problems (e.g., hypertension, diabetes, chronic liver and kidney disease) frequently seen in individuals who are homeless, tuberculosis and HIV/AIDS are endemic in this population. Other infectious and communicable diseases have been described, many of which are seldom seen by today’s clinician; e.g. diphtheria and infestations that result from an organism carried by lice that is the cause of trench fever. Skin diseases are extraordinarily common and can lead to costly hospitalizations for cellulitis. Foot care is a critical component of the health care of individuals who are homeless; timely podiatry can avoid limb- and life-threatening infections. Hypothermia, frostbite, trauma and violence are more common among individuals who are homeless. Poor nutrition among individuals who are homeless causes anemia as well as growth and development problems in children, and exacerbates medical problems in adults (O’Connell, 1999).

Individuals who are homeless also face many special difficulties which confound their

medical treatment, including unmet basic needs (food, shelter, clothing, etc.), lack of a telephone and mailing address, limited access to refrigeration (for both food and medication) and difficulty in locating and transporting themselves to health care providers (McMurray-Avila, 1997).

**Older adults with disabilities.** In 1999, approximately 34.5 million people in the U.S. are over the age of 65. This represents 12.7 percent of the total U.S. population (U.S. Census Bureau, 1999a). In 1997 (the most recent year for which data are available), an estimated 4.6 million adults aged 65 and older received care through the Medicaid program. Using this 1997 number as an estimate of the number served in 1999 indicates that Medicaid serves approximately 13 percent of older adults. The number of adults over age 65 is steadily increasing; by the year 2030, adults over the age of 65 are expected to constitute approximately 20 percent of the U.S. population (U.S. Census Bureau, 1999b).

Adults over the age of 65 have a higher rate and increased risk of functional disability. In 1994-95, more than half of the older adult population reported having at least one disability, and one-third reported limitations in activities due to chronic health conditions. More than 14 percent of the older adult population report difficulties in carrying out certain activities of daily living (ADLs) and 21 percent report difficulties with certain other instrumental activities of daily living (IADLs). ADLs include bathing, dressing, eating, and getting around the house. IADLs include preparing meals, shopping, managing money, using the telephone, doing housework, and taking medications (Administration on Aging (AoA), 1998).

Mental illness also is a significant co-morbidity. For example, among older Americans experiencing a physical health problem, depression rates are high; e.g., 12 percent of people hospitalized for conditions such as hip fractures or heart disease (National Institutes of Health, 1992). Mental health problems place older adults at greater risk of developing physical health problems and even dying, including risk of suicide. Although fewer older adults attempt suicide than younger people, the rate of completed suicide is highest among elderly men, who account for approximately 80 percent of suicides in those age 65 and older (Blazed, 1994; Moscicki et al., 1998; CDC, 1996). As a result of their increased rates of disability and chronic illness and comorbidities, older adults accounted for more than two-thirds of all hospital stays and almost half the total number of inpatient hospital days in 1995 (Administration on Aging, 1998).

Older adults with disabilities often require specialty care and home- and community-based services (Saucier, 1995). Although many older individuals live in the community, others require more comprehensive, residential services in nursing homes or assisted living facilities. The Medicaid program provided institutional long term care services to older adults at a cost of \$25.6 billion in 1995, almost \$8,000 per elderly beneficiary. Home



health care expenditures for older adults exceed \$3 billion (Kaiser Commission on the Future of Medicaid, 1997). The range of acute and long term care services required by this population indicates the need for flexibility in the design of a benefit package.

Approximately 10 percent of all older adults have incomes below the Federal poverty level. An additional six percent of this population is “near-poor” with income less than 125 percent of the Federal poverty level (Administration on Aging, 1998). Although virtually all individuals over 65 and certain disabled populations in the United States are enrolled in the Medicare program, Medicare requires cost-sharing that sometimes is beyond the means of low-income older adults and individuals who are disabled. Medicare’s coverage of long term care services (and some acute care services, such as outpatient prescription drugs) is limited. Thus, in addition to the 4.6 million beneficiaries who are eligible for services under Medicaid as well as Medicare, another 1.9 million have their Medicare premiums, deductibles and/or copayments paid by Medicaid.

**Non-elderly adults who are disabled or have a chronic condition.** Although older adults have the highest prevalence and risk of disability than any other age group, non-aged adults also have existing disabilities or chronic illnesses that place them at risk for disability. The 1990 Census found that an estimated 10.4 percent of the noninstitutionalized population aged 16 to 64 (or 16.4 million people) had a disability that manifests as an inability to work, or limitation in mobility or self-care (Census Bureau, 1999c). Some of these disabilities originate in childhood as a developmental disability; others result from trauma or diseases arising in adulthood, such as multiple sclerosis. Some are the result of “rare” or “orphan” diseases such as Friedreich’s Ataxia, Balo Disease, Coffin Siris syndrome, and Catel Manghe Syndrome. The National Association for Rare Disorders (NARD) defines a rare disorder as one that affects fewer than 200,000 people in the United States. NARD currently identifies more than 5,000 rare disorders.

Infection with the HIV virus is a well known chronic condition that increases an individual’s risk of disability if it progresses to AIDS. In 1996, the Centers for Disease Control and Prevention estimated that between 650,000 and 900,000 individuals were infected with HIV in 1992 (the most recent estimate available) (Karon, et al., 1996). In 1997 (the most recent full year for which estimates are available) an estimated 270,841 persons were living with AIDS (CDC, 1998b). The Medicaid program plays a critical role in caring for individuals with HIV/AIDS. HCFA actuaries estimate that Medicaid pays for care provided to over half of the population with AIDS at an estimated cost to both the Federal and State governments of 3.5 billion dollars in 1998 (HCFA, 1998a). Forty-four States and the District of Columbia enroll beneficiaries with HIV/AIDS in Medicaid managed care (Rawlings-Sekunda, 1999).

Non-aged adults who have mental or physical disabilities or a chronic condition have

diverse health care needs. This population may overlap with other groups discussed in this report, sharing defining characteristics as well as service needs. Many adults with disabilities require some assistance with ADLs, enhanced medical and social services from experienced providers (both medical and mental health), medications, habilitation, case management, transportation, durable medical equipment, assistive technology, hospice, and long term care.

## **Identification of Individuals with Special Health Care Needs Essential for Safeguards**

The diversity and intensity of the special population groups' needs, and the frequent presence of co-occurring conditions, create a challenge to serving these groups. Multiple conditions must be treated simultaneously, often by multiple service providers and with multiple funding streams (e.g., children in foster care may receive services funded by the school under an Early Intervention Plan, foster care through Titles IV-E and IV-B, Medicaid, and possibly public mental health or substance abuse funds). These service issues are addressed in the following chapters, along with safeguards that address access to services, continuity and coordination of care, monitoring quality, and utilizing appropriate payment mechanisms.

For many of these safeguards to be implemented, the State must identify individuals with such needs to the MCO at the time of enrollment, or the MCOs must identify them soon after enrollment. Several States (e.g., Missouri, Maryland, Vermont, Ohio, Utah, and Delaware) report that they provide enrollee eligibility information which may help to identify individuals with special health care needs to MCOs via electronic transmission on a daily or monthly basis (APHSA, 1999). Where individuals with special health care needs are not known to the State and the MCO at the time of enrollment (e.g., through a Medicaid eligibility code), screening of Medicaid enrollees can help MCOs identify these individuals.

Although not routinely or uniformly practiced, a number of States are beginning to screen (or require their MCOs to screen) new enrollees to help identify beneficiaries in need of case management services or specialized care. For example, Missouri reports that a health status questionnaire is administered at the time of enrollment. Similarly, Ohio has an enrollment service contractor ask a series of questions at the time of MCO enrollment to identify individuals with either special health care needs or continuity of care considerations. Utah has recently started to use a health risk assessment tool that is administered by staff who enroll Medicaid beneficiaries in MCOs. Health risk is assessed using a computerized program; the risk level is then sent to the MCO. Individuals who are deemed "high risk" are offered case management services (APHSA, 1999).

Maryland Medicaid officials report that each new MCO enrollee is sent a self-administered health risk assessment screening survey with their MCO enrollment information. Maryland officials note that most enrollees complete the screening survey and return it to the enrollment broker who then forwards it to their MCO with their other enrollment information. The survey is designed to help the MCOs identify enrollees who are high risk in order to arrange an appointment with a health care provider to conduct a comprehensive health assessment within 15 business days of the individual's enrollment. State officials note that MCOs are required to have a health care professional assess all new MCO enrollees within 90 days of enrollment (King, 1999).

In contrast, Vermont and New York report that they require MCOs to conduct health assessments on all new enrollees. The goal of these assessments is to identify enrollees who have special health care needs. New York notes that they require MCOs to provide the State with a description of how the MCO will ensure that primary care providers conduct formal health assessments. Each MCO must also inform the State about how it will identify the needs of these individuals and case manage delivery of services to members with complex or chronic medical conditions. In addition, New York requires MCOs to provide a description of training and tools provided to primary care providers to assist them in identifying individuals with special health care needs (APHS, 1999).

In spite of such practices, obstacles exist to fully identifying all enrollees with special health care needs.

### *Obstacles to Identification*

Evidence suggests that MCOs typically do not have mechanisms in place to uniformly identify all individuals with special health care needs among their enrollees. The New England Serve Project found that MCOs generally were unable to report the numbers of children with special health care needs among their enrollees (New England SERVE, 1997). Another study of individuals with disabilities in Medicaid managed care found that, despite receiving higher rates for enrollees with special health care needs, most MCOs are not likely to know whether a new Medicaid enrollee has a chronic condition or disability (Kaiser Commission on Medicaid and the Uninsured, 1999). This partly reflects MCO practices, but also results from: 1) the newness of the perceived need to identify individuals with special health care needs; 2) the underdevelopment of approaches and available tools for use in identifying individuals with special health care needs; 3) matters of timing; and, 4) confidentiality concerns on the part of enrollees and their providers.

**Recent perception of need.** Identification of beneficiaries with special health care needs received little attention under FFS Medicaid (except in outreach efforts to increase the enrollment of eligible individuals), presumably either because it was believed that FFS

Medicaid was appropriately serving beneficiaries with special health care needs or because no designated entity was accountable for delivering timely and appropriate care to these individuals. Even in voluntary Medicaid managed care initiatives, identification of individuals with special health care needs did not receive much attention. The issue has emerged only recently, along with States' more recent efforts to mandate the enrollment of greater numbers of beneficiaries with special health care needs into MCOs. As a result, Medicaid agencies today typically do not employ mechanisms for designating a beneficiary as having special health care needs.

When a special health care need is linked to Medicaid eligibility (e.g., receiving SSI), or can be ascertained from claims or encounter data (e.g. psychiatric diagnosis or use of psychiatric services), identifying a beneficiary with special health care needs can be more readily accomplished. However, other special health care needs (e.g., homelessness) are more difficult to detect. Collecting certain information on special health care needs (e.g., substance abuse, seriously and persistently mentally ill, presence of a certain disease) may raise confidentiality concerns.

A number of States have taken the initiative to ask beneficiaries for additional information at the time of eligibility determination and enrollment in an MCO. This additional information includes languages spoken and need for translation/interpreter services as well as the existence of any special health care needs. Other States could use the Medicaid enrollment or MCO choice process more aggressively to identify Medicaid beneficiaries with special health care needs. However, States attempting to identify beneficiaries with special health care needs from among all Medicaid beneficiaries will need screening tools that can effectively and efficiently identify these individuals.

**Screening tools to identify individuals with special health care needs are evolving.**

Whether the State or an MCO identifies beneficiaries with special health care needs, identification might not be as simple as asking, "Do you have any special health care needs?" Although the question likely will identify all beneficiaries with special health care needs who want their condition known, it might not be very specific in that it likely will label individuals as having special health care needs when in fact their needs are only routine. For example, beneficiaries with acute, self-limiting conditions, such as recovery from surgery, broken bones, and chronic conditions that are not necessarily complex (e.g., hypertension) might respond that they have special health care needs. Maryland reports that the first health assessment screening tool they used identified a large number of false positive readings; it identified individuals as "high risk" (and therefore in need of an appointment with a health care professional within 15 business days, instead of the 90 days required for all enrollees), when in fact, they were not high-risk. The State, MCO and consumer representatives worked to refine the instrument so that it would be more useful in identifying only those individuals in need of expedited appointments (King, 1999). More

refined tools need to be available for States and/or MCOs to use to identify beneficiaries with special health care needs and chronic conditions as defined in this study.

The need for tested and validated tools is increasingly being recognized by experts who care for individuals with special health care needs. Several instruments are becoming available that might help MCOs identify individuals who have special health care needs. The Pra Instrument (A Probability of Repeated [Hospital] Admissions), a tool developed by the University of Minnesota under Robert Wood Johnson's Chronic Care Initiatives in HMOs, has been validated as a reliable means to identify older individuals who might benefit from interventions designed to avert health crises and expensive care (Pacala et al., 1997). The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) is a similar instrument that can be used in screening children to detect those who currently have special health care needs (Stein, Westbrook and Bauman, 1997). The QuICCC contains 39 question sequences that can be administered by lay interviewers within seven to eight minutes. Tools for other populations such as nonaged adults are not yet well developed.

**Timing.** Unfortunately, a one-time request for information or screen for special health care needs, at the time of enrollment in Medicaid or in an MCO, will not be completely effective in identifying all beneficiaries with special health care needs. At the time of enrollment in Medicaid or an MCO, beneficiaries may not have special health care needs (e.g., homelessness, in foster care, chronically ill or even aged), but could develop some later. If the beneficiary, or his or her family, does not inform the State Medicaid agency or the MCO about the development of a special health care need, mechanisms for identifying individuals with special health care needs will need to be employed repeatedly.

**Confidentiality.** A study of six Medicaid managed care initiatives found that, despite financial incentives, many providers are reluctant to identify individuals with HIV because of confidentiality and other concerns (Rawlings-Sekunda and Kaye, 1998). Individuals who are homeless might find it embarrassing to admit the circumstance (Dreyfus and Tobias, 1998) and other individuals might be embarrassed to disclose substance abuse or mental illness. Risk screens also may meet with resistance among individuals who fear being labeled for more intense observation and monitoring. Especially when administered at the point of enrollment, risk screens have the potential to be viewed by the beneficiary as an aggressive act that might be perceived as identifying him or her for adverse treatment by the MCO.

### *Stronger Action Needed*

In a study conducted by the Economic and Social Research Institute, fewer than half of 58

Medicaid capitated and primary care case management initiatives<sup>3</sup> that were evaluated require MCOs to contact a new enrollee (with or without a disability) within a given time period to identify care needs (Regenstein and Schroer, 1998). HCFA's proposed rule to implement BBA provisions pertinent to Medicaid managed care could partially remedy this situation. The Notice of Proposed Rulemaking would require MCOs to conduct an initial health assessment of each enrollee within 90 days of their enrollment. The proposed rule would require States to ensure that MCOs have procedures to identify enrollees with complex and serious medical conditions in a timely manner, and that an appropriate treatment plan is implemented (HCFA, 1998b).

Other State Medicaid agencies could follow the lead of the States discussed above and develop mechanisms to identify beneficiaries with special health care needs prior to managed care enrollment. States should ensure that eligibility information that helps to identify beneficiaries with special health care needs is transmitted to MCOs upon enrollment. State eligibility codes identify beneficiaries who potentially have a special need; e.g., SSI beneficiaries, and children in foster care. In addition, all other beneficiaries whose capitation rate is risk-adjusted are known to the State. After transferring this information to MCOs, States should require the MCO to make quick contact with these enrollees in order to have their health needs assessed and a treatment plan developed and implemented.

Likewise, States could also follow the lead of other States and use enrollment brokers to identify beneficiaries who have special health care needs. For enrollees not otherwise identified, utilization and diagnosis codes should be reviewed to identify high-risk conditions, preventable hospitalizations/ER visits, poly-pharmacy or other conditions that suggest the need for intervention. States should further experiment with other practices they believe could improve identification of beneficiaries with special health care needs at the time of Medicaid eligibility determination and enrollment in a MCO; e.g., asking beneficiaries or their caregivers if they are currently homeless or in foster care.

HCFA should require State Medicaid agencies to report on the number of enrollees with special health care needs in Medicaid managed care. This could be helpful in addressing the information gap that currently exists about beneficiaries with special health care needs currently enrolled in Medicaid MCOs and in State Medicaid programs overall. In addition, HCFA, in collaboration with other DHHS agencies (e.g., SAMHSA, HRSA, CDC) should support and participate in developing new tools to identify beneficiaries with special care needs to assist HCFA, State Medicaid agencies and other State health agencies to

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<sup>3</sup> Of the 58 systems, 36 are capitated and 22 are primary care case management.

effectively identify individuals with special health care needs.

## CHAPTER THREE

### Educate and Involve Stakeholders

**Summary:** *In order for Medicaid managed care initiatives to effectively and efficiently meet enrollee needs, HCFA, States, beneficiaries or their families and caregivers, managed care organizations (MCOs), and other stakeholders need to work together to design, implement, and evaluate these initiatives. For this collaboration to be successful, stakeholders need a strong understanding of the needs, strengths, and limitations of each partner involved in delivering Medicaid managed care services to populations with special health care needs. However, there is evidence indicating that this understanding is not always present, and that the special knowledge of these stakeholders is not always applied to Medicaid managed care initiatives for populations with special health care needs.*

**Actions to be taken by the Department of Health and Human Services:**

*HCFA will continue to work with States to establish and implement mechanisms for involving beneficiaries, their families (as appropriate), and other stakeholders in the design, implementation, and evaluation of managed care initiatives for beneficiaries with special health care needs. In doing so, HCFA will work with other Departmental agencies such as the Health Resources and Services Administration and the Substance Abuse and Mental Health Services Administration to facilitate the involvement of families, advocacy organizations and other stakeholders.*

**Recommendations for action by others:**

**Recommendation 3:** *States and MCOs should establish and implement mechanisms for involving beneficiaries, their families (as appropriate), health and social service agencies (as appropriate), and other stakeholders in the design, implementation, and evaluation of managed care initiatives for beneficiaries with special health care needs.*

**Recommendation 4:** *States should educate beneficiaries with special health care needs, their families (as appropriate), and other stakeholders during the transition to managed care and during enrollment in their MCO. Beneficiary education should promote understanding of: 1) how managed care works; 2) MCO provider network provisions; 3) Medicaid benefits provided by the MCO; 4) State's responsibilities to provide access to Medicaid State Plan services not included in the MCOs' contract, and the mechanisms enrollees can use to obtain these; 5) beneficiary rights and*



*responsibilities as MCO enrollees; 6) MCO responsibilities for care coordination, 7) MCO grievance and appeals mechanisms; and 8) the State fair-hearing process. This should include development and distribution of consumer information materials that accommodate impairments that may limit the use of such information. MCO and provider education should address the clinical and nonclinical service needs of enrollees with special health care needs.*

***Recommendation 5:*** *States should use mechanisms such as ombudsman programs, beneficiary information hotlines, or other consumer advocacy approaches to provide direct assistance to enrollees with special health care needs in understanding and navigating both the State’s managed care initiative and the MCO in which they are enrolled.*

### **Many Different Stakeholders Affect the Success of Managed Care**

A number of different parties should be involved in the design, implementation, and evaluation of Medicaid managed care initiatives for beneficiaries with special health care needs. They include consumers and their caregivers and advocates, State and local public agencies serving populations with special health care needs, MCOs, and health care providers with experience in serving populations with special health care needs (General Accounting Office (GAO),1996a); Consortium for Citizens with Disabilities, 1996; Wunsch, undated).

**Consumers, caregivers and advocates.** For several reasons, consumer involvement may be the most significant ingredient in establishing a successful Medicaid managed care program. First, a basic tenet of producing any high-quality product (in this case, an effective managed care program for individuals with special health care needs) is to design the program to meet customer needs. W. Edwards Deming, the internationally renowned leader in quality improvement, believed that, “The consumer is the most important part of the production line. Quality should be aimed at the needs of the consumer, present and future.”(Deming, 1982). Second, evidence indicates that consumers play an important role in improving health outcomes (Greenfield, Kaplan and Ware, 1985; Greenfield, Kaplan et al.,1988; Kaplan, Greenfield and Ware, 1989; McGill, Rost, Flavin, Cole et al, 1991; Center for the Advancement of Health and Milbank Memorial Fund, 1999). Research on mental illness documents improved compliance with treatment and better outcomes when consumers and family members actively engage in treatment planning and are educated about the illness and treatments. Family involvement in planning and delivery of services has become a hallmark of “best practice” provision of mental health services for children and adolescents with behavioral and emotional disorders and their families (Hall, Edgar and Flynn, 1997). Without the input of consumers, managed care initiatives designed to serve these vulnerable populations run

the risk of being less than fully effective in providing high-quality health care to Medicaid beneficiaries with special health care needs.

Informal caregivers (i.e., family and friends) also are important because they are highly knowledgeable about the needs of individuals who require special health care. Approximately 25.8 million family members provide personal assistance each year to members of their household for an average of 17.9 hours per week. This yields an estimated 24 billion hours of informal caregiving by family members per year, with an estimated economic value of \$196 billion. The economic value of this informal caregiving dwarfs that of formal home health agencies (\$32 billion) and nursing home care (\$83 billion) (Arno, Levin, and Memmott, 1999). Further, some individuals with special health care needs, either because of age (e.g., children with special health care needs) or disability (e.g., those with serious and persistent mental illness) may not be able to fully advocate on their own behalf. In such instances, their caregivers or consumer advocates also provide a voice for their needs.

**Other State and local agencies.** Because of the great need for coordination between Medicaid MCOs and other programs (see Chapter 6), the involvement of governmental officials outside of the State Medicaid agency is key to the design of managed care initiatives (Saucier, 1995). The primary mission of many government agencies is to provide health and related services to populations with special health care needs (e.g., State and local mental health programs, Ryan White comprehensive AIDS programs, Maternal and Child Health programs, Programs for Children with Special Health Needs, the Older Americans Act network, child welfare agencies, special programs for the homeless, et al.). These programs possess a high degree of knowledge about individuals with special health care needs. Incorporating this knowledge into the design and implementation of Medicaid managed care programs can help ensure that: 1) MCO services meet the unique and often more intense needs of enrollees with special health care needs; and, 2) coordination with services not provided by MCOs is in place. For example, when Oregon Medicaid expanded the Oregon Health Plan (OHP) to include enrollees with special health care needs (i.e., the aged, blind, and disabled) and include mental health and chemical dependency services, much more coordination was needed with State and local agencies than was the case when OHP served the non-disabled eligible Medicaid beneficiaries (Mittler and Gold, 1999).

**Managed care organizations.** By virtue of their contracts with States, MCOs are direct partners with the State and are responsible for providing services to enrollees with special health care needs. Working with State Medicaid agencies and other stakeholders can help MCOs to adapt their routine practices and structures (such as provider networks, utilization management practices and care management procedures) to meet the service needs of beneficiaries with special health care needs before their enrollment. Because MCOs are continuously evolving, reforming and reshaping as a result of mergers, acquisitions and

other changes in their network or service system, States and other stakeholders need to collaborate with MCOs on an ongoing basis. This can help maintain an understanding of the features of managed care and how they can best be used to address the needs of populations with special health care needs.

**Health care providers with experience in serving individuals with special health care needs.** Input from providers who have substantial experience in caring for individuals with special health care needs should be obtained. Doing so can point out; for example, 1) differences in the length of time needed to examine and treat enrollees with special health care needs as compared to healthier patients; 2) structural and equipment modifications that may be necessary at service delivery sites, such as examining tables that can be lowered to accommodate patients with spinal cord injuries; and 3) the implications of childhood development on care of individuals with disabilities.

### **Education Essential to Effective Stakeholder Involvement**

The ability of stakeholders to effectively participate in the design, implementation and evaluation of Medicaid managed care programs depends upon their knowledge of: 1) the services required by individuals with special health care needs; 2) the processes MCOs use to deliver health care services; and, 3) the characteristics of the State Medicaid program under whose auspices the MCO and its health care providers deliver care. Each stakeholder group, despite having specific knowledge to assist in the design, implementation and evaluation of Medicaid managed care programs for enrollees with special health care needs, often requires increased knowledge about the targeted populations, their service delivery needs, and Medicaid managed care.

#### *Improve Beneficiary Knowledge of Managed Care*

**Need.** Evidence indicates that effective education of consumers about managed care is not implemented consistently. Even after beneficiaries are enrolled in managed care, they often lack knowledge about basic concepts, elements and practices, and the differences between managed care and FFS. This has been documented for Medicaid, Medicare and commercial health care consumers (Rowland, Rosenbaum, Simonet et al., 1995; Isaacs, 1996; McGee, Sofaer, and Kreling, 1996; GAO, 1996; Molnar, Soffel and Brandes, 1996; Dooha, 1998; Barents Group, LLC, 1998 and Hibbard, Jewett, Engelmann et al, 1998). However, because of poverty and other factors such as literacy and educational levels, the lack of knowledge may be even more acute for Medicaid beneficiaries (Perkins, Olson, Rivera and Skatrud, 1996). In part, this could be due to the lack of consumer knowledge about health care in general, across fee-for-service and managed care. In recognition of this, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, in

its Consumer Bill of Rights stated that, “Consumers have the right to receive accurate, easily understood information and some require assistance in making informed health care decisions about their health plans, professionals, and facilities.”(Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997)

**Educational considerations.** Education of Medicaid beneficiaries should address a number of special considerations. Written and other educational material need to accommodate individuals with limited reading levels and poor health literacy (i.e., lack of understanding of health and health care terminology such as “primary care provider,” “prior authorization,” “co-payment,” “non-covered benefit,” or “medically necessary”). Information should also be prepared in different languages for those whose language of preference is not English.

In addition, information strategies for populations with special health care needs should recognize that the existence of disabilities can impair receipt and understanding of information. For example, State staff familiar with cognitively impaired beneficiaries report that written materials are seldom helpful to this population; one-on-one education with the beneficiary and family is needed (GAO, 1996). HCFA market research for Medicare beneficiaries found that the blind reported better knowledge than low-vision beneficiaries of Medicare services, payment, Medicaid coverage, HMOs, choosing/finding a doctor and staying healthy, possibly because the blind have stronger support systems (Barents Group LLC, 1998a). Individuals with hearing impairments can also differ in their needs. The primary form of communication for the profoundly deaf is visual, such as American Sign Language (ASL) or print materials. Like the blind, established support groups are available to assist these beneficiaries. Beneficiaries who are not profoundly deaf, but are hard-of-hearing report a greater need for face-to-face, in-person communication that provides opportunity to read lips and ask for clarification. Closed-captioning on videotapes, television programs and advertisements also is needed to compensate for hearing deficiencies (Barents Group LLC, 1998b).

Educational strategies that reflect these needs are important to enrollees with complex health care requirements because they might have a greater need to understand how to function in a managed care environment (Lee and Scott, 1996). At times, information strategies for populations with special health care needs need to be directed to family members, who often are the real decision makers, especially for children and beneficiaries with cognitive disability or mental health problems.

**Current practices.** State Medicaid agencies most often educate beneficiaries about MCOs during the process of assisting beneficiaries in selecting an MCO. A 1996 study of State efforts to educate and enroll Medicaid beneficiaries highlighted the efforts of Minnesota, Missouri, Ohio and Washington State as exemplary. These States use a variety of

approaches to educate beneficiaries before and during their enrollment.

- C Minnesota uses public employees to provide in-person education and counseling.
- C Ohio uses in-person education and counseling, but delegates the functions to an enrollment broker.
- C Missouri uses an enrollment broker that employs a combination of in-person, telephone, and mail strategies.
- C Washington State uses mail and telephone counseling.

All four States' education and enrollment efforts are augmented by community groups, such as maternal and child health advocates, and by the MCOs, which are contractually required to inform enrollees on a continuing basis about MCO services and operations (GAO, 1996a). To facilitate an understanding of and enrollment in their Medicaid managed care initiative, Maryland issues a booklet entitled, "HealthChoice and People with Special Health Care Needs." The booklet addresses topics such as how to select an MCO, how to obtain assistance from their MCO and/or physicians, and how to secure specialized services. Maryland also issues a pamphlet describing the goals of the public mental health system, how to obtain mental health services, and how to appeal denials (APHSA, 1999).

Enrollee education should be an ongoing activity. For example, in collaboration with the local Developmental Disabilities board, CalOPTIMA developed a consumer handbook for enrollees with disabilities, based upon the questions asked most commonly by individuals with disabilities or with unique or multiple needs. The handbook is published as a supplement to the member handbook provided to all members of CalOPTIMA upon enrollment. CalOPTIMA also has new-member orientation programs specifically for members with disabilities. The purpose of the orientation is to educate members with disabilities about the managed care process, other community services, how to receive assistance from a liaison program and how to access "carve-out" services. New members are notified of these sessions in their enrollment packets and, if necessary, CalOPTIMA visits individual members in their homes. CalOPTIMA also uses disability-specific inserts in large font for its quarterly newsletter. The inserts are sent only to members with disabled enrollment codes and include such topics as: "How to Get Durable Medical Equipment," "Accessing Mental Health Services," and "Respite Care for Families" (Dewane, 1999).

It would be beneficial for these practices to be adopted more widely by MCOs. A 1999

survey<sup>4</sup> sponsored by Family Voices, revealed that families of children with special health care needs who receive Medicaid experience problems with their MCO's provision of information about (1) useful services or resources outside the MCO, (2) how to file a complaint, and (3) issues of interest to the family (Krause and Wells, 1999).

**BBA provisions.** The BBA provides that Medicaid enrollees and potential enrollees in managed care receive information about managed care entities. In a September 1998 proposed rule, HCFA proposed that information furnished to enrollees and potential enrollees take into consideration the special health care needs of beneficiaries, such as visual impairments or limited reading proficiency. HCFA proposed that information be provided to all new enrollees at the time of enrollment and to potential enrollees upon request. Information would need to be given about the benefits provided under the contract. Further, the information would need to be in sufficient detail to ensure that enrollees receive the services to which they are entitled. The names and locations of network providers, procedures for obtaining services and the MCO's policy on referrals for speciality care also would need to be provided. Any Medicaid benefits not covered under the contract would need to be specified along with information on where and how to obtain these benefits, including how transportation is provided. Lastly, information would need to be supplied on MCO grievance and appeal procedures and the State fair-hearing process.

States should undertake strong mechanisms to educate beneficiaries and their caregivers during transition to and while enrolled in MCOs. Topics should include managed care in general, how to choose a MCO, how to use the MCO once chosen, and the information categories identified in HCFA's proposed rule. HCFA has developed, under contract, a technical assistance guide to help State Medicaid agencies and others provide easily understood information to Medicaid beneficiaries. The guide, "Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies," addresses low literacy, cultural sensitivity, and translation into languages other than English, as well as information on how to help consumers understand and use information. Copies of this guide were sent to State Medicaid agencies in October 1999. States can use this guide and other materials to develop educational materials that will address the communication barriers; such as visual impairment, of populations with special health care needs.

### *Educate MCOs and Providers about Special Health Care Needs*

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<sup>4</sup> Results are from a nationwide survey of families with children with special health care needs. The sample was drawn from Family Voices mailing lists and State Title V and SSI recipients. The sample of 5,408 families of diverse socio-economic backgrounds yielded 2,220 responses (41.5%). Of these, 430 were identified as enrolled in Medicaid in States that had mandatory enrollment of SSI recipients in managed care at the time of the survey (AZ, CO, DE, FL, KS, MA, MD, OR, TN, and DC). Results reported represent these 430 families.

**Need.** MCOs and their providers need to be educated about the “special health care needs” of enrollees, the other systems of care from which enrollees receive services, and the unique aspects of treatment of individuals with special health care needs. These were the findings of a HCFA-commissioned review of literature and 51 in-depth interviews with national organizations and agencies, state agencies, advocacy groups, community-based organizations, MCOs and health providers in Tennessee and Colorado. In this study, family advocates reported low knowledge among MCOs about the special health care needs of children. Family advocates and some MCOs reported that MCO customer service representatives are not accustomed to children with special care needs and can over or under react to acute situations. Further, some MCOs demonstrated a lack of understanding of the importance of durable medical equipment (DME). For example, children with special health care needs who need DME most likely will need DME throughout their lives, and equipment must be sized properly as they grow. Advocacy groups note that MCOs may not consider these and other child development issues (Barents Group LLC, 1999c). Others report that commercial MCOs newly serving populations with special health care needs under Medicaid may not possess knowledge and expertise about networks and systems necessary to serve large numbers of elderly and disabled individuals (Checkett, 1996). In spite of this, about 30 percent of the Medicaid respondents of the 1999 Family Voices survey reported that their MCO does a “poor” job at giving families a chance to offer advice. Twenty-one report that their MCO does a “good” or “excellent” job at giving families a chance to advise their staff, and 35 percent reported that they didn’t know (Krause and Wells, 1999). A survey of the nation’s largest managed behavioral health MCOs revealed no uniform endorsement of treatment planning that involves the patient and family (Hall, Edgar and Flynn, 1997).

Individuals with special health care needs should be involved in developing and implementing their treatment plans. The Consumer Bill of Rights and Responsibilities states that this involvement is one of the seven fundamental rights of all health care consumers: “The right to fully participate in all decisions related to their health care.” Further, in order to sustain this right, “health care professionals should ensure that persons with disabilities have effective communications with members of the health care system making such decisions” (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997).

**Educational activities.** Evidence of activities to educate MCOs about populations with special health care needs is limited. Although designed with State Medicaid Agencies in mind, publications such as *Can Medicaid Work for Homeless People*, *Guidance for State Medicaid Programs*, are useful guides for MCOs and providers (Wunsch, undated). CalOPTIMA developed a resource guide for its network primary care providers. The guide informs primary care physicians about the special health care needs of members with disabilities, program requirements and resources available to providers and members,

“carved-out” services (i.e., mental health, dental health) and how to obtain services from other programs. CalOPTIMA also organized a special educational series, *Improving Health Care for Members with Disabilities*, which brought together the professional community to learn more about serving members with disabilities and other complex medical conditions. CalOPTIMA also conducts regular educational sessions to inform and guide its network case management staff about serving members with special health care needs. Sessions include information about SSI, adult day care programs for the brain-injured, incontinence assessments, depression, case management, and in-home supportive services. Evaluations of CalOPTIMA’s educational programs show that they successfully meet MCO and provider educational needs regarding individuals who are disabled or have special health care needs (CalOPTIMA,1999).

Wisconsin’s HMO initiative convenes sessions with regional mental health/substance abuse providers, subcontractors, consumers, counties and advocates to discuss the effectiveness of treatments and to brainstorm about improvements. This provides an opportunity for MCOs to share best practices despite their competition with each other. Information-sharing helps the system in continuous improvement and gives technical assistance to MCOs and providers in mental health and primary care (Riley, Rawlings-Sekunda and Pernice, 1997).

More activities to educate MCOs and providers are needed. States, as influential purchasers of managed care services, can serve as catalysts for such efforts.

#### *Educate All Stakeholders About the State’s Managed Care Strategy*

All stakeholders, including enrollees and providers, should be educated about their State’s managed care initiative (Gold, Spare and Chu, 1996). Educating stakeholders can take many different approaches. One example is CalOPTIMA’s one-day conference called, “Effectively Serving People with Disabilities through Medi-Cal Managed Care” that educated stakeholders about CalOPTIMA and how to best serve individuals with special health care needs. Sessions included why and how States use managed care to serve populations with special health care needs; consumers’ perspectives on Medicaid managed care for individuals with disabilities; case management; the development of partnerships and networks to serve individuals with disabilities; and the special health care needs of individuals with AIDS and children (Stepnick, Rybowski and Bahtia, 1997). States can use forums, such as advisory committees, to achieve the same goal. In addition, because other health and social service agencies will also play a key role in identifying individuals with special health care needs and coordinating and providing care, it is important for States to take advantage of opportunities to educate these stakeholders about the State’s strategy for managed care, and existing Federal and State policies with respect to Medicaid and managed care.



## **Enrollees with Special Health Care Needs May Need Assistance to Act on Information**

Education alone may not help enrollees navigate MCOs' structures and processes, a fact corroborated by the findings of a beneficiary survey in New York which revealed that "an overwhelming majority of Medicaid managed care enrollees encountered problems using their MCO." The three most common problems enrollees cited were: 1) receiving a plan membership card; 2) getting appointments; and, 3) obtaining care from specialists (New York City Task Force on Medicaid Managed Care Ombudsman Feasibility Study, 1997). This and other reports indicate that not all beneficiaries have the knowledge or skills to effectively act on education, once provided, or to communicate their service needs to program designers. Some training or assistance may be needed to help them understand Medicaid and managed care, as well to represent their views and interact with their MCO and State managed care initiatives (Judge David L. Bazelon Center for Mental Health Law and the Legal Action Center, 1998). Individuals with complex and debilitating health care needs should have access to assistance from someone who can intervene on their behalf.

### *Consumer Advocacy Programs Can Help Address Overall Quality*

Consumer advocacy programs also are increasingly used to educate and assist MCO enrollees, and to detect and inform States of potential problems. For example:

- C Utah reports that it has a program to assist elderly and adult disabled individuals understand and learn the skills of self-advocacy. Newly enrolled elderly and adult-disabled individuals receive a booklet that offers basic information about Medicaid MCOs and describes methods on how to become assertive in their encounters with the health care system. These new enrollees are also offered the opportunity to participate in-depth training on information and skills described in the booklet. Utah officials hope to eventually disseminate the booklet and provide the educational opportunities to all Medicaid MCO enrollees (APHSA, 1999).
- C The State of Tennessee's TennCare program has contracted with an organization that represents over 40 advocacy groups to oversee the TennCare Consumer Advocacy Line. The primary function of this telephone hotline is to assist beneficiaries with special health care needs to understand and navigate an MCO environment (APHSA, 1999). This is one of three Medicaid-operated hotlines available in Tennessee. The other two hotlines serve the general Medicaid population and the mental health population, respectively (Rawlings-Sekunda, 1999).

In *Medicaid Managed Care: A Guide for States*, NASHP reports that "the biggest change

since the 1996 survey is the increase in the use of ombudsman programs.” From 1996 to 1998, ombudsman programs increased from 10 States (26 percent of the total States with risk programs) to 25 States (56 percent of the total) (Kaye, et al., 1999). Ombudsman programs are available through State Departments of Insurance, county or local-level health agencies, MCOs and advocacy groups (Lee and Scott, 1996; Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997).

Ombudsman programs established to represent individuals who reside in nursing homes and other institutional care facilities have been successfully implemented for many years. Although there are other ombudsman programs that vary by populations, organizational structure, and scope of services, all seek to empower and assist MCO consumers and improve their overall quality of care (Horvath and Kaye, 1996; Lee and Scott, 1996; New York City Task Force on Medicaid Managed Care Ombudsman Feasibility Study, 1997; Rawlings-Sekunda, 1999). Important functions pertaining to managed care enrollees include:

- C **Educating enrollees about MCO rules of participation, enrollee rights and responsibilities, and how to select the MCO (if given a choice) and the provider(s) that best meet their needs;**
- C **Assisting enrollees to navigate State and MCO managed care structures and processes;**
- C **Helping enrollees (and their families) resolve problems that may arise with MCOs.** Most consumer advocacy programs investigate consumer problems and act as informal intermediaries between enrollees and MCOs (Rawlings-Sekunda, 1999). Their role in formal in-plan dispute resolution systems and the State's fair-hearing process (see Chapter 7) vary considerably from simply connecting the enrollee with the appropriate office to actively assisting and representing the enrollee throughout the process (Lee and Scott, 1996; Rawlings-Sekunda, 1999).
- C **Collecting and analyzing information about the types (and amount) of problems enrollees experience, how the MCO resolves or addresses the problem(s) and methods that might correct (or improve) systemic problems.** Feedback mechanisms collect and analyze information about the types of problems enrollees experience, how often the problems occur and how MCOs resolve the problems. This can help identify and correct problems, and improve the performance of MCOs and the State's overall managed care initiative. To effect change, the information needs to be fed back to MCOs and State Medicaid agency staff so they can take appropriate action. Feedback mechanisms used by consumer advocacy programs include: 1) meeting periodically with MCO staff to discuss particular

cases and patterns of problems; 2) meeting periodically with State Medicaid agency staff to discuss patterns of problems; 3) making recommendations to MCOs and Medicaid agencies to address problems identified; and, 4) issuing reports on services provided and trends identified (Lee and Scott, 1996).

Finally, consumer advocacy / ombudsman programs can provide a valuable service by helping MCO staff to understand, communicate, and provide care to enrollees with special health care needs.

A growing number of MCOs are hiring “member advocates,” that are distinct from member services employees and from independent ombudsman-like programs, in order to advocate for Medicaid enrollees. Although concern exists about the member advocate’s lack of independence from the MCO, the mechanism generally is perceived as valuable by MCOs, States and consumer representatives (National Health Law Program and Cecil G. Sheps Center for Health Services Research, 1997).

### **Formal Strategy and Commitment of Resources Needed**

Existing Federal and State laws and Medicaid program policy require States to include involved parties in planning for Medicaid managed care programs. Federal Medicaid law requires State Medicaid agencies to form and consult with a Medical Care Advisory Committee (MCAC) about health and medical care policy, and policy development and program administration. The MCAC must include consumer groups, consumer organizations and providers. In 1994, the DHHS took steps to facilitate further public input into the design of mandatory managed care State initiatives secured under section 1115 waivers. That year, DHHS published a Federal Register notice of the procedures DHHS expected States to use to involve the public in developing waived managed care initiatives. At the State level, all 50 States and the District of Columbia have enacted legislation that requires States, before implementing certain rules or standards, to publish the text of the rule and provide opportunity for public comment (Perkins, Olson, Rivera Skatrud, 1996).

The purpose of these requirements often is not appreciated until plans have gone awry. For example:

- C An evaluation of the District of Columbia’s managed care demonstration program, “Managed Care System for Disabled and Special Needs Children,” found an initial lack of consultation by the Medicaid agency with the community, and parents in particular, which created implementation problems (Coulam, et al., 1998).

- C A five-year (1995-1999) national study that explored the effect of managed care on children and adolescents with emotional and substance abuse, and their families found that family members were involved in initial planning and implementation of managed care reform in only one of 10 States (Stroul, Pires and Armstrong, 1998). The results were misinformation, unrealistic expectations and the need for mechanisms (one to two years after the start of some managed care initiatives) to adjust the system and make it more responsive to stakeholders needs and concerns. Improvements have been noted. States are beginning to: 1) create family advisory groups; 2) include family members of youth with emotional disorders on established planning and advisory bodies; 3) hold focus groups; 4) consult with family organizations regularly; and, 5) hire family advocates to fulfill various roles within managed care systems (Stroul, Pires, Armstrong, and Meyers, 1998).

Consequently, States are increasing attention to developing effective strategies for stakeholder involvement.

#### *State and MCO Strategies for Stakeholder Involvement*

**Mechanisms to involve consumers.** A 1996 review of State practices regarding consumer participation in the design and implementation of Medicaid managed care (for Medicaid beneficiaries in general) reported use of at least one of nine basic mechanisms to involve consumers: advisory boards, hotlines, grievance procedures, ombudsman programs, plan-level member advocates, focus groups, consumer surveys, hiring of beneficiary employees, and public hearings. The same study concluded that these mechanisms did not always result in successful involvement of Medicaid beneficiaries. Only three mechanisms (ombudsman, member advocates and focus groups) consistently were noted to be helpful in improving consumer protection and program accountability. Consumers or consumer advocates cited the remaining six mechanisms to be less effective in offering “real” opportunities for ongoing involvement (Perkins, Olson, Rivera and Skatrud, 1996).

The involvement of consumers and other stakeholders in the design and implementation of Medicaid managed care initiatives has increased since 1996. More than 90 percent of States report that they solicit input from advocates, consumers, MCOs and other interested parties. More than 80 percent also report soliciting input from local public health agencies and provider agencies. More than 70 percent report soliciting input from local governments, school-based health centers, and Title X family planning providers. States report a marked increase from 1996 through 1998 in the means used to gather public input. In 1998, more than 90 percent of States used ad hoc or regularly scheduled meetings; 90 percent used advisory groups; and 78 percent reported using work groups. Eighty percent of States offered stakeholders the opportunity to review and comment on written materials

such as requests for proposals and contracts (Kaye, Pernice and Pelletire, 1999).

**Practices to achieve involvement.** A study of strategies for effective consumer involvement across all 50 States identified practices that can achieve more effective involvement of consumers and other stakeholders. For example, effective advisory boards should: 1) have strong community orientation and organizations; 2) operate at the local level; 3) target special populations such as children with special health care needs or the disabled; 4) frequently use task-oriented subcommittees; 5) have a membership that includes consumers and consumer advocates that reflect the ethnic, racial and cultural composition of the Medicaid managed care program; 6) compensate consumer members for travel, child care and attendance; 7) provide resources to consumers and advocates to keep them informed and able to participate in complex media discussions; 8) meet at sites other than the State capitol, such as county offices, community centers, and public housing sites; 9) have the Board set agendas, rather than the State Medicaid agency; and, 10) have consistent State agency attendance (Perking, Olson, Rivera and Skatrud, 1996). Best practices in the use of other approaches to consumer involvement also have been identified (National Health Law Program and Cecil G. Sheps Center for Health Services Research, 1997). Reasons for the limited success of all approaches were attributed to lack of consumer knowledge about the mechanism, inadequate funding or commitment to the mechanism, and haphazard design and implementation, often without key stakeholder participation (Perkins, Olson, Rivera and Skatrud, 1996). The ability of some low-income consumers to participate actively also can be affected by limited literacy and English proficiency and lack of financial resources, transportation, child care and telephone service.

Involvement of only one constituency is not sufficient. Adequate planning and consensus among all affected parties, including: beneficiaries with disabilities and their advocates, MCOs, and other State officials, are critical to developing effective Medicaid managed care, especially during transition periods, according to the nine States with the strongest systems to serve beneficiaries with disabilities. In two States, advocates and State officials cited the value of consensus meetings, which often involve MCO management and medical staff, in ensuring a smooth transition to managed care; three States cite the importance of ongoing meetings among stakeholders to address issues as they arise (GAOa, 1996). Stakeholder involvement can address program design, implementation and evaluation.

**Involvement in program design and implementation.** A number of States have demonstrated the feasibility of involving stakeholders in the design and implementation of Medicaid managed care initiatives for populations with special health care needs:

- C Oregon's Medicaid staff held weekly meetings with MCO representatives, beneficiary representatives, and State social services agencies for more than a year

before bringing beneficiaries with disabilities into managed care. These meetings covered topics such as building a common understanding of case management and case workers. Following implementation, Medicaid staff met regularly with MCO management, medical directors and advocacy and social service agency representatives to discuss payment rates, data reporting, and other matters relating to health care. These groups occasionally formed subcommittees to study specific problems; e.g., reviewing practice guidelines and issues pertaining to children with disabilities (GAOa, 1996).

- C In Colorado, the Medicaid Managed Care Contracting Disability Working Group, composed of individuals who are disabled and their family members, MCO administrators and State personnel, formulated recommendations to address risk-adjusted rates and choice of home health agency (Perkins, Olson, Rivera and Skatrud, 1996).
- C Under Vermont's section 1115 waiver, a Quality Improvement Advisory Committee, composed of consumers, advocates, MCO representatives, providers and State staff, was established to assist the State with ongoing and comprehensive improvement of its managed care program. The advisory committee formed technical groups that focused on children with special health care needs, issues surrounding medical necessity, and behavioral health (Ammering and Mitchell, 1998).
- C CalOPTIMA uses several mechanisms to involve beneficiaries and other stakeholders. Its 13-member advisory committee is composed of community advocates (one seat is reserved for a representative of individuals with disabilities), MediCal beneficiaries and representatives of the county social services agency and health care agency. In addition, CalOPTIMA has established key workgroups to focus specifically on issues affecting enrollees with special health care needs, including: 1) an internal workgroup to target operational issues and priorities, such as service authorization and case management; and 2) an external work group consisting of advocates and other representatives from the disabled community to identify barriers to care experienced by enrollees with disabilities, ensure continuity of care and delivery of care in a sensitive and appropriate manner, evaluate the effectiveness of the current system and develop collaborative strategies with contracted health networks to improve the system of care (Dewane, 1999).

**Involvement in evaluating and monitoring managed care programs.** States can work with consumers and other constituents to evaluate and monitor managed care systems. For example, in 1995, Colorado Health Networks (CHN), a public-private partnership between ValueOptions and eight nonprofit community mental health centers, developed a Quality Improvement Steering Committee (QISC) to assist the State Medicaid agency in its

transition from FFS managed behavioral health to a managed care model. CHN established an Internal Quality Management and Improvement (IQMI) program that performed extensive monitoring and solicited input from consumer advisory boards, clinical advisory committees and quality management committees. The QISC is composed of 15 people, including Medicaid mental health consumers from each region and providers from each CMHC. CHN also includes focus groups consisting of consumers, family-members, providers, and caregivers. These groups collect updated information on treatment and quality of life issues. CHN has an aggressive program to employ consumers, including hiring a consumer as Director of Consumer Affairs. Consumers are involved in peer counseling and self-help workgroups (Britton, 1999).

## CHAPTER FOUR

### Match Services to Needs

***Summary:** Populations with special health care needs require diverse health care services. In addition to primary and specialty medical and dental care, additional medical support, patient and family support, and enabling services, they also might require unique services to accommodate or treat their special health care needs. Many of these services are covered Medicaid benefits; others are not. State Medicaid benefit coverage policies are key to maximizing Medicaid's ability to provide health services that match the health care requirements of populations with special health care needs. Ensuring that MCO enrollees with special health care needs receive services to meet their needs also requires that MCOs have in place policies and practices that incorporate knowledge about their special health care needs. In particular, MCOs may need to adopt new or modify existing practices with respect to comprehensive enrollee assessments and the application of medical necessity criteria. However, ongoing problems assessing new technology throughout the U.S. health care system will continue to thwart the provision of some appropriate services to enrollees who need them.*

***Action to be taken by the Department of Health and Human Services:***

*HCFA will evaluate State efforts to: 1) address medical necessity in their MCO contracts, consistent with the State's fee-for-service Medicaid approach; and, 2) ensure MCO compliance with contract specifications.*

*DHHS will continue to play a leadership role in the assessment and dissemination of new technologies in health care.*

***Recommendations for action to be taken by others:***

***Recommendation 6:** States should develop policies and procedures for their managed care initiatives that are designed to provide care to enrollees with special health care needs in the "most integrated setting" appropriate to the needs of qualified individuals with disabilities.*

***Recommendation 7:** States should require MCOs to perform a comprehensive assessment and periodic reassessment of the needs of each enrollee with special health care needs. MCOs should involve each beneficiary and (as appropriate) his or her*



*family in the development of his or her treatment plan.*

***Recommendation 8:*** *States should ensure that necessary services and supports, including therapies and adaptive equipment, are reasonably available to enrollees who depend on them in order to function. Key mechanisms for ensuring the appropriate delivery of needed supports and services include the use of drug formularies and purchasing lists for durable medical equipment.*

***Recommendation 9:*** *State contracts with MCOs should contain clear language regarding the extent of the MCO's responsibilities to provide services necessary to provide health care, diagnostic services, treatment and other Medicaid-covered services to correct a health condition discovered through the early and periodic screening, diagnostic, and treatment (EPSDT) Medicaid benefit. State Medicaid agencies should clearly inform beneficiaries about this EPSDT benefit and the statutory obligation of the State to provide the service regardless of whether the needed Medicaid service is included in the MCO's contract with the State or in a given State's Medicaid plan.*

***Recommendation 10:*** *States should include a requirement in their contracts that MCOs adhere to explicit State specifications for medical necessity. These specifications should provide that medical necessity determinations for enrollees with special health care needs should not always require improvement or restoration of functioning, but may also provide services needed to maintain, or substitute for the loss of, functioning.*

***Recommendation 11:*** *States should take advantage of the benefit flexibility within Medicaid law to maximize the ability to ensure that needed benefits are both available and provided to Medicaid enrollees with special health care needs.*

## **Diverse Health Services Required**

Populations with special health care needs require routine health monitoring and maintenance, specialized care for their particular disability or illness, and services to help compensate for loss of functioning caused by a disability. This often necessitates benefit packages that include: preventative and primary care services; specialty physical and mental health/ psychosocial services; occupational, physical and speech therapy; home and community based services, including services that support family needs; medical equipment; prescription medications; “enabling” services; and institutional long term care services. In general, benefit packages often need to be broader in scope and more flexible in design to meet individual needs. Care coordination services (discussed in Chapter 6) also are an integral component of a benefits package for populations with special health care

needs.

The Federal Medicaid program requires that certain of these services be provided by specifying them as “mandatory” Medicaid services for some Medicaid beneficiaries. States are permitted to offer certain other “optional” services at their discretion. Additionally, States may provide alternative or additional services if the State provides evidence that provision of these services will meet certain requirements and if the State receives permission of the Federal government to deliver these “waiver services.”

**Preventative and primary care service.** Individuals with special health care needs require routine preventive and primary health care to maintain overall good health, prevent secondary disabilities, and prevent common ailments (Young, 1997). However, evidence exists that routine health care often is overlooked and some basic primary care for children with special health care needs can be missing. For example, children with mental retardation, cerebral palsy or Down’s syndrome often experience growth retardation and need to have special attention paid to their nutritional needs for growth and development (Taylor, Wheeler, Taylor, and Griffin, 1996). Female psychiatric patients may be at risk for not receiving basic women’s health care, such as breast and pelvic examinations, Pap tests and mammograms (Steiner, Hoff, Moffet, et al, 1998). Outpatient dental services for individuals who are homeless, mentally ill or who abuse alcohol and drugs also can be overlooked. The literature reports poor oral hygiene, a high degree of dental neglect and periodontal disease (Dicks, 1995; Tesini and Fenton, 1994; Pearlman and Miller, 1998). Without early detection and provision of effective dental treatment, oral opportunistic infections may have serious adverse consequences for individuals with HIV infection (Fleishman, Schneider, Garcia, et al. 1997). Primary medical and dental care is a mandatory Medicaid service for certain Medicaid beneficiaries.

**Specialty health care services.** Individuals who have special health care needs also require access to a wide range of specialty health care services, including specialty physician and dental services; occupational, physical, and speech therapy; and hospital services. These include subspecialists and pediatric specialists as circumstances require. For example, an individual suffering from Alzheimer’s disease could need access to services from geriatricians, geriatric psychiatrists, neurologists, nurses and social workers (Leonard, 1997). Young children with developmental delays or with diagnosed conditions that have a strong chance of resulting in developmental delays might need services that include physical therapy, occupational therapy, speech-language pathology and services, audiology services and respiratory therapy (Fox and McManus, 1996). Individuals with a substance abuse problem might require freestanding and outpatient detoxification or hospital-based detoxification, as well as opioid substitution therapies, such as methadone treatment (Kushner and Moss, 1995). Individuals with HIV who abuse alcohol and drugs

could require: inpatient treatment for medical and psychiatric problems, medical management of detoxification, and basic substance abuse counseling by psychologists and psychiatrists (Selwyn and Batki, 1995). Constructing an adequate provider network and enabling access to these specialty services is discussed in Chapter 5.

**Services provided in the home and in the community.** Under the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), States are required to make Medicaid benefits available “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”(28 C.F.R. 35.130(d)). The “most integrated setting” is defined as one which “enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” The culmination of the principle of “integration” was the 1999 Supreme Court decision in *Olmstead v L.C.* 527 U.S. 581 which said that,

“Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life . . . Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment . . . Unnecessary segregation, isolation and institutionalization of people with disabilities is discrimination.” . . . “People with disabilities have a civil right to be provided with services and/or benefits in most integrated settings.”

Services that are often used to accomplish this goal include home health care services, personal care services, and patient and family support services.

Home health care services (as defined by the Medicaid program) include: 1) part-time or intermittent nursing services (as defined in the State Nurse Practice Act) that are provided by a home health agency, 2) home health aide services provided by a home health agency, and 3) medical supplies, equipment and appliances suitable for use in the home. Home health care is a mandatory Medicaid benefit for beneficiaries who are entitled to services in a nursing facility under a State plan. Almost all State Medicaid MCO contracts require coverage of home health services, with half of the States providing some description of services that must be covered (Rosenbaum, Smith, Shin, et al, 1998).

Personal care services (also known by other names such as personal attendant services, personal assistance services, or attendant care services) include (as defined by the Medicaid program) a range of human services that enable individuals with disabilities and chronic conditions to accomplish tasks that they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance or assisting so that the individual can perform the task for him/herself. Such assistance most often

relates to performance of Activities of Daily Living (ADLs) such as eating, bathing dressing, toileting, transferring and maintaining continence, and to performance of Instrumental Activities of Daily Living (IADLs). IADLs are more complex life activities and include personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management and money management. In the Medicaid program, State Medicaid agencies may offer personal care services as an optional benefit. This optional benefit would allow for personal care services to be provided separate from home health aides services provided under the mandatory Medicaid home health care services benefit. This allows its provision to individuals who may not be entitled to services in a nursing facility under a State's Medicaid plan. Medicaid personal care services must be authorized in accordance with a treatment or service plan approved by the State.

Patient and family support services include such services as home delivered meals, transportation, companion services, chore services, and respite care (Mollica and Kaye, 1997). Individuals with special health care needs require such services to support them and/or their caregivers in compensating for the loss of functioning associated with a disabling or chronic condition (Scanlon, 1997). These services also enable individuals to remain in their homes rather than live in institutions and to access health care, attend school, and engage in recreational activities. In addition, support services are critical to preventing secondary disabilities, because such services help a person with a disability avoid behaviors that might lead to secondary conditions (Young, 1997). Nondisabled individuals with special health care needs also require access to some of these services, such as family support services for children in foster care and transportation services for individuals who are homeless. Families and other regular providers of care also need respite services; i.e., the provision of a substitute caregiver for a defined time period to provide the primary caregiver with temporary relief from the stress of caregiving. Respite care is often one of the most difficult services for which to obtain coverage. Respite care, companion services and chore services are available in Medicaid only under section 1115 and 1915 waivers.

**Durable medical equipment.**<sup>5</sup> Durable medical equipment (DME) includes oxygen tanks, ventilators, wheelchairs, crutches, braces, prosthetic devices, orthotic devices, hearing aides, eyeglasses, feeding equipment, and other supplies and corrective appliances or devices. A child needing DME needs equipment appropriate to his or her size, with frequent adjustments to accommodate growth and development (Fox and McManus, 1996). Without appropriate DME, children may be limited in their ability to participate in age-appropriate

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<sup>5</sup> There is technically no Medicaid benefit entitled, "Durable Medical Equipment (DME)." The Medicaid program uses the terminology "supplies, equipment and appliances," which is the language included in the Medicaid home health care services benefit.

activities such as attending school and playing with other children.

Provision of DME is made available under Medicaid in two ways. First, as described above, Medicaid's mandatory home health services benefit includes coverage of medical supplies, equipment and appliances, suitable for use in the home. However, the scope of medical equipment to be offered is defined by States subject to Federal guidelines. Medicaid policy allows States to use lists of preapproved DME items but also requires States to have procedures for beneficiaries to request items not on the list. In evaluating these requests, States cannot deny coverage because an item is not necessary to meet the needs of "most" Medicaid beneficiaries. Further, each State must make its process for requesting nonlisted items and its evaluation criteria available to the public (HCFA, 1998f). Some State Medicaid programs place limits on what is considered DME (Rosenbaum, Smith, Shin, et al., 1998). In 1998, approximately 96 percent of State Medicaid contracts required DME coverage, but many did not define it (Kaye, Pernice, and Pelletier, 1999). Second, Federal Medicaid law allows for the provision of dentures, prosthetic devices and eyeglasses as a separate category of Medicaid optional services distinct from the home health services benefit.

**Prescription drugs.** The availability of needed prescription drugs is critical to many individuals with special health care needs. Prescribed medications are an optional benefit under State Medicaid plans, but all States have chosen this option. Once this option is chosen, States must generally cover Food and Drug Administration (FDA)-approved drugs of manufacturers participating in the Medicaid drug rebate program, including drugs newly approved by the FDA. States are permitted to manage the benefit through controls such as prior authorization, drug utilization review, and permissible exclusions. Most State Medicaid managed care contracts specify coverage of "pharmacy services" or "prescribed drugs" without further descriptions, while some States specifically list limitations and exclusions of pharmacy benefits (Rosenbaum, Smith, Shin, et al, 1998). According to the NASHP State survey of 1998 Medicaid managed care initiatives, 76 percent of State Medicaid programs require their MCOs to provide some type of prescription drug coverage for Medicaid enrollees (Kaye, Pernice, and Pelletier, 1999). As populations with special health care needs transition into managed care, it is important that drug regimens not be interrupted without a medical evaluation. For example, comprehensive prescription drug benefits are critical for individuals living with HIV/AIDS, because the emergence of combination therapy has revolutionized HIV/AIDS treatment. These Medicaid enrollees require continued drug coverage that reflect recent advances in HIV/AIDS treatment (Rawlings-Sekunda and Kaye, 1998). HCFA highlighted this existing requirement in a June 1996 letter to State Medicaid Directors about three protease inhibitors the FDA approved for the treatment of HIV/AIDS and the requirement that these be covered under Medicaid.

Coverage for prescription drugs can become complicated when a patient receives care from

both a primary care provider and a mental health provider. The primary care provider might be part of a network of an MCO under contract to provide physical health services, while the mental health provider might be under contract to a separate MCO to provide behavioral health services. These separate entities might have different drug formularies and overlapping responsibility for prescription drugs. Similar issues exist when pharmacy benefits are not a covered service under (are “carved out” of) the State’s contract with the MCO. The use of care coordination services and policies and procedures governing information sharing can help clarify these discrepancies (Riley, Rawlings-Sekunda, Pernice, 1997).

**Enabling services.** Enabling services comprise an extensive array of services, devices and activities aimed at reducing barriers to accessing needed care. Depending on an enrollee’s special health care needs, a customized mix of enabling services may be required. An enrollee who is homeless might need outreach, transportation, education and information services, while a child with special health care needs might require nutrition and transportation services. Individuals with HIV/AIDS might need transportation, housing and food assistance (Lewis-Idema and Jonas, 1994) and child care to attend medical appointments. Older adults who are disabled and the frail elderly often require enabling services to assist them to access health care. For example, financial management and transportation may be required (O’Connell, 1999). Other possible enabling services include home visits, interpretation services and translation of written materials (Kaye, Pernice, & Pelletier, 1999).

States maintain various requirements for enabling services in their Medicaid managed care initiatives. Either they require MCOs to provide specific enabling services or they leave it to the MCO’s discretion to determine what enabling services it provides. A recent NASHP survey found that Medicaid agencies frequently require MCOs to provide care coordinators, interpreters, and translation of written material. Although not required by contract to do so, some MCOs voluntarily offer outreach workers, enrollee needs assessments, home visits, and nonemergency transportation (Kaye, Pernice, & Pelletier, 1999). For example, several Minnesota MCOs provide cellular telephones to high-risk pregnant women without home telephones. Other MCOs subsidize tuition for children with asthma to attend special asthma camp (Gold, Sparer, and Chu, 1996). Minnesota’s Medicaid Program also has incorporated “value-added” features; e.g., the Provide-a-Ride program providing Medicaid enrollees with 90,000 cab rides per year for physician / dentist appointments and hospital visits, and multilingual staff fluent in a number of languages, including Spanish, Russian, Chinese, Hmong and Vietnamese (Riley, 1997a). In the District of Columbia, Health Services for Children with Special Needs (HSCSN) provides limited-use telephones, transportation to appointments and home modifications (Coulam, Irvin, Teitelbaum, et al, 1998).

**Institutional long term care services.** Individuals who have special health care needs sometimes require institutional long term care services, which State Medicaid programs typically provide through FFS. However, a few States have developed, or are developing, approaches to include institutional long term care services in capitated managed care initiatives. Arizona has operated a capitated long term care program (Arizona Long Term Care System - ALTCS) for the elderly and physically disabled and mentally retarded and developmentally disabled populations since 1988. ALTCS covers acute care, nursing facility care, intermediate care facility care for the mentally retarded, as well as case management, home and community based services, and behavioral health services. Minnesota's Senior Health Options (MSHO) program also is a managed care arrangement that offers both institutional and community-based long term care services to enrollees dually eligible for both Medicare and Medicaid. In addition, HCFA has approved the use of capitated institutional long term care services in Texas.

**Special service needs.** Although all populations with special health care needs share the general service needs described above, some populations require specific services unique to their condition. Children with special health care needs, including children in foster care, require extensive screening services for physical, mental, behavioral, developmental and emotional health, and risk assessment (McManus and Fox, 1996). To ensure early, continuous assessment and follow-up services, every child should have a medical home. New models for medical homes for foster care are particularly important. When children in foster care enter the child welfare system, they should receive an immediate health screening to identify possible problems stemming from physical or sexual abuse, neglect, or other previously unidentified medical problems. A comprehensive evaluation should be conducted to collect baseline medical, developmental and mental health information. Counseling services should be available to help children cope with their dislocation or abandonment (Dreyfus and Tobias, 1998). Coordination of services is especially crucial for children in foster care because they tend to move from foster home to foster home. Many child welfare systems have developed variations of "medical passport" systems to assist in locating, collecting and organizing basic health information for children in out-of-home care and ensure that the information is readily available to foster care parents, child welfare agencies and Medicaid providers. Much of this information currently is collected through FFS claims data, but with the movement of children in foster care into Medicaid managed care, MCOs may have an increased role in the design and maintenance of medical passports for children in foster care (Lutz and Horvath, 1997).

### **State Medicaid Programs Determine Service Coverage**

All services described above can be made available to Medicaid beneficiaries to some extent as mandatory, optional or waiver Medicaid services. However, under Federal Medicaid laws, States are allowed significant flexibility in determining the benefits to be

covered under their Medicaid programs. While States must include certain services that are specified in law as “mandatory,” as well as services needed to treat conditions detected through the early and periodic screening, diagnostic and treatment (EPSDT) benefit for children, Federal Medicaid law identifies other services as “optional” and allows these to be provided at the discretion of the State. In addition, sections 1915(b) and (c) and section 1115 waiver programs also allow additional health-related services to be covered in State Medicaid managed care initiatives subject to HCFA approval and a determination that they are cost-effective. These Medicaid statutory provisions result in considerable variation in the type and amount of covered services from State to State.

With respect to Medicaid managed care, if a service is covered under a State’s plan, and the State’s contract with the MCO limits the benefit, the State must provide for the service outside the contract and inform the enrollee that these benefits are available outside the MCO as well as how and where they can be obtained.

**Mandatory services.** Federal law requires that all State Medicaid programs cover specified mandatory services (listed in Table 1) for all categorically needy<sup>6</sup> beneficiaries. Medicaid law also requires that certain types of services be covered if a State elects to offer a medically needy program. Requirements for medically needy populations differ from requirements applicable to categorically needy populations. States that choose to have a medically needy program must provide: 1) prenatal and delivery services for pregnant women; 2) ambulatory services for individuals under 18 and individuals entitled to institutional services; and, 3) home health services for individuals entitled to nursing facility services. In addition, if the State provides coverage for medically needy persons over age 65 or under 21 in institutions for mental disease or coverage for the medically needy in intermediate care facilities for the mentally retarded (ICFs/MR), it must cover either the same services as those that are mandatory for the categorically needy or an alternative package defined in the law. State Medicaid programs must provide that the services it makes available to categorically needy beneficiaries are not less in amount, duration and scope than the services the State makes available to medically needy beneficiaries. Further, the State must provide that Medicaid covered services available to categorically and medically needy beneficiaries are equal in their amount, duration and scope.

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<sup>6</sup> “Categorically needy” refers to actual or potential recipients of cash assistance under AFDC or SSI programs, along with pregnant women and children entitled to poverty-related coverage. “Medically needy” refers to persons who, except for income and resources, meet the criteria for categorically needy coverage. These persons become entitled to medically needy protection when their income and resources, after deducting incurred medical expenses, fall below the medically needy standards.



The EPSDT benefit further requires States to provide children with basic health screening, vision, hearing, and dental services at specified intervals that meet recognized standards of medical and dental practice and at other intervals as necessary to determine the existence of certain physical or mental illness conditions. It also requires that States must provide health care services covered by Medicaid that are identified through the EPSDT program as “medically necessary” for eligible children, even if those services are not part of the covered services in that State’s plan.

**Table 1: MEDICAID MANDATORY SERVICES FOR CATEGORICALLY NEEDY.**

Physician services	Home health services (for individuals entitled to nursing facility care under the State plan)
Early and periodic screening, diagnostic and treatment (EPSDT) services for individuals under age 21	Other laboratory and x-ray services
Nurse-midwife services	Inpatient hospital services
Nursing facility (NF) services for individuals 21 or older	Outpatient hospital services
Federally qualified health center services	Medical and surgical dental services
Services of certified nurse practitioners and certified family nurse practitioners	Rural health clinic services
Family planning services	

**Optional services.** States may also provide additional, “optional services” to their categorically needy Medicaid populations. Under Federal law these services include, but are not limited to: physical therapy; occupational therapy; speech pathology and audiology services; services for individuals with speech, hearing and language disorders; prosthetic devices; rehabilitative services; preventive services; transportation services; respiratory care services; prescribed drugs; and personal care services, to name a few. Coverage varies widely from State to State. For example, all States provide for prescribed drugs; and almost all States provide for clinic services, prosthetic devices, rehabilitative services and transportation services. About half of the States cover personal care services and private duty nursing, and only a few States provide for medical social worker services and respiratory care services.

**Waiver services.** Under certain circumstances, Medicaid law allows States a number of options to develop innovative methods for delivering Medicaid services as well as other

health-related services not offered in the Medicaid State Plan. The Omnibus Budget Reconciliation Act (OBRA) of 1981 established two options: section 1915(b) (“freedom-of-choice”) and section 1915(c) (“home and community-based services”) waiver programs. These waiver options give States greater flexibility in managing their Medicaid programs by allowing them to develop cost-effective alternative methods of service delivery or reimbursement. The 1915(b) waiver option also permits States to require beneficiaries to enroll in HMOs or other managed care programs, or to select cost-effective providers from whom beneficiaries must obtain all nonemergency care. The 1915(c) waiver allows States to offer an alternative health care package for persons who otherwise would be institutionalized under Medicaid. The 1915(b) and 1915(c) waivers are subject to HCFA approval, and must meet a cost effectiveness test.

Section 1115 waivers (“research and demonstration” waivers) allow States to deviate from many standard Medicaid requirements in order to test new ideas of policy merit. For example, States may use 1115 waivers to: cover new services, offer different service packages or different combinations of services in different parts of the State, or change Medicaid eligibility criteria to cover new or expanded groups of beneficiaries. Section 1115 waivers are subject to HCFA approval, and must meet a budget neutrality test.

The use of additional health-related services has grown as States design consumer-driven supports and service packages in their section 1915(b) or section 1115 managed care waivers. Section 1915(b)(3) permits States to provide additional services to Medicaid beneficiaries that are funded through cost savings gained through the use of more cost effective medical care. These services typically are the same as optional Medicaid services. To calculate savings under section 1915(b)(3), the State must set a capitation rate for managed care services that is no greater than the Upper Payment Limit (UPL) and/or the contractor must supply the additional services within the capitation rate.

States may want to take advantage of the benefit flexibility inherent in 1915(b)(3) and 1115 waivers to expand the Medicaid benefit package to meet the health-related service needs of Medicaid enrollees with special health care needs. However, the benefit package, which is subject to HCFA approval, is still constrained by limits on program expenditures. Similar to the restriction on section 1915(b) programs related to calculating “savings,” section 1115 waivers must meet a test of budget neutrality which constrains total program spending.

Although the number of Medicaid MCOs that provide special and enabling services is growing and the variety of services increasing, these special and enabling services are applied to enrollees on a case-by-case basis. The success or failure of these services should be evaluated to create a body of knowledge for more general application. States can be more prescriptive about the use of enabling services when the evidence for use is established through research and evaluation. Researchers should conduct longitudinal

studies on the service needs and outcomes for populations with special health care needs.

## **MCO Practices Also Can Influence Provision of Services**

While responsible for providing benefits coverage, MCOs also are responsible for promoting appropriate utilization of services. They do this through: 1) utilization management practices (discussed in Chapter 5); 2) medical necessity criteria; and, 3) technology assessments. The last two are used to make coverage decisions. In addition, while not generally listed as a covered service in contracts between States and MCOs, assessment of the service needs of enrollees with special health care needs is an important step to ensure they receive the appropriate services.

### *Assessment of Enrollee Needs*

Because all enrollees with special health care needs have by definition “special” health care needs, an assessment of an enrollee’s physical, social, and psychological needs is necessary to identify those special needs. Assessment of needs is generally regarded as an essential component of providing appropriate care to enrollees with complex health conditions. For this reason, in its proposed rule to implement the BBA managed care provisions, HCFA proposed that all enrollees with complex and serious health conditions receive an assessment of those conditions in conjunction with the MCO identifying appropriate treatment. However, the assessment of enrollee needs has not historically received much attention in Medicaid managed care (or FFS). For example, while 80 percent of State Medicaid MCO contracts address case management, most of the 80 percent did not describe case management components (including assessment). Contract provisions addressing assessments were not included in the nationwide study of Medicaid managed care contracts implemented in 1998 (Rosenbaum et al., 1998).

### *Determination of Medical Necessity*

Medical necessity is a concept that is used (along with other criteria) to determine whether insurers will pay for covered services. While the literature about medical necessity is substantial, it offers no universally accepted definition and little agreement about how to apply medical necessity standards or what elements, such as appropriateness or cost effectiveness, should be included (Jacobson, Asch, Glassman, et al, 1997). How the practice is applied in situations involving enrollees with special health care needs can affect patient access to services.

Some medical necessity standards require “substantial improvement” or “restoration of

function” as a condition for authorizing therapies or certain types of medical equipment. However, individuals with disabilities, or who are chronically ill, suffer frequently from conditions that preclude substantial improvement or restoration of function. Strict application of a narrow definition of medical necessity can conflict with the needs of an enrollee who has a special health care need, especially if the service offers little hope for improvement, but great hope for maintaining personal independence, ability to work, or an existing quality of life. Application of such medical necessity definitions by Medicaid MCOs could prevent enrollees with disabilities from receiving useful therapy and/or equipment when the need is based on maintenance of existing function or substitution for lost functioning (GAO, 1996b).

**Medicaid provisions.** Federal Medicaid law does not contain a definition of medical necessity, nor does it require States to have explicit written provisions addressing medical necessity in the State plan. Current Medicaid regulations: 1) require that each Medicaid service provided for in a State’s plan must be “sufficient in amount, duration, and scope to reasonably achieve its purpose;” 2) prohibit Medicaid agencies from arbitrarily denying or reducing the amount, duration or scope of a required service solely because of the diagnosis, type of illness or condition; and 3) allow States to “place appropriate limits on a service based on such criteria as medical necessity or on utilization control procedures.” (42 CFR Part 440.230, 1998).

With regard to children with special health care needs enrolled in State Medicaid programs, medical necessity and its application takes on a slightly different picture. Federal law stipulates that any federally allowed Medicaid service *must* be provided if it is medically necessary to correct or ameliorate a defect or physical or mental condition discovered as a result of an EPSDT screening. It also stipulates the Medicaid-allowed service must be provided even if it is not included in that State’s Medicaid plan.

A survey and analysis of Medicaid managed care contracts found that 30 of 42 States include in their contracts (or RFPs) provisions related to defining the medical necessity standards a MCO is to use to make coverage decisions. These States use a variety of approaches to do so. Most contracts either require covered services to be medically necessary or they expressly exclude services that are not medically necessary. When States further define medical necessity, some States define it in ways that might be interpreted as more restrictive than the above provisions in Federal law (Rosenbaum, Smith, Shin, et al., 1998).

Because of the potential impact of medical necessity decisions on access to services, clear specifications for medical necessity in State Medicaid MCO contracts are essential to ensure that covered services will be accessible to Medicaid enrollees with special health care needs. The proposed Medicaid rule to implement the BBA Medicaid managed care

provisions would require that States explicitly address medical necessity in their contracts with MCOs. States should review these contract provisions to ensure that they include as medically necessary, services to maintain existing function or substitute for the loss of functioning. For example, New York Medicaid specifies that medically necessary care is to encompass, “health care and services that are necessary to prevent, diagnose, manage or treat conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with such person’s capacity for normal activity, or threaten some significant handicap.” (APHSA, 1999)

### *Assessment of New Technology*

The decision to cover new and emerging treatments and devices additionally can be influenced by properly conducted technology assessments of these services. Currently, the United States has a widely decentralized system of health care technology assessments in which multiple public and private sector entities conduct assessments with little or no cooperation or coordination (Kamerow, 1997). These assessments play a key role in the decision making of MCOs and insurers as they determine the technologies they will offer. When the Congressional Office of Technology Assessment was eliminated in 1995 without replacement by an objective bipartisan assessor, the environment for technology assessment became even more fragmented. The result is that MCOs often conduct their own assessments and States perform technology assessments within multiple, overlapping agencies (Bergthold, 1995).

Among the groups that conduct technology assessments are MCOs, government agencies and academic medical centers. In collaboration with Kaiser Permanente, the Blue Cross Blue Shield Association operates a Technology Evaluation Center that assesses new and emerging technologies to help member plans make coverage decisions (Aubry, 1998). In 1997, AHCPR established twelve Evidence-based Practice Centers (EPCs) that develop evidence reports and technology assessments on clinical topics that are “common, expensive, and/or are significant for the Medicare and Medicaid populations” (AHCPR, 1998b). Areas of assessment at the EPCs pertinent to populations who are disabled and chronically ill include management of acute chronic obstructive pulmonary disease, criteria for determining disability in patients with end-stage renal disease and the management of cancer pain. Other MCOs (including Prudential and Aetna), clinical and specialty organizations and the FDA also conduct or finance technology assessments.

HCFA also is broadening its role in technology assessment. In a Federal Register notice on April 27, 1999, HCFA announced a new procedure for making Medicare coverage decisions. This new procedure is open, participatory and fully compliant with Federal Advisory Commissions Act. When HCFA or its national panel of experts, the Medicare Coverage Advisory Committee, finds that a careful and thoughtful review of a procedure,

device, drug, etc., is necessary, a notice to that effect will be placed on the HCFA web site. HCFA will keep stakeholders and other interested parties aware via this internet site of the progress toward coverage decisions. In making coverage decisions, HCFA will actively work with AHRQ to obtain assessments, working through the established network of EPCs and other qualified vendors. In addition, in the Fall of 2000, the President directed HCFA to provide Medicare coverage of clinical trials. This will facilitate research and produce information about new technology which will be helpful to Medicaid beneficiaries, especially those receiving both Medicare and Medicaid.

To ensure that MCOs have accurate and up-to-date knowledge of technology assessment to use in determining medical necessity, results of these assessments need to be accessible to providers of health care services to populations with special health care needs. Access to technology assessments should be improved, and financial barriers to obtain results of proprietary studies need to be reduced. Many databases have been developed to share results of technology assessments across the country and around the globe. HealthSTAR provides citations for health service research and technology assessment, and the National Institutes of Health Clinical Trials Registry provides a database of government and privately funded clinical trials for serious and life-threatening conditions, mandated by the FDA Modernization Act of 1997 (Goodman, 1999). The continuation of this trend and increased use of the Internet can lead to greater dispersment of the technology assessments.

To reduce unwarranted duplication, provide more consistency in MCO coverage decisions, and target resources to assess untested health care practices more effectively, more collaboration and cooperation among these groups should occur. By working together to become more efficient in the technology assessment process, these groups could conduct assessments that are too expensive for a single group to pursue (The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998). Although the potential exists for more effective collaboration among States, between States and Federal government, and between States and the private sector, commitment and resources are required of all involved. Further action at the Federal level would be needed to coordinate and support further efforts at technology assessment, and reduce the current costs to the health care system of conducting duplicate technology assessments.

## CHAPTER FIVE

### Enable Access to Experienced Providers

**Summary:** *A growing body of evidence indicates that the more experienced health care providers are in certain types of health care, the better are health care outcomes. “More experienced” providers are those health care practitioners and institutions that have treated a greater number (volume) of individuals with certain types of health conditions or in need of certain types of treatment. When caring for a population that is known to include children, older adults with disabilities, enrollees with specific clinical conditions such as AIDS, or with known environmental stressors such as homelessness or placement in foster care, providers are needed who have experience in pediatric and geriatric care, the treatment of the identified clinical condition, and caring for populations who are in foster care or homeless. This has implications for how MCOs structure their provider networks, allow for access to out-of-network providers, and manage service utilization.*

*Federal and State governments, as well as private sector groups, have established standards for MCO provider network adequacy and utilization management practices. Because of the growing evidence of the importance of provider experience to outcomes, these standards need to begin to address the issue of experienced providers. However, several challenges to building adequate provider networks and appropriately managing utilization exist, including: 1) the unpredictability of need for certain specialty providers; 2) lack of quantifiable standards for numbers of experienced providers; 3) geographic maldistribution of providers; 4) nationwide shortages of certain types of providers; 5) the lack of criteria for what constitutes “sufficient” experience; and, 6) the subjective nature of “need.” However, strategies exist to begin to address these issues and promote better access to experienced providers for populations with special health care needs.*

#### **Action to be taken by the Department of Health and Human Services:**

*HCFA will monitor State implementation of BBA requirements for MCO provider network adequacy and access to specialists, and provide technical assistance to States in implementing practices to address the need for experienced providers. Efforts by the Department of Health and Human Service’s Office of Civil Rights (OCR) to encourage more States, MCOs, and providers to seek technical assistance from OCR on Americans with Disabilities Act (ADA) requirements will continue and will be strengthened.*

**Recommendations for action by others:**

**Recommendation 12:** States should require MCOs to: 1) prospectively plan for the need for certain experienced providers; and, 2) have policies and procedures in place to address unanticipated need for other experienced providers.

**Prospectively:** When a State prospectively plans to enroll beneficiaries with special health care needs in MCOs, States should require MCOs to include in their networks: 1) providers with experience in caring for pediatric and geriatric populations; 2) providers with experience in treating prospectively identified clinical conditions (e.g., HIV/AIDS); and 3) providers with experience in caring for individuals who are homeless or in foster care, to the extent these providers exist in the MCO's service area and to the extent the applicable population is enrolled.

**Unanticipated need:** Because States will not be able to prospectively identify all clinical conditions affecting enrollees, and because of obstacles to prospectively including all needed experienced providers in an MCO's network, States should require MCOs to have policies and practices in place to address the unanticipated need for, or limitations in the availability of, certain experienced providers within their service area. States should consider requiring that these policies include provisions to allow an enrollee to use an out-of-network provider if a provider experienced in treating the enrollee's health condition is not readily available within the MCO network.

**Recommendation 13:** States should require MCOs to take into account the unique needs of enrollees with special health care needs when implementing utilization management policies; including when authorizing an adequate number of direct access visits to specialists when required under an approved treatment plan. This should include considering standing referrals to specialists and use of specialists as primary care providers in appropriate situations.

**Recommendation 14:** States developing managed care initiatives for beneficiaries with special health care needs should ensure that MCOs and providers are as physically accessible as possible to populations they will serve, consistent with the Americans with Disabilities Act. If all providers or MCOs are not accessible, the State should assist enrollees with disabilities to locate providers or MCOs capable of meeting their unique needs.



## Medicaid Managed Care Expected to Improve Access

“Access” is a word used to encompass a broad set of issues that address the degree to which individuals and groups are able to receive needed services from the health care system (Institute of Medicine, 1993). These issues include whether or not:

- C a particular health service exists for use by individuals;
- C individuals know about the availability of the service;
- C individuals know when they need the service;
- C individuals know how to obtain the service when they need it;
- C individuals are able to receive the service in a timely fashion; and,
- C significant societal, organizational or personal differences (e.g., language, culture or lack of transportation) affect appropriate use of health care services (The National Committee for Quality Assurance (NCQA), 1995).

In part, States turned to managed care to achieve enhanced access to health care for Medicaid beneficiaries. Low reimbursement rates and cumbersome administrative requirements in FFS Medicaid had discouraged physicians, especially specialists, from participating in the Medicaid program (GAO, 1993). In addition, the reluctance of physicians to practice in low-income or isolated communities further restricted access to providers (Families USA, 1998a). States saw managed care as a way to increase access to quality health care while simultaneously decreasing costs (Holahan, Zuckerman, Evans and Rangarajan, 1998). However, to date, information on the success of managed care in achieving this for the Medicaid population in general is both limited and mixed. Information on populations with special health care needs is even more limited, but raises some issues.

The earliest studies of access in Medicaid managed care yielded mixed findings. In two demonstrations perceived access to care was reported as improved; objective measures (e.g., waiting times) showed mixed results in one site, and equivalent results in another (Freund, et al., 1989). A later study by the General Accounting Office (GAO) found that capitated managed care programs in five States provided access that was slightly better than in traditional FFS programs (GAO, 1993). However, a comprehensive examination of managed care for pregnant women and children found that available research did not support

claims of uniformly improved access for children and pregnant women enrolled in Medicaid (Freund and Lewit, 1993). In 1995, the Kaiser Commission on the Future of Medicaid reviewed the literature on Medicaid and managed care for the prior 20 years. It found that most studies showed a decline in the use of specialists and emergency rooms, but mixed (and therefore inconclusive) evidence - or evidence showing no change - about managed care's effect on the number of physician visits, use of preventive health services or inpatient hospital care (Kaiser Commission on the Future of Medicaid, 1995). These same conclusions were reached more recently (Szilagyi, 1998).

Researchers theorize that inconsistencies in findings can be explained in part by variations in such State practices as use of voluntary versus mandatory enrollment; different approaches to payment of MCOs; differences in MCO structures, financial arrangements and utilization management practices; and the different methodologies used to measure access (Kaiser Commission on the Future of Medicaid, 1995; Hughes and Luft, 1998). Szilagyi (1998) notes that because of variation in the organization and operational practices of MCOs, "it is possible to observe even greater variability among different types of managed care plans than between managed care plans and FFS arrangements." However, little research has been done that compares the effects on access of different State program designs or differences in the structure and operation of MCOs.

Most research on the effects of managed care on access has addressed either Medicaid enrollees in the aggregate or enrollees who are not disabled; few studies have focused on access of enrollees with special health care needs. The sparse research that focuses on these groups provides the basis for some of the concerns about the enrollment of special health care needs populations in managed care.

- C A 1995-1996 Kaiser/Commonwealth Fund survey of 7,000 low-income individuals (including Medicaid beneficiaries) in Florida, Minnesota, Oregon, Tennessee, and Texas found that Medicaid beneficiaries in managed care are more likely to report difficulties in access to care than either commercial enrollees or Medicaid enrollees receiving FFS Medicaid. Medicaid managed care enrollees in poor health were the most likely to experience problems obtaining care. Thirty-six percent reported one or more access problems (Lillie-Blanton and Lyons, 1998).
- C Preliminary results from the five-year, nationwide Health Care Reform Tracking Project (HCRTF) indicate that managed care has resulted in greater access to basic behavioral health and community-based services for children and adolescents requiring mental health services. However, results also indicated that access to inpatient hospital care has been reduced and it has been more difficult for youths with serious emotional disorders to obtain needed services (Stroul, Pires, Armstrong and Meyers, 1998).

C A nationally representative 1996 survey of Medicare managed care enrollees and disenrollees found that the vast majority of beneficiaries enrolled in Medicare risk plans do not have problems making appointments and are satisfied with their access to specialty and inpatient care. On the other hand, vulnerable subgroups such as the nonelderly disabled, the oldest old (i.e., those 85 years of age or older), those with functional impairments, those in fair or poor health and those with worsening health were more likely to report access problems. The study found that although this was partially due to a greater need for care among vulnerable subgroups, even after adjusting for differences in their level of need for care, some vulnerable subgroups still were more likely than their counterparts to experience access problems. While vulnerable subgroups were also more likely to experience access problems in the FFS sector, study results indicated that some of the vulnerable subgroups - particularly the oldest old and those in fair or poor health - are more likely to report access problems in Health Maintenance Organizations (HMOs) than in FFS (Nelson, et al, 1996). While this was a study of Medicare, not Medicaid, the findings are important because substantial overlap of MCO contracting occurs under the Medicaid and Medicare programs. Further, until recently, most States have not enrolled older adults into Medicaid managed care programs, so the only available studies of older adults' experience in managed care are those of Medicare enrollees.

While informative, all of these studies have significant limitations. First, they are subjective assessments of access; i.e., because the "right" amount of service utilization is not known, perceived limitations in access might represent either a failure to access appropriate services or an inability to receive a service that, while desired, is not needed (Freund and Lewit, 1993; GAO, 1997). In addition, the Kaiser Commission on the Future of Medicaid noted that, "the lack of agreed-upon standards for the appropriate distribution of primary and specialty services for given population groups makes it difficult to judge the appropriateness of declines in use of specialty service by managed care beneficiaries. More refined measures are required to determine whether the reductions in utilization of service are actually medically necessary care or inappropriate care." (Kaiser Commission on the Future of Medicaid, 1995). Third, when inadequate access is identified, its causes are not always easy to discern or attribute (Freund and Lewit, 1993; GAO, 1997).

Reports of problems with access to providers by enrollees with special health care needs within particular State Medicaid managed care initiatives have also caused concern. For example, the start-up of Tennessee's managed mental health and substance abuse program, "TennCare Partners," was marked by difficulties for behavioral MCOs in contracting with providers, difficulties for providers in determining referrals for their patients, and an overall reduction of mental health and substance abuse services by as much as 15%. In some cases, patients received little or no care (Chang, et al., 1998).

These studies and reports consistently identify certain features of MCOs that influence access (both beneficially and adversely). These include financial incentives, the adequacy of MCO provider networks, and MCO utilization management practices. Other features of MCOs that affect access are beneficiary health education and services of consumer advocates (see Chapter 3) and the presence or absence of “enabling services” (see Chapter 4) such as transportation and communication assistance. Physical barriers such as poor transportation, inaccessible medical response systems, and inaccessible physician offices, have imposed economic and social costs on Americans with disabilities and have undermined efforts to educate, rehabilitate, and employ individuals with disabilities. Titles II and III of the Americans with Disabilities Act (ADA) are helping to break down many barriers, thus enabling society to benefit from the skills and talents of individuals with disabilities, and to provide these individuals with the opportunity to participate more fully in society. See Appendix B for a more extensive discussion of the ADA.

This chapter discusses provider network adequacy and utilization management. “Provider network adequacy” refers to the numbers, geographic location and experience of primary care providers and specialists within an MCO’s provider network. “Utilization management” refers to MCO (as well as indemnity or FFS insurance) mechanisms to access specialists or specialty care, and to authorize the amounts and duration of services to be provided.

## **An “Adequate Network” Enables Access to Experienced Providers**

### *Experienced Providers Important to Good Quality Care*

**Clinical experience.** A growing body of evidence indicates that the more experienced health care practitioners and institutions are in certain types of health care, the better the health care outcomes. Studies of cardiac bypass surgery, angioplasty, and heart transplants have shown a positive connection between volume and outcome in all cases; the more procedures performed per hospital (or where studied, per physician) the better the outcomes, including fewer immediate deaths and lower complication rates. Volume-outcome relationships have been reported for a variety of other surgical procedures, including hip replacements; certain types of aneurysm repairs; and hip, knee, colorectal, and cancer surgery (Institute of Medicine (IoM), 1999). Evidence of volume-outcome benefits is not limited to surgical interventions. For example, studies show improved outcomes as a result of increased experience in the treatment of heart attacks (Theimann, 1999), systemic lupus erythematosus (Ward, 1999) and HIV/AIDS.

Providers with experience in treating HIV/AIDS have a positive impact on the survival of the patient, and facilities with greater experience in caring for HIV/AIDS patients make

more effective use of additional resources, compared with those with less experience (Kitihata, Koepsell, Deyo et al., 1996; Stephenson, 1996). Because of this, and the rapidly evolving state of treatments, the DHHS along with the Henry J. Kaiser Family Foundation sponsored an expert panel that developed recommended standards for using new antiretroviral drugs. The panel stated, “When possible, the treatment of HIV-infected patients should be directed by a physician with extensive experience in the care of these patients. When this is not possible, the physician treating the patient should have access to such expertise through consultations” (CDC, 1998c).

The President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry (Advisory Commission) also acknowledged the value of “experience.” In its Consumer Bill of Rights (CBoR), the Advisory Commission identified a “Right to Information Disclosure” as a fundamental Right. In articulating the Right, the Advisory Commission identified health professionals’ “experience with performing certain medical or surgical procedures (e.g., volume of care/service delivered), adjusted for case mix and severity” and the volume of certain procedures performed at health care facilities, as information that should be disclosed to consumers (Advisory Commission, 1997).

While the link between experience and improved outcomes of care has not been demonstrated for every clinical condition, it is reasonable to believe that “practice makes perfect” - or at least “practice is likely to make better” - may apply in other situations as well. This is the reason that the disciplines of medicine, nursing, dentistry, and other allied health professions offer advanced training programs to provide practitioners with more intensive experience in caring for certain types of patients with rare or complex clinical conditions. This is also the reason why beneficiaries, consumer advocates, experts in clinical care of individuals with special health care needs, the Advisory Commission, and HCFA have all recommended or implemented strategies to provide certain individuals with special health care needs with direct or streamlined access to specialists under certain circumstances. While a “specialist” is not always synonymous with an “experienced provider,” specialists in some circumstances can offer a greater likelihood of “experience;” e.g., a typical pediatric rheumatologist is more likely experienced in providing care to a child with rheumatoid arthritis than a typical adult rheumatologist or family medicine practitioner.

Further research is essential to more fully explore the link between “experience,” use of specialists, and improved outcomes. First, while public and private sector efforts to address network adequacy focus on access to “specialists” as a proxy for access to “experienced providers,” the effect of the use of specialists on improved outcomes is not as well established as is the effect of experience. For example, the IoM study on volume and specialization and the relationship to better outcomes for certain types of cancer care reported that well-designed studies are needed to better understand the relationship

between institutional specialization and outcomes and “Very little can be said about the effects of physician specialization on outcomes of cancer care” (IoM, 1999). Second, most of the above research has addressed care delivered in inpatient settings for the treatment of acute conditions. Research is needed on the effects of experience in the ambulatory management of chronic illness and other disability-related conditions.

Other factors affecting health outcomes include: age, genetic traits, personal health practices of a patient, and the environment in which he or she lives. Of these, when MCOs establish their provider networks, they will more reasonably be able to address provider experience in caring for individuals of certain ages (i.e., pediatric or geriatric) and care of individuals living in certain environmental situations (e.g., who are homeless or in foster care). Assessing providers based on their knowledge of genetics or their knowledge of the effect of personal health practices on health outcomes, while not impossible, would be less feasible. This report therefore addresses provider experience in pediatric and geriatric care, experience in providing care to individuals who are homeless or in foster care, as well as clinical experience.

**Experience with the effects of age.** The effect of patient age on clinical care is widely acknowledged. Children react to treatment differently than adults, and the childhood developmental process has significant implications for health care treatment. During this century, the leading causes of childhood morbidity have shifted from infectious diseases to chronic conditions. Increasingly, pediatricians are finding developmental, behavioral, and environmental causes and consequences of these conditions (McManus and Fox, 1996). The changing dynamics of child development affect these conditions and their consequences differently at different stages of illness and can alter the expected outcome of treatment. Illness and disability can delay a child’s normal development, sometimes irreversibly, possibly requiring the services of pediatric subspecialists (American Academy of Pediatrics, 1998) or other specially trained primary care providers who have knowledge and experience in chronic illness management and behavioral-developmental pediatrics (McManus and Fox, 1996).

The normal physiologic processes of aging also have implications for the care of older adults, especially those who are disabled. Altered or nonspecific presentation of disease, loss of functional ability, and the occurrence of multiple pathology resulting in disease-disease and disease-treatment interactions are common in older adults (Besdine, 1997). Further, older adults have a greater prevalence of chronic conditions. By age 75, older adults can expect to have two to three medical conditions. More than half of older adults report at least one disability, and one-third report limitations in activities due to a chronic condition (see Chapter 2) (Administration on Aging, 1998). The acute care problems of older adults often are the manifestations of these chronic diseases; because older individuals are burdened by more disease, even a small change in health status can trigger a

catastrophic event.

Older adults need physicians and other practitioners skilled in analyzing multiple physical problems and how they interact with one another, as well as with an individual's environment. Gaps in clinical experience and knowledge easily can result in clinical misdiagnosis, or overlooking or dismissing illnesses as the "normal" process of aging because clinicians are not trained to recognize the different ways that diseases and drugs affect older patients. For example, proper treatment of diabetes in the presence of heart failure and dementia is different from the treatment of diabetes alone. Confusion, lethargy, and falls may be assessed as "old age" when they often are signs of drug interactions or other underlying illnesses. Urinary incontinence often goes undetected or is dismissed as a natural consequence of aging even though it is treatable by exercise or medication. Many health care professionals inappropriately view depression as an inevitable part of growing old, but approximately 5 million individuals who are elderly suffer from serious and persistent symptoms of depression (National Health Policy Forum, 1999).

**Expertise in the effects of environment.** Individuals with special environmental risk factors (e.g., foster care or homelessness), also require knowledgeable health care practitioners who understand the conditions for which they are particularly at risk. Children in foster care need providers with expertise in diagnosing or treating abuse and neglect as well as the mental and physical health conditions and developmental delays more frequently present in children in foster care (Kaye, Horvath, and Booth, 1998). Individuals who are homeless need providers experienced in delivering both routine health care and in diagnosing and treating non-routine conditions more frequently experienced by the homeless (e.g., malnutrition, physical violence, communicable diseases, skin diseases, strains and sprains from carrying their belongings for extended periods, and the more acute presentation of chronic health disorders such as hypertension, diabetes, and dental disease). Individuals who are homeless also need providers and services that are accessible through locations they frequent, such as shelters and food kitchens (Wunsch, 1998).

### **Promoting Adequate Provider Networks**

In establishing and evaluating provider networks to serve populations with special health care needs, it is reasonable for States and MCOs to consider: 1) clinical experience (volume) in caring for certain complex or rare conditions; 2) knowledge and experience in serving pediatric and geriatric populations; and, 3) knowledge and experience in serving populations experiencing certain environmental risk factors (e.g., homelessness and foster care). Some MCOs may already be doing this. A 1999 survey sponsored by Family Voices and conducted by Brandeis University found that families of children with special health care needs were generally satisfied with their MCO's ability to provide skilled and

experienced primary care providers, specialty doctors, and other specialists, such as physical, speech and occupational therapist. A majority (82 percent) reported that their child's primary care provider is skilled and experienced. Sixty percent also indicated they believed their MCO did a good or excellent job at approving speciality care -including referrals to physician-specialists, physical therapists, and home health services. (Nineteen percent said their MCO did an "okay" job, 11 percent responded that their MCO did a poor job, and nine percent didn't know.) (Krauss and Wells, 1999).<sup>7</sup>

### *Current Efforts*

**Consumer Bill of Rights.** The CBoR established by the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry states that, "Consumers should have the right to a choice of health care providers that is sufficient to ensure access to appropriate high-quality health care." The CBoR explicitly identified provider network adequacy as one component of that Right when it stated that health plans should provide access to "sufficient numbers and types of providers to assure that all covered services will be accessible without unreasonable delay....." It further stated that if a health plan has insufficient numbers or types of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer gets the benefit from out-of-network providers at no greater cost (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998). The CBoR did not elaborate on what constitutes "sufficient numbers or types."

**National Association of Insurance Commissioners (NAIC).** The NAIC Model Act (Act) includes language similar to, and exceeding, language in the CBoR. The Act identifies a number of approaches to determining adequacy of provider networks, including provider - covered person ratios by specialty, primary care provider - covered person ratios, geographic accessibility, waiting times for appointments, hours of operation, and the volume of technological and specialty services available (NAIC, 1996). Although the Act specifies these approaches and allows for use of other approaches, it does not specify

numerical or objective criteria to determine adequacy. Sixteen States have adopted this model Act or related legislation or regulations for managed care plans (Cook, 1999).

**Private accreditation standards.** Private sector MCO accreditation organizations

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<sup>7</sup> Results are from a nationwide survey of families with children with special health care needs. The sample was drawn from Family Voices mailing lists and State Title V and SSI recipients. The sample of 5,408 families of diverse socio-economic backgrounds yielded 2,220 responses (41.5%). Of these, 430 were identified as enrolled in Medicaid in States that had mandatory enrollment of SSI recipients in managed care at the time of the survey (AZ, CO, DE, FL, KS, MA, MD, OR, TN, and DC). Results reported represent these 430 families.



similarly include content on provider network adequacy in their accreditation standards. The NCQA specifies that an MCO is to ensure that its network is sufficient in numbers and types of practitioners, recognizing the special health care needs of enrollees. The MCO is expected to implement mechanisms designed to ensure the availability of specialty care practitioners. NCQA also does not specify any numerical criteria to determine adequacy, but states that the MCO is to establish quantifiable, measurable standards. NCQA evaluates the reasonableness of the MCO's standards and their application by the MCO (NCQA, 1998). The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) similarly requires organizations to, "determine and provide the appropriate health care disciplines and specialists to meet member health care needs (JCAHO, 1996).

**QISMC.** Quality standards for MCOs disseminated by HCFA for voluntary use by States also include content that addresses network adequacy. Quality Improvement System for Managed Care (QISMC) standards for organizations contracting with Medicare or Medicaid specify that an MCO is to maintain and monitor a network of appropriate providers, "sufficient to provide adequate access to covered services and to meet the needs of the population served." The MCO also is to: 1) offer a panel of primary care providers from which the enrollee may select a provider; 2) provide or arrange for necessary specialty care; and, 3) provide a treatment plan for enrollees with complex or serious medical conditions that specifies an adequate number of direct access visits to specialists to accommodate the treatment plan (HCFA, 1998c).

**BBA provisions.** The BBA contained two provisions pertaining to provider network adequacy. Section 4704(b)(5) - Demonstration of Adequate Capacity and Services - requires that an MCO demonstrate to both the State and the Secretary of HHS that it has the provider capacity to serve the expected enrollment within the MCOs' service area. The MCO must provide assurances, in a time and manner determined by the Secretary, that it provides access to preventive and primary care services and maintains a sufficient number, mix and geographic distribution of providers of services. Specialty services are mentioned in the second provision, Section 4705 - Quality Assurance Standards. Section 4705 requires States to establish access standards as part of their overall quality assessment and improvement strategy. The standards are to ensure that covered services are available within reasonable time frames and provided in a manner that ensures continuity of care and adequate primary and specialty services capacity.

The proposed rule on Medicaid managed care would implement these two provisions, in part by linking them. Under the proposed regulations, the access standards established by the State as part of its quality assessment and improvement strategy would have to be met by the MCO, and the MCO would have to provide assurances to the State that it met the standards. The regulatory provisions were proposed to ensure that all enrollees, including

those with special health care needs, have access to medically necessary services provided by the MCO while providing States the maximum flexibility to meet the unique needs of their States' populations. Thus, although the preamble to the proposed regulation gives numerical and objective examples of standards that could be adopted by States, it does not include specific geographic access standards or specific enrollee - provider ratios. Instead, the preamble notes that, "because enrollees' specific needs, the types of providers used by an MCO to meet those needs, and other factors such as the availability of public transportation, will vary for each MCO, we are not proposing a single set of fixed guidelines for all populations and circumstances, such as prescribed primary physician-enrollee ratios" (HCFA, 1998b). The proposed regulations specify that States and MCOs must consider the anticipated enrollment in the MCO; expected utilization of services recognizing enrollee characteristics and health care needs; numbers and types of providers required to furnish the contracted services; number of network providers not accepting new patients; and, the geographic location of providers, including whether the location provides physical access for enrollees with disabilities. States would be permitted to develop their own access standards as part of an overall quality assessment and improvement strategy.

**State Medicaid agency practices.** Although the proposed network adequacy requirements have not yet been published as final regulations, State Medicaid agencies typically address provider network adequacy in their managed care initiatives. In 1998, forty-four of 45 States (98 percent) with risk-based managed care initiatives considered provider network capacity when selecting MCOs with which they contracted; 42 (93 percent) also considered the adequacy of the MCOs specialty networks (NASHP, 1999).

States also include requirements for provider network adequacy in their contracts with MCOs. These specifications address primary care provider network requirements; and most States also stipulate that specialty care providers and hospitals and other institutions must be included in the MCO's network and system. Approximately half of contracts contain specifications for specialty care provider-patient ratios. Contracts typically do not contain provisions (beyond the use of specialists) that address the experience of providers caring for populations with special health care needs. Some that do so are as follows:

- C Florida (for mental health providers): "The contractor's array of direct service mental health providers for adults and children must include providers that are licensed or eligible for licensure, and demonstrate two years of clinical experience in the following specialty areas..... adoption, separation and loss, victims and perpetrators of sexual abuse, victims and perpetrators of physical abuse, court-ordered evaluations and expert witness testimony...."(Rosenbaum, et al., 1998).
- C Florida: "The plan must use specialists with pediatric expertise for children where the need for pediatric specialty care is significantly different from the need for adult

specialists (e.g., a pediatric cardiologist for children with congenital heart defects).”(Rosenbaum, et al., 1998).

- C Rhode Island (for mental health providers): “The network must include providers experienced in serving low income populations, subspecialists or specialty providers experienced in child abuse, sexual abuse, or domestic violence, rape, dual diagnosis (mental health and substance abuse) and children’s mental health in sufficient numbers.....” (Rosenbaum, et al., 1998).
- C Massachusetts requires each plan to have a sufficient number of experienced primary care providers (PCPs) in its network who specialize in the treatment of individuals with “end-stage” AIDS. This is a realistic requirement for this state in which 65 percent of the members of the Massachusetts Academy of Family Physicians reported in 1997 having HIV-positive patients in their practice, and 46 percent reported having AIDS patients (Rawlings-Sekunda and Kaye, 1998).
- C Wisconsin’s Independent Care Program required its contractor to “subcontract with providers with knowledge and experience relevant to the needs of the disabled population.” Wisconsin Medicaid staff prepared a report to identify providers that served many individuals with disabilities in the MCO’s service area and reviewed a list of subcontracted providers submitted by the MCO against that list (National Academy for State Health Policy, 1997).

States also address access to experienced providers through other mechanisms. For example, Pennsylvania requires MCOs to “...consider the special medical needs of each member when assigning a PCP to ensure that the member’s PCP is trained and experienced in treating the member’s special needs.”(Rosenbaum, et al., 1998).

States use a variety of mechanisms to monitor compliance with network adequacy requirements. Before entering into a contract, States might require documentation that a provider network is sufficient in terms of numbers, types of providers, and geographic location. Evidence can consist of signed attestations from MCOs about their provider network, provider information files or sometimes geographic mapping of the provider network by the MCO or State. Requests for documentation may be repeated annually as part of ongoing monitoring. At a higher level of review, some States require the MCO to submit periodic reports about the condition of the network. Most often these are on a monthly or quarterly basis and might include information such as the number of members assigned to a PCP, provider terminations or utilization data. States also use Medicaid enrollee feedback mechanisms such as complaints and member surveys to monitor network adequacy. These are used as “red flags” to identify problems at the individual practitioner and network levels. Some States monitor network adequacy through direct contact with individual providers.

This involves making direct contact with a provider's office to determine appointment availability and 24-hour availability (PricewaterhouseCoopers, 1999).

### *Further Refinement Needed*

In spite of these national and state, public and private efforts to promote network adequacy, prospective construction of a network of providers with the experience to address all of the health care needs for an enrolled population is difficult for a number of reasons. They apply equally to managed care and FFS health care, and include: 1) unpredictable need; 2) lack of quantifiable standards; 3) geographic maldistribution of providers; 4) national shortages of certain experienced providers; 5) lack of criteria for experience; and, 6) the subjective nature of "need."

**Unpredictable need.** An MCO will be able to prospectively identify some, but not all, of its need for experienced providers. For example, the need for geriatricians and providers with experience in the care of individuals with HIV/AIDS can be anticipated, if older adults or individuals with HIV/AIDS enroll. However, an MCO may not be able to predict the need for providers experienced in caring for all rare conditions. MCOs frequently do not contract with providers or specialists they may need infrequently until a specific need is identified. Therefore, States cannot prospectively fully assess the adequacy of an MCO's current provider network for all types of clinical conditions (GAO, 1997).

**Lack of quantifiable standards.** Quantifiable, agreed-upon criteria or standards for the number and types of specialists or experienced providers needed to serve a population, are lacking in both FFS and managed care. Requirements (like those described above) for specialists often are vague and expressed in terms of an objective (e.g., "provide access to necessary specialty care") that cannot be measured before a contract is awarded (GAO, 1997).

**Geographic maldistribution of providers.** Some geographic areas may not contain certain specialists, subspecialists, or other experienced providers. Thus the NAIC Managed Care Plan Network Adequacy Model Act states that the MCO, "shall establish and maintain adequate arrangements to ensure reasonable proximity of participating providers to the business or personal residence of covered persons. In determining whether a [MCO] has complied with this provision, the Commissioner shall give due consideration to the relative availability of health care providers in the service area under consideration" (NAIC, 1996).

**National shortages in certain experienced providers.** The nation as a whole lacks health manpower with the knowledge and skills to serve all individuals with special health care needs. Numerous Federal studies and private sector reports conclude that the U.S. health care system lacks practitioners trained to meet the special health care needs of older

Americans (National Health Policy Forum, 1999). This also is true for other populations with special health care needs. For example, the supply of pediatricians and family physicians educated and experienced in treating children with more complex problems at different stages of childhood development is limited (McManus and Fox, 1996). Several states also have shortages of specialists in child and adolescent substance abuse services (Stroul, Pires, and Armstrong, 1998).

**Lack of criteria for experience.** When documentation of a provider's experience is not conferred through board certification or other credentialing (e.g., a specialty board certification program for HIV/AIDS care or care for the homeless does not exist), the criteria for determining when a provider is acceptably experienced is unknown. Further, experience may not always equate to specialization. Although evidence demonstrates that experience matters, how much experience is necessary generally has not been determined.

**Subjective nature of need.** State Medicaid programs and MCOs need to grapple with a question that does not always have clear answers. Specifically, "How much of what kind of experience is needed to adequately serve a beneficiary with a particular health care need? Because the link between volume or specialization and improved quality outcomes has not been strongly documented by research findings for all clinical conditions, concern has been expressed that States or MCOs could use lack of research findings to deny access to providers with a level of experience needed by an enrollee. States and MCOs therefore might need to develop utilization management policies and procedures that recognize the two types of errors inherent in the imperfect science of utilization management: 1) providing access to a more experienced provider, which might incur additional costs but not ensure better outcomes than those achieved through the use of a provider with less experience; or, (2) requiring care to be delivered by a provider with less experience, with an increased risk of decreased health outcomes.

### *Approaches to Strengthen Provider Network Adequacy*

While these are difficult problems, they should not be ignored in the development of provider networks. Approaches to strengthening the adequacy of provider networks include the following:

**Implement proposed BBA regulations.** Implementation of the BBA proposed rules on access standards and provider capacity is the first step in ensuring that all enrollees, including Medicaid enrollees with special health care needs, obtain access to an adequate provider network. HCFA will need to monitor implementation of these regulations to ensure that States consider populations with special health care needs when developing

access standards and appropriately include experienced providers in an MCO network (See Chapter 7 for a discussion of State monitoring). In addition, internal and external grievance and appeals mechanisms must be in place to accommodate current limitations in provider network adequacy standards and limitations in the definition of “experienced providers.” (Grievances and appeals are also discussed in Chapter 7.)

**Plan for the unexpected.** MCOs should have procedures to ensure access to experienced providers whose expertise was not previously anticipated. This can take place in two different ways. The MCO either can identify experienced providers within its service area and make arrangements for them to participate, or the MCO can allow access to providers even though the MCO may not choose to enter into formal arrangements with those providers on an ongoing basis; i.e., allow access to the providers on an “out-of-network” basis. This latter approach is consistent with the CBoR, which states that, “If a health plan has an insufficient number or type of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer obtains the benefit outside the network at no greater cost than if the benefit were obtained from participating providers (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997).” New Jersey uses this approach; its contracts require MCOs to allow for out-of-network referrals when the MCO’s network cannot meet enrollees’ needs (Rawlings-Sekunda and Kaye, 1998).

**Compensate for limits in health manpower.** When experienced providers are not geographically accessible within a MCOs’ service area, an MCO might need to make other arrangements to secure expertise in the care of enrollees with special health care needs. A variety of mechanisms can be used. For example, when tertiary care is required, some MCOs contract with “Centers of Excellence” across the nation (Schulman et al., 1997). However, when ongoing ambulatory care is needed, it may not be feasible for enrollees to travel great distances. In such cases, an MCO might pursue consultation arrangements with experienced providers outside of its service area or telemedicine services. The State and MCOs can work together to develop additional approaches to ensure expertise. In Tennessee, which is a rural state with few HIV patients and a small number of physicians with significant HIV experience, it was considered unreasonable to expect that all MCOs have the internal capacity to care for enrollees with HIV/AIDS. Rather, MCOs, providers, consumers, and advocates developed AIDS Centers of Excellence, using experienced providers as gatekeepers or consultants (Rosenbaum, et al., 1998).

**Adopt policies that recognize the growing evidence base in support of experienced providers.** When constructing their provider networks, MCOs should consider the experience of individual and institutional providers in certain clinical areas, in treating pediatric and geriatric populations, and in caring for populations with certain environmental risk factors (such as homelessness or foster care). While there is evidence that some

MCOs do consider “volume of procedures performed” as a precondition for allowing certain surgical procedures to be performed at individual facilities, this practice varies by the maturity and underlying structure of the health care market (Schulman, et al., 1997). States might wish to include content that requires MCOs to consider provider experience (volume) when constructing their provider networks.

**Create mechanisms to facilitate enrollee and MCO agreement on use of experienced providers.** How much experience is required before a practitioner should be considered experienced? How much more experience equates to improved outcomes? Because the answers to these questions are not always known, opinions about the use of a particular provider over others could differ. Because Medicaid enrollees are insulated from the potential financial effects of using an out-of-network provider, they might more readily seek a provider whom they believe has more experience. Although MCOs might be willing to provide access to more experienced providers, they understandably will be reluctant to implement administrative practices that count and compare the number of patients seen or hours of care delivered by multiple experienced providers. At present, if an enrollee and his or her MCO do not agree about access to a particular experienced provider, the enrollee may exercise internal complaint mechanisms and can seek disenrollment for cause. States and MCOs also might wish to experiment with developing new approaches to determine appropriate use of out-of-network providers when questions about level of experience arise.

### **Utilization Management Policies and Practices**

Over the last decade, utilization management programs have proliferated and are now used by nearly all MCOs to contain costs. Utilization management programs review requests for medical treatment on a case-by-case basis and certify that the treatment is clinically appropriate and medically necessary (Wickizer and Lessler, 1998). Although primary care providers are responsible for the majority of the health care concerns of a patient enrolled in a MCO, the MCO retains some authority over particular service use through utilization management techniques. Prior authorization for many services needed by enrollees with special health care needs is customary, including: hospital admissions, expensive tests, medications, ancillary therapies, mental health services, home health services, out-of-network specialty services and some in-network specialty services (Fox and McManus, 1996).

Some evidence exists that utilization management programs can make access to specialist services difficult for individuals with special health care needs (Clancy, Lanier, Grady, 1996). In addition to creating unnecessary barriers to care, utilization management practices also can cause dissatisfaction among MCO enrollees (NCQA, 1998). In a study of

effects of managed care on behavioral health services, prior authorization processes were reported to complicate access to services and create a barrier not present in previous fee-for-service Medicaid systems. Representatives of the child welfare and juvenile justice systems in several States stated that the prior authorization process caused significant delays in receiving services (Stroul, Pires and Armstrong, 1998). A number of standards-setting bodies thus have promulgated standards for MCO utilization management practices.

### *Initiatives to Promote Appropriate Utilization Management*

**Consumer Bill of Rights (CBoR).** Recognizing the reliance of some individuals with special health care needs on specialist care, the CBoR states that, “Consumers with complex or serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan’s network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan” (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997).

**Accreditation organizations.** NCQA developed 12 standards that address utilization management. These address the structure of an MCO’s utilization management program, clinical criteria for use in decision making, delegation, timeliness of decisions, use of medical information in making decisions, procedures for denials, evaluation of new technology, coverage of emergency services, drug formulary use, criteria for making utilization management decisions, ensuring appropriate service and coverage, and standards for use of appropriate personnel in making utilization management decisions. This last standard states, “The MCO has procedures for using board-certified physicians from appropriate specialty areas to assist in making determinations of medical appropriateness.” The standard for ensuring appropriate service and coverage also states, “The MCO facilitates the delivery of appropriate care and has mechanisms in place to detect and correct potential underutilization and overutilization of services.”(NCQA, 1998). JCAHO also addresses utilization management in its accreditation standards. Neither the NCQA nor JCAHO explicitly address access to specialists or experienced providers; their accreditation terminology refers to utilization management of “services.”

**QISMC.** QISMC standards for organizations contracting with Medicare or Medicaid also follow the content of the CBoR. QISMC standards specify that an MCO is to: 1) provide or arrange for necessary specialty care; and, 2) provide a treatment plan for individuals with complex or serious medical conditions that specifies an adequate number of direct access visits to specialists to accommodate the treatment plan. QISMC standards pertaining to service authorization are similar to NCQA and JCAHO utilization standards in that they also do not explicitly mention providers, but instead refer to managing services (HCFA, 1998c).



**BBA.** The proposed BBA managed care rules would require MCOs to identify in a timely manner enrollees with complex and serious medical conditions. Once they identify these enrollees, MCOs would be required, through appropriate health care professionals, to assess their conditions, identify appropriate medical procedures for monitoring or treating them, and implement treatment plans that specify an adequate number of direct access visits to specialists. The proposed BBA managed care regulations would also require MCOs to put in place policies and procedures for processing requests for initial and continued authorization of services.

**Existing State Medicaid agency practices.** States recognize the use of utilization management as an appropriate means to promote appropriate utilization of services. In a nationwide study of Medicaid managed care contracts, 34 of 42 States required utilization review in their contracts with MCOs (Rosenbaum et al, 1998). Some States also appear to recognize that utilization management practices can create unnecessary barriers to care in some circumstances. In 1998, 18 States required MCOs to allow specialists to serve as primary care providers and 11 required MCOs to allow standing referral to specialists in certain situations. These figures could possibly underestimate the extent of these practices; the remainder of States report that these practices are adopted voluntarily by many MCOs (Kaye, Pernice and Pelletier, 1999).

Some States also allow self-referrals to specialists. Most States allow this for family planning and obstetrical/gynecological services, but some also allow self-referral for mental health/substance abuse services. Missouri and Rhode Island contracts require that, “The health plan (must/agrees to) have written policies and procedures that permit members to self-refer to an in-network mental health provider, rather than obtaining a referral from their primary care provider” (Rosenbaum, et al, 1998). Massachusetts requires that its MCOs permit direct access to mental health and substance abuse providers by self-referral as well as by referral from a State agency, school health personnel, and primary care provider (McManus and Fox, 1996).

Thus, while recognizing the appropriateness of utilization management within managed care, HCFA and States have undertaken strategies to make utilization management more sensitive to populations with special health care needs. A significant step in this direction will be to implement HCFA’s proposed rule requiring MCOs to identify enrollees with complex and serious medical conditions on a timely basis to assess their conditions and implement treatment plans that specify an adequate number of direct access visits to specialists. The proposed BBA managed care regulations that would require MCOs to put in place policies and procedures for processing requests for initial and continued authorization of services also will help. States must implement, and HCFA must monitor, implementation of these proposed rules, once finalized. States that do not require MCOs to allow the use of specialists as primary care providers might wish to adopt this practice

under certain circumstances.

## CHAPTER SIX

### Provide Coordinated and Continuous Care

**Summary:** *The complex and chronic nature of the health of individuals with special health care needs necessitates care and service from many providers and services internal and external to the MCO. Ensuring necessary care for these individuals requires continuity of care and coordination of formal providers, caregivers, and programs that deliver services to enrollees. State requirements for care coordination and continuity of care vary and often are a statement of goals, rather than specifically required practices. This is a reflection of: 1) the lack of generally accepted definitions or standards of practice for care coordination and continuity of care; 2) the lack of MCO authority and capacity to coordinate all health-related services; and, 3) in some instances, lack of organized systems of care external to MCOs with which MCOs can form linkages. Yet, realizing the importance of care coordination, several States are beginning to implement, or are requiring their MCOs to implement, care coordination programs. Over time, with the help of external evaluations, States, policymakers, and stakeholders should be able to determine what features of care coordination programs best meet the needs of individuals with special health care needs.*

**Recommendation 15:** *In contracts with MCOs, States should: 1) explicitly require MCOs to coordinate the care of Medicaid enrollees with special health care needs; and, 2) clearly delineate the scope of MCO responsibilities for care coordination (including coordination with any other Medicaid Prepaid Health Plans (PHPs) or MCOs in which individuals are enrolled). States should share this information with local public and private sector organizations that also serve Medicaid enrollees with special health care needs.*

**Recommendation 16:** *Federal, State and local agencies that provide services to populations with special health care needs should work together to increase efforts to coordinate care across different service systems.*

**Recommendation 17:** *States should have mechanisms to promote continuity of care in their managed care initiatives. These should include requiring MCOs to allow enrollees undergoing a course of treatment for a disabling or chronic condition at the time they involuntarily change MCOs, or when their provider is terminated by a MCO for other than cause, to continue seeing that provider for up to 90 days to allow for the transition of care. In order for this to be implemented, the provider must agree to: 1) accept the MCO's regular payment rate as payment in full; 2) provide all necessary information to*

*the MCO; and, 3) promptly transfer all medical records with patient authorization during the transition period.*

## **Coordination and Continuity**

The complex health care needs of individuals with special health care needs require provision of services by the MCO as well as an array of additional agencies and programs. Some of these services may not be medical, but may be critical to good health. For example, researchers report that poor housing can “tip fragile children with chronic diseases from health into sickness” (Sandel and Sharstein, 1998). Frail elderly individuals living at home may need nonmedical personal care assistance and home-delivered meals. Foster care families may need respite care to sustain their caregiving efforts. Individuals with HIV/AIDS who lack proper nutrition are more susceptible to opportunistic illnesses (Rawlings-Sekunda and Kaye, 1998). Individuals who are homeless and have diabetes may need access to refrigeration to store medications. And almost 12.6 million Americans require some assistance to help them dress, eat, go to the bathroom, clean house, move from the bed to a wheelchair, remember to take medication, and perform other activities that make it possible for them to live at home (King and Wright, 1999).

A study conducted by the National Academy for State Health Policy (NASHP) found 129 separate programs administered by 14 different Federal agencies serving individuals with disabilities, including ACTION, Maternal and Child Health block grants, Ryan White CARE Act programs, Housing Opportunities for People with AIDS, Older American Act services, Rehabilitation Act services, Shelter Plus Care, Special Education grants, Supportive Housing grants and Veterans services (Scully, Selser, Shed and Riley, 1994). A large number of state- and locally administered home care programs, protective services, guardianship services, housing subsidies, fuel assistance, weatherization, community action, and other programs also provide an invaluable network of providers and services essential to maintain the health and functioning of individuals with special health care needs. The informal assistance of family members, neighbors, and friends also is essential to many medically vulnerable individuals. (See Chapter 3.)

Another phenomenon that both necessitates and challenges effective care coordination is the practice used by many State Medicaid agencies of deleting or “carving out” certain Medicaid benefits from the services that an MCO is to provide to enrollees under its contract with the State. Sometimes Medicaid services are carved out because the State prefers to provide them to MCO enrollees on a FFS basis; (e.g., medications). Alternatively, a service may be carved out because the State prefers to enter into a special arrangement with another prepaid capitated entity for the provision of that service only; e.g., behavioral health or dental services. When a State contracts with a prepaid, capitated MCO to provide a less than comprehensive array of services, it is referred to in the

Medicaid program as a Prepaid Health Plan (PHP). In 1998, 20 States had contracts with PHPs, the majority of which were for behavioral health and dental care (HCFA, 1998e). PHPs pose added challenges for coordination of health care. Issues such as: 1) the exchange of specific treatment information between the specialty PHP and the primary MCO; 2) what happens when prescribed drugs are covered under the primary MCO, but are prescribed by practitioners participating in the specialty PHP; and, 3) procedures for notification of each plan in the case of critical events, have implications for health care overall (Teitlebaum, Rosenbaum, Burgess and DeCourcy, 1999).

It is possible for a beneficiary with special health care needs to be enrolled in multiple prepaid managed care entities - an MCO for ongoing medical care and two PHPs - one for behavioral health services and the other for dental services. Sometimes a Medicaid beneficiary is enrolled in two comprehensive MCOs as well as multiple PHPs. When an individual is both a Medicaid and a Medicare beneficiary (is dually eligible), he or she can be enrolled in two comprehensive MCOs; one for their Medicaid services, and another for their Medicare services. If mental health or dental services are also provided through a PHP, a Medicaid beneficiary can be enrolled in multiple MCOs and PHPs.

### *Care Coordination Defined*

The term “care coordination” has evolved. Historically, “case management” was used to describe the process of assessing the needs of an individual who was part of the “target population” of an agency or funding program, and authorizing a plan of care for the individual’s service needs. The case management function was intended to ensure that authorized services were delivered in a timely and appropriate manner and had the desired effect on an individual’s health or functional status. The term “case” management changed to “care” management to reflect the fact that the *care* of an individual (not the individual), is the object of management. “Case” or “care” management is widely perceived as a mechanism for actively involving the consumer, families, and caregivers to determine a service plan that can best meet consumer needs (Case Management Society of America, 1995 and National Chronic Care Consortium, 1995). Care coordination similarly indicates a sensitivity to patient desire for coordination, as opposed to being managed. In practice, case management, care management, and care coordination often are used interchangeably. Significantly, no standard definition of any of these three terms is in widespread use.

**Medicaid statute.** Medicaid law (section 1915(g)(2) of the Social Security Act) defines targeted case management as a State plan option to provide “services which will assist individuals eligible under the plan in gaining access to needed medical, social, educational and other services.” Federal law does not further define case management, allowing States the flexibility to develop and use their own definitions.

**MCO accreditation organizations.** The National Committee on Quality Assurance’s

(NCQA) accreditation standards require an MCO to “ensure” and “monitor” the continuity and coordination of care that MCO enrollees receive across practices and provider sites that are part of the MCO, and between general medical care and behavioral health care. Coordination between general medical and behavioral health is to include “exchange of information” between medical and behavioral health practitioners, promotion of appropriate diagnosis, treatment and referral of behavioral health disorders commonly seen in primary care, evaluation of the use of psychopharmacological medication, and coordination of timely access for appropriate treatment and follow-up (NCQA, 1998).

The Joint Commission on the Accreditation of Healthcare Organization’s (JCAHO) accreditation standards define “coordination of care” as “the process of coordinating care or services provided by a network, including referral to appropriate community resources and liaison with others in order to: 1) meet the ongoing identified needs of individuals, 2) ensure implementation of the plan of care and 3) avoid unnecessary duplication of services.” (JCAHO, 1998).

**Assertive Community Treatment.** Assertive Community Treatment (ACT) programs have been used to serve individuals with serious and persistent mental illness for a number of years. Programs based on ACT principles employ interdisciplinary treatment teams, shared caseloads, 24-hour mobile crisis teams, assertive outreach for treatment in individuals’ own environments, individualized treatment, medication, rehabilitation and supportive services. Assertive Case Management (ACM) programs which incorporate shared caseloads also provide this array of individualized community-based services.

The evidence base for ACT and ACM has recently been reviewed by the Schizophrenia Patient Outcomes Research Team (PORT), with support from the AHCPR and the National Institute of Mental Health. With respect to individuals with schizophrenia who are at high risk for discontinuation of treatment or for repeated crises, the PORT concluded:

Randomized trials have demonstrated consistently the effectiveness of these programs [ACT and ACM] in reducing inpatient use among such high-risk patients. Several studies also support improvements in clinical and social outcomes. These studies suggest that both ACT and ACM are superior to conventional case management for high-risk cases (Lehman, Steinwachs, 1998).

In June 1999, HCFA sent a letter to all State Medicaid Directors advising them of the benefits of ACT and ACM for individuals with schizophrenia. The letter clarified that programs based on ACT principles can be supported under existing Medicaid policies. A number of States currently use ACT services as a component of their mental health service package.

## *Care Coordination Components*

In addition to the lack of a shared definition of care coordination, evidence is lacking (with the exception of ACT and ACM programs for individuals with serious mental illness) that care coordination results in improved clinical or functional outcomes (The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998). Despite the lack of an agreed-upon definition or standards and lack of evidence of effective models, some activities are frequently thought of as components of or necessary for care coordination. These include risk screening, assessment, planning care, service coordination, transition planning, and monitoring and reassessment.

**Risk screening.** Risk screening consists of identifying enrollees who are most likely to benefit from care coordination (Wholey, Burns and Lavisso-Mourey, 1998). As discussed in Chapter 2, several States use screening mechanisms to identify high-risk enrollees.

**Assessment.** Coordination of care begins with an accurate and comprehensive assessment of an enrollee's needs. This was discussed in Chapter 4.

**Planning care.** A plan of care is developed based on the results of the assessment. This generally involves a team, including, at a minimum, a care coordinator, enrollee/family members, and the primary care physician. Other providers in the network who may be the providers of needed services may also be included, such as therapists and home health workers. Care plans can include short- and long-term treatment goals, action plans (including sequence, frequency and duration of interventions needed and who is to provide the interventions), and target dates to achieve any specified goals. Because the care plan's ultimate effectiveness depends in part on the enrollee's understanding of and motivation to follow the plan, the enrollee (and/or, as appropriate, the enrollee's family) has a role in the design of a care plan to the extent he or she is willing and able.

Consumer-centered (or family centered) care planning means understanding and integrating the consumer's (and/or, as appropriate, the consumer's family's) views and preferences in care planning decisions. Care plans should emphasize provision of services and educational instruction that help enrollees to, for example: recognize symptoms and complications of common diseases, reduce risk, learn self-care techniques, and improve nutrition. For example, HIV/AIDS drug therapies are not effective unless individuals adhere strictly to complicated treatment regimens that involve taking many medications throughout the day. Yet a survey of 665 individuals with HIV nationwide found that 43 percent acknowledged not taking their medications as prescribed (Gallant, 1998). Some programs have found that using care coordinators to provide one-on-one education is much more successful than educating through a single encounter with the physician (Rawlings-Sekunda and Kaye, 1998).

**Service coordination.** Coordination is required of care providers who are within the MCO's network, as well as providers not a part of the MCO's network but significantly involved in the care of the enrollee with special health care needs; e.g., AIDS care organizations. Depending on the enrollee, the nature and intensity of service coordination will vary - from very simple with low amounts/intensity of enrollee interaction to very complex with high amounts/intensity of interaction. For example, newly-identified HIV patients and those with multiple HIV-infected family members often require greater care coordination; once care providers and plans are established, they may require less. All older beneficiaries and beneficiaries with a disability that are in the Oregon Health Plan receive some type of care coordination, but intensive coordination services are based on need. The Community Medical Alliance in Boston promotes self-direction for adult members with disabilities and offers care coordination services when preferred by the member.

Sharing information is an important component of service coordination. When information needs to move across providers and care settings, hardcopy or verbal information on change in status, procedures and recommendations for care, typically moves slowly, potentially disrupting care. Many are hopeful that electronic patient records and electronic transmission of data can help coordinate care better. The On Lok PACE site recently received a grant to develop an electronic record that can be accessed by providers within the network caring for the same member. Colorado plans to develop an automated record that the PCP and community providers can access through a secure Internet. The record, which could be read only by a enrollee's providers, would include assessment data, care plans, service encounters, and progress notes. Vermont's Department of Aging and Disabilities is testing assessment software. The Problem Knowledge Couplers software (developed by PKC Corporation) is contained on a laptop and links state-of-the-art medical and social science knowledge with information on an enrollee's unique needs and circumstances. It also allows for electronic transmittal of all consumer information among providers (with permission), thus resulting in real-time information sharing (Johnson-Lamarche, 1999).

Confidentiality laws can delay effective coordination by limiting the health record information available to providers. A 1997 study found that 37 States have laws that require physicians to maintain confidentiality of medical records, 26 require other health care professionals to maintain confidentiality, 33 require it of health care institutions, nine require it of employers or other nonhealth care institutions and four require it of insurers (Gaston, Lazzarini and Flaherty, 1998). In accordance with requirements of the Health Insurance Portability and Accountability Act of 1996, the Federal government is to play a greater role in designing rules for confidentiality of health information. State Medicaid agencies should take action to promote appropriate and confidential sharing of enrollee information by specifying in their contracts with MCOs the extent to which the MCO is expected to share enrollee information with other providers that serve the enrollee, and



clarifying that such information sharing is consistent with State laws addressing confidentiality.

**Transition planning.** Individuals are most vulnerable during critical transitions, such as admission or discharge from a hospital or nursing facility, entrance to school, the death of a spouse or parent, change in provider, the initiation of a new treatment, or enrollment into managed care. For a child, developmental changes such as puberty can trigger complications in health status. Individuals with special health care needs undergo numerous transitions, some of which go undetected. Transition planning attempts to create a supportive environment for change and helps an enrollee exercise informed choices whenever possible.

States have used different strategies to ensure continuity of care during transitions between fee-for-service and managed care or between MCOs (Horvath and Kaye, 1998):

- C Missouri and Nebraska provide a 45-day transition period for DME, oxygen, and other chronic care services in order to prevent an enrollee from being unable to obtain this service when entering the managed care system.
- C New Jersey requires MCOs to honor existing treatment plans until transition plans are developed (within 60 days).
- C During the open enrollment period in Arizona, transition coordinators at each MCO monitor rosters of beneficiaries entering and leaving the MCO. MCOs share information that identifies members who are hospitalized, have had or are about to have surgery, are undergoing chemotherapy, have durable medical equipment on order, are receiving care management, or are noncompliant.
- C Utah reports that its MCO contracts contain a provision that allows for a transition period when a beneficiary moves from FFS or from one MCO to another. A beneficiary may continue to receive care or services from a current provider for a specific amount of time (30 days) while the MCO works with the beneficiary to establish a new provider.
- C Enrollment counselors in Oregon complete a Continuity of Care Referral (CCR) form when members have special or complex medical or social needs requiring the immediate attention of the MCOs. The CCR form is sent to the MCO to alert the Exceptional Needs Care Coordinator (ENCC) at the MCO about the services being received by enrollees or the needs to be addressed. The EECN reviews the form and sends it to the selected PCP. The ENCC position is a critical link to ensure that no interruptions in care occur and that the MCO is fully aware of the needs of new

members with complex care requirements.

**Monitoring and reassessment** of an enrollee's health, functional status, adherence to treatment as well as life changes help the care coordinator modify the care plan and the quality of care provided, and anticipate or prevent acute episodes or declines in health and functional status. For example, the care coordinator working for Managed Health Care Systems of New Jersey, notifies the medical director whenever concerns are raised that an enrollee with HIV/AIDS receives less than optimal care from the primary care physician so that corrective action may be taken (Rawlings-Sekunda and Kaye, 1998).

Periodic, formalized reassessment of an enrollee's health and functional status and progress toward goals is necessary to ensure the effectiveness of services, determine if services are still needed and identify other services that might be required.

### *Continuity of Care Defined*

Providing continuity of care is considered an important dimension of care coordination. A review of literature reveals various dimensions of continuity of care, including: 1) continuity of provider; 2) continuity of location or treatment site (i.e., group practice); 3) continuity of medical record; and, 4) continuity of care coordination (Lou, 1999; Mainous and Gill, 1998; Roos, Roos, Gilbert and Nicol, 1980; O'Malley and Forrest, 1996; Donaldson, 1996). Most of the literature addresses provider continuity. Record continuity is also important for populations with special health care needs such as children in foster care who may change providers frequently. The Institute of Medicine (IoM) defines provider continuity (in the context of primary care) as care that is provided over time by either the same individual or the same team of health professionals. Record continuity is defined as mechanisms that promote effective and timely communication about an individual's health information (about events, risks, advice, and patient preferences) among patients, family, primary care providers, and specialists.

Research on the benefits of continuity of care has yielded mixed findings. Several studies indicate that continuity of care can improve levels of satisfaction as well as preventive and ambulatory care; decrease hospital and emergency department utilization; and lower costs (Donaldson, 1996; O'Malley and Forrest, 1996; Mainous and Gill, 1998; Christakis, Wright and Koepsell et al., 1999; Weiss and Blustein, 1996; Cornelius LJ, 1997). However, other studies point out opposing views; e.g., that being cared for by the same doctor over time does not guarantee a good patient-doctor relationship and that access to more specialized care may be more advantageous than continuity (Freeman and Hjortdahl, 1997; Kitahata, Koepsell, Deyo et al., 1996). A recent review of 24 studies on the association between continuity of care and health outcomes indicated that the provision of continuity of care "may not necessarily benefit or be desired by all patients equally, and its relationship to

health status and outcomes remains unclear” (Lou, 1999).

Moving into an MCO from a FFS system or from one MCO to another can be a challenge for any enrollee, particularly for enrollees with special health care needs. Enrollees with special health care needs may have a longstanding relationship with a provider (or team of providers). Because enrollees with special health care needs might use multiple providers (including specialists, therapists, behavioral health providers or others) the chances that one or more of these providers might not participate in the beneficiary’s MCO network are high, resulting in the potential for *discontinuity* of care.

Clinician continuity is one way to provide continuity, at least within primary care. Being aware of how a patient handles symptoms like pain or recurring complications of a chronic condition are examples of how sustained personal relationships between a patient and clinician can be beneficial (Donaldson, 1996). However, because of the mobility of the population, or the possible loss of eligibility by Medicaid enrollees, clinical continuity might not always be realistic. In such situations, continuity of the patient record takes on greater importance. For example, children in out-of-home (foster) care frequently experience multiple changes in foster home placement and concurrent changes in physicians and social workers, with resulting lack of adequate recordkeeping and poor communication among providers. This factor contributes to lack of adequate health care supervision such as comprehensive physical and mental health screening, referral, and follow-up (Lutz and Horvath, 1997). However, the IoM notes that while record continuity is important, it cannot substitute for clinical continuity because, for example, information such as family, sexual, or emotional problems often is intentionally excluded from the record due to confidentiality concerns.

Continuity of care also is promoted through practices that allow for “transitional care” when an enrollee changes MCOs involuntarily, or when an MCO no longer contracts with a provider for other than cause. The President’s Consumer Bill of Rights states that all MCOs should provide consumers with “transitional care” to allow enrollees undergoing a course of treatment for a chronic or disabling condition at the time they involuntarily change MCOs, or at a time when the provider is terminated by an MCO for other than cause, to continue seeing that provider for up to 90 days to allow for transition of care, as long as the provider agrees to certain conditions. These conditions include: 1) accepting the MCOs’ regular payment rate as payment in full; 2) providing all necessary information to the MCO; and, 3) promptly transferring all medical records (with patient authorization) during the transition period (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997). NCQA’s Accreditation Standards for July 1, 2000 through June 30, 2001 similarly require that when a practitioner’s contract is discontinued, given certain conditions, the MCO is to allow enrollees to have continued access to that practitioner under two circumstances: 1) enrollees undergoing active treatment for a chronic or acute medical condition should have access to their discontinued practitioner

through the current period of active treatment or for up to 90 days, whichever is shorter; and 2) women enrollees in their second or third trimester of pregnancy should have access to their discontinued practitioner through the postpartum period.

### *State Requirements*

A nationwide survey of Medicaid managed care programs asked States about their requirements for administrative case management, targeted case management and care coordinators (although these terms were not defined in the study). As noted in Table 2 below, of the 37 States enrolling individuals who are older adults and/or SSI-eligible, for either their entire Medicaid managed care program or for a special managed care initiatives:

- C 16 States require MCOs to provide administrative case management, the traditional utilization-focused type of case management;
- C 18 States require MCOs to provide care coordination (some States may have reported primary care providers as care coordinators);
- C 12 States require MCOs to provide case management targeted to specific populations (targeted case management); and,
- C 15 States require individual enrollee needs assessments (although States might have interpreted this to mean risk screening tools) (Kaye, Pernice and Pelletier, 1999).

**Table 2: MCO REQUIREMENTS FOR CARE COORDINATION**

Administrative Case Management	Targeted Case Management	Care Coordination	Individual Enrollee Needs Assessment
<b>California</b> <b>Colorado</b> <b>Connecticut</b> <b>District of Columbia</b> <b>Florida</b> <b>Indiana</b> (for SSI) <b>Minnesota</b> <b>Montana</b> <b>New Mexico</b> (for poverty level pregnant women) <b>New York</b> <b>North Carolina</b> <b>Ohio</b> <b>Pennsylvania</b> <b>South Carolina</b> <b>Vermont</b> <b>Wisconsin</b> (for SSI)	<b>Arizona</b> <b>Colorado</b> <b>District of Col.</b> (for the CSHCN waiver) <b>Florida</b> <b>Iowa</b> (for behavioral health) <b>Indiana</b> <b>Kentucky</b> <b>Massachusetts</b> <b>Montana</b> (for AFDC & related, SSI children) <b>Pennsylvania</b> <b>Tennessee</b> (for poverty level children, aged non-nursing home, CHIP, other) <b>Wisconsin</b> (for aged in nursing homes, SSI, CHIP, other)	<b>California</b> <b>Connecticut</b> <b>District of Columbia</b> ( CSHCN waiver) <b>Florida</b> <b>Indiana</b> (poverty level pregnant women, SSI) <b>Kentucky</b> <b>Massachusetts</b> (poverty level pregnant women, aged non-nursing home, SSI children, other) <b>Minnesota</b> (for aged) <b>Montana</b> <b>New York</b> <b>Ohio</b> <b>Oregon</b> (elderly, disabled) <b>Pennsylvania</b> <b>South Carolina</b> <b>Texas (STAR+PLUS)</b> <b>Utah</b> <b>Vermont</b> <b>Wisconsin</b> (aged, SSI)	<b>Arizona</b> (for aged) <b>California</b> <b>Colorado</b> <b>Connecticut</b> <b>Florida</b> <b>Georgia</b> <b>Illinois</b> (for aged) <b>Kentucky</b> (aged non-nursing home, SSI, other) <b>Massachusetts</b> (poverty level pregnant women, aged non-nursing home, SSI children, other) <b>New York</b> <b>Ohio</b> ( ABC Program) <b>Pennsylvania</b> (SSI kids) <b>Texas</b> (STAR+PLUS) <b>Utah</b> <b>Wisconsin</b> (aged, SSI)

However, these are self-reported data, and the exact meaning of the terms as reported by States is unclear. This lack of clear definition of terms is underscored in a 1997 national study of all State Medicaid MCO contracts. Review of contract language discovered that, although case management services were addressed in almost 80 percent of States, most of these contracts did not define the benefit in detail (Rosenbaum et al., 1998). Examples of State care coordination activities follow:

**C Maryland.** Medicaid agency officials report that they require each of their MCOs to have designated special needs care coordinators. They also require MCOs to have a comprehensive plan of care, which emphasizes the use of case management services, for each of the following populations: children with special health care needs, individuals with a physical disability, individuals with a developmental disability, pregnant and postpartum women, individuals who are homeless, individuals with HIV/AIDS, and individuals with a need for substance abuse treatment (APHSA, 1999).

**C New York.** Medicaid agency officials report that they require MCOs wishing to

participate in the Medicaid program to demonstrate their ability to comply with specific requirements, including:

- satisfactory case management systems to ensure all required services are furnished on a timely basis;
- satisfactory systems for coordinating service delivery with out-of-network providers, including behavioral health providers;
- policies and procedures to allow for the continuation of existing relationships with out-of-network providers, when considered to be in the best medical interest of the member;
- satisfactory methods for interacting with school districts, child protective service agencies, early intervention officials, and behavioral health and developmental disabilities service organizations for the purpose of coordinating and ensuring appropriate service delivery; and,
- satisfactory systems for coordinating service delivery between physical health, substance abuse and mental health providers (APHS, 1999).

**C Ohio.** Ohio officials report that they require MCOs to describe and illustrate their approach to managing acute or complex chronic illness, injury or other health-related condition. The MCOs are required to address the following areas:

- how the MCO identifies the need for ongoing treatment or scheduled services among new enrollees to ensure care coordination during the initial months of MCO enrollment. The MCO also is asked to describe this process for enrollees with three conditions--a pregnant women in her third trimester, a child with special health care needs and an enrollee receiving behavioral health services;
- how the MCO identifies enrollees who need case management whether due to catastrophic, acute, or complex illness or injury, or other conditions or issues including the specific criteria employed (e.g., diagnosis, cost, utilization);
- the mechanisms the MCO uses to coordinate services both within the MCO's network, (specifically between PCPs and specialists), and with community agencies or providers outside the MCO's panel (this includes but is not limited to: community and/or social support services, public health clinics, transportation and mental health/substance abuse services);
- when (e.g., certain diagnoses) and how (e.g., referral processes) the MCO uses specialists as PCPs;
- how the MCO initiates, monitors, and under what circumstances discontinues services;
- how patient-specific care plans are developed, implemented, and evaluated;

- including which providers and/or MCO staff are responsible and involved; and,
- any subcontracts used by the MCO for case management services.

**C Utah.** Utah reports that its MCO contracts specify the required elements of a treatment plan. The plan must be based on an assessment of health care needs. It must include methods for monitoring outcomes, and contain procedures and criteria for making referrals and coordinating care with specialists. The treatment plan must also provide for continuity of care and include procedures to address the need for social services from community and other resources (APHS, 1999).

The national contract study also found that the contracts' specifications tended to be written as recommendations rather than requirements, although numerous examples exist of State efforts to articulate some level of relationship with various agencies such as: State and local public health agencies, State and local mental health and addiction treatment agencies, State senior service programs, early intervention programs, special education services, children with special health care needs service agencies, WIC, school health clinics, homeless health care programs, child welfare agencies, adult welfare agencies, juvenile justice agencies and adult correction agencies (Rosenbaum et al., 1998). This lack of clarity about care coordination /case management likely is due to:

- 1) the overall weak state of the "art" of care coordination - in general. A lack of evaluations exists of different approaches to care coordination with a parallel lack of evidence that care coordination in its varied manifestations maintains or improves health outcomes;
- 2) the lack of a commonly agreed-upon definition of care coordination; and,
- 3) an appreciation that MCOs (as well as FFS providers) are not able to fully coordinate all health and health-related care that can affect enrollee health and functioning.

### **MCO Authority and Capacity to Coordinate Services**

The ability of an MCO to coordinate care for enrollees is related directly to its authority. An MCO can be held most accountable for ensuring that care is coordinated and continuous within its own network of providers. State Medicaid agencies also can place substantial responsibility on an MCO to work collaboratively with other Medicaid service providers outside its network. MCOs face their biggest challenge in developing effective and meaningful relationships with the dispersed services and programs that fall outside the

jurisdiction of the Medicaid program.

### *Coordination of Contracted Medicaid Services*

As noted above, an MCO is most accountable for care coordination within the scope of its defined benefit package. In this arena the MCO is responsible for authorizing and paying for services that provide timely and responsive care to meet the complex conditions of enrollees with special health care needs. While the growth of disease management programs within MCOs has been documented (Disease Management News, 1999), little is known about how care coordination is performed within these disease-specific programs, or how care coordination is performed more generally within Medicaid MCOs. Mathematica Policy Research is conducting a study of five States (WA, OR, NM, DE, and CO) that will describe approaches to care coordination undertaken by Medicaid managed care initiatives serving vulnerable populations, including the aged, blind, or chronically ill. The study aims to produce a manual on care coordination that will: 1) describe the different approaches to the design, implementation and operation of care coordination programs; 2) review the experiences to date; and, 3) describe the best practices among States and MCOs.

### *Coordination of Noncontracted Medicaid and Other State-funded Services*

State Medicaid agencies might also require an MCO to assume responsibility for coordinating care with other Medicaid and State-funded services outside of the contracted benefit package. For example, Pennsylvania's contract language requires MCOs to "...act as liaisons with various government offices, providers, public entities and county entities which shall include but not be limited to Office of Children, Youth and Families; county children and youth agencies; WIC agencies; Head Start agencies; juvenile detention centers; school-based health centers; organizations providing services to individuals with HIV/AIDS; public health entities; Office of Mental Retardation; county mental retardation agencies; Office of Mental Health; county mental health agencies; various counties' Corporation for Aging...." The MCO must demonstrate that its staff will "...ensure coordination between the MCO and other health, education, and human services systems." In responding to Pennsylvania's RFP, behavioral health contractors must describe how they work with various health and social service agencies, and must have formal letters of agreement with county mental health/mental retardation offices, county juvenile probation offices, county drug and alcohol agencies, county children and youth agencies, and Area Agencies on Aging (Rosenbaum, et al, 1998).

Since the State has authority to influence the manner in which Medicaid and other State-funded providers organize and deliver their services, linkages can be arranged that create new and expanded systems of care across these programs. These arrangements offer particular benefits to populations with special health care needs who have increased



dependence on behavioral health services, home and community-based care services, school-based clinics, transportation services, prescription drugs, durable medical equipment, nursing facilities and residential care homes (some or all of which may not be included in an MCO's benefit package).

Linkages with other state-funded services can take many forms. Examples of approaches to such coordination include: case management teams with staff from other MCOs, MCO-directed coordination, provider-level coordination, interagency teams, interagency agreements, subcontracts, and coordination of funding.

**Care coordination teams with staff from other MCOs and organizations.** Care coordination teams might include behavioral health specialists or long term care providers that are part of a separate managed care organization, as well as other service providers external to the MCO such as school nurses, staff from Children with Special Health Care Needs Programs, child welfare caseworkers, Ryan White case managers, hospital discharge planners or home health agency representatives. Given the potential for conflict in roles and authority among parties, these processes can be quite challenging: Who should pay for the function of convening multiple parties outside the network of an MCO? How can conflicting incentives of each party be reconciled, such as incentives for a hospital discharge planner to arrange for quick placement into a nursing facility while a care manager may prefer community-based care? Who has final authority? If both the behavioral health organization and the MCO can order prescriptive drugs, how is care coordinated, how is information shared, and how are benefits paid?

**MCO-directed coordination.** The Oregon Health Plan requires each contracted MCO to create and make available Exceptional Needs Care Coordinators (ENCC) to all Medicaid enrollees who are elderly, have disabilities, or are children in foster care. The goals of the ENCC program are to ensure timely access to providers and consideration of an enrollee's special health care needs. ENCCs coordinate community supportive and social service systems with the medical system, and can refer enrollees to an existing organized, funded, and cohesive community service network of nonmedical service providers.

A recent evaluation of the ENCC program suggests that, while the program is meeting its fundamental goals, weaknesses exist. Because participating MCOs are given great flexibility to design their program as they deem appropriate, ENCCs function differently in different MCOs. Some MCOs appear to have ENCCs functioning as both a patient advocate and a high-cost case manager, which may cause conflicts. Also, because advocates and providers are not always aware of the roles of ENCCs, they do not use

ENCCs as fully as they might (Mittler and Gold, 1999). However, as the State and MCOs gain experience with these programs, they are likely to further refine ENCC roles.

**Provider-level coordination.** Tennessee’s AIDS Centers of Excellence (subcontractors to each of the MCOs contracted by TennCare) have medical care coordinators and case managers at each site. The medical care coordinators handle medical issues such as mental health, treatment education/adherence, inpatient facilities placements and discharges, communication among providers, drug and alcohol treatment referrals, and respite care/adult care referrals. Case managers handle housing and supportive services such as testing and counseling, environmental assessment, religious/spiritual issues, income and home-related issues, harm reduction (active users), and criminal behavior (Community Liaison Committee, 1997).

**Interagency teams.** Colorado’s integrated managed care program for individuals dually eligible for Medicare and Medicaid includes staff from the county Department of Social Services (DSS) on its care coordination team. The DSS is the single entry point for long term care services and is responsible for managing Medicaid community-based waiver services. Although authority for authorizing services rests within the respective agencies, the arrangement facilitates a comprehensive approach to service planning.

In addition, many other entities, such as organizations funded under the Ryan White Act, have specialized expertise in dealing with specific populations. These organizations have knowledge and experience to enhance access to needed services and facilitate adherence to complex treatments, and might already be coordinating the nonmedical care of MCO Medicaid enrollees. These agencies also are potential members of interagency teams.

**Interagency agreements.** Several States have established interagency agreements or memoranda of understanding that deal specifically with care coordination or case management services. Missouri Medicaid officials report that they have interagency agreements with the Department of Health (DOH), Bureau of Special Health Care Needs, to provide administrative case management (service coordination) for children with special health care needs, and DOH’s Bureau of HIV/AIDS Care and Prevention to provide service coordination activities for individuals in the Medicaid AIDS Waiver program (APHS, 1999).

**Coordination of funding.** In Massachusetts, the Medicaid agency and the Department of Mental Health (DMH) initiated a joint procurement for mental health services in 1995. Since July 1996, the two agencies have combined funding for coverage of emergency mental health services and inpatient acute mental health services for uninsured DMH consumers with funding for a more extensive set of mental health and substance abuse services for Medicaid members. A single managed care contractor, the Massachusetts Behavioral Health Partnership (MBHP), provides these services to DMH and Medicaid agency consumers. As the State mental health authority, DMH also participates fully with the Medicaid agency to manage the contract with MBHP and to advise on critical policy

matters (Fiske, 1999).

**Subcontracts.** In addition, MCOs could subcontract with organizations that traditionally have provided care coordination services to Medicaid beneficiaries to provide this service for their enrollees.

All these approaches to coordinating MCO benefits with those of other Medicaid and State-funded services depend on State involvement, commitment, and funding. MCOs cannot negotiate meaningful arrangements when comparable requirements do not exist for other capitated or FFS providers, unless they are willing to purchase such services. Arrangements should be mutual and seen as part of a broader goal of organizing and enhancing a State's *system* of services for populations with special health care needs.

### *Coordination of All Required Services, Regardless of Payment Source*

An MCO has limited authority to effect coordination with other service providers. A broad array of institutional and community-based providers serve populations with special health care needs. MCOs typically coordinate care with these providers through referral arrangements and information sharing. For example, Massachusetts requires MCOs to focus on care coordination services for four at-risk populations: individuals with disabilities (including HIV/AIDS), women with high-risk pregnancies, individuals who are homeless, and children in State custody. The ultimate goal is for care coordinators to provide (according to contract language) “linkage with staff in other agencies and/or community service organizations if the agency/organization is already involved in meeting the enrollee’s needs, or if the agency/organization is identified as helpful in meeting such needs” to “ensure timely and coordinated access to all Medicaid-covered services, including behavioral health services, and non-MCO covered services.” (Commonwealth of Massachusetts, 1997).

Several factors affect the level of MCOs’ success in care coordination. First, coordination can be eased through the existence of a comparable system of care with which the MCO can link. Umbrella agencies, such as the Area Agencies on Aging (AAoA), have an infrastructure and staff that devote time and resources to work directly with MCOs. Second, coordination can be facilitated when a symbiotic relationship exists between agencies. By affiliating with AAoAs, the MCO can tap into an organized system of case management that may not exist within the MCO. The AAoA preserves its traditional role as services move from a FFS to a managed care environment. But the missions of the two organizations may differ: as an advocacy organization generally not at risk for the cost of care, the AAoA might have different expectations for service scope and levels than the MCO. Collaboration and mutual understanding are required to coordinate services successfully.

The likelihood that separate care managers from each agency or service system will oversee separate service plans - oftentimes unaware of an enrollee's dependence on other service providers - further complicates care coordination. Add the lack of authority to order or deliver services outside of its covered benefits, and the MCO has limited power to coordinate the full scope of care for enrollees with special health care needs. Indeed, an MCO might not be aware of other services provided to the enrollee that could affect care. An enrollee with special health care needs could have multiple case managers with no one authority to ensure continuity of care across providers. Providers outside an MCO's network might be concerned about the MCO serving as lead coordinator. One concern is that the MCO's care coordination might be focused more on utilization management and cost control than on access to the appropriate continuum of services needed. A second concern is that the MCO will "medicalize" the delivery of nonmedical care (such as personal care assistance). For example, aging advocates have expressed concern that MCOs with long term care benefits may not provide the flexible benefits of nonmedical services needed to support beneficiaries in the home setting (Kane et al., 1996).

In 1995, the District of Columbia's Medicaid agency received authority through a section 1115 demonstration waiver to establish a managed care initiative, Health Services for Children with Special Health Care Needs, Inc (HSCSN), that serves children with disabilities and special health care needs. Care coordination (referred to as care management in the program) is a central feature of the system. A care management team consisting of registered nurses, clinical social workers, physician assistants and care manager associates is established for each enrollee.

An evaluation of this system found that while primary care physicians, specialists, and parents are generally favorably disposed toward the care management process, the program highlights specific challenges of coordinating the care of a population with special health care needs (even when the plan is dedicated to only serving that population). When designing the program, officials specified that more complex cases would be assigned to care managers with more experience. Managers handling more complex cases would also be assigned fewer enrollees. In practice, care managers found that they spent far more time with enrollees than expected, primarily due to managing multiple family and social problems that directly affect the health and well-being of the enrollee. As a result, care managers, in general, experienced an overload of cases. The program has also experienced difficulties coordinating with other agencies. Although program officials have made strides in working with hospitals and the foster care

program, they continue to experience problems with public health clinics, residential treatment facilities, and the school system (Kidder, Hale, Coulam, et al., 1998).

## **State Medicaid Agencies Can Facilitate Care Coordination by MCOs**

MCOs are faced with several challenges to ensuring that all enrollees with special health care needs receive beneficial care coordination. They include the following: 1) The state of the art with respect to care coordination is underdeveloped. No agreed-upon standards exist for care coordination, and there are few well-defined models of care coordination. Further, evaluations of care coordination are sparse and fail to demonstrate effectiveness, or even multiple well-defined approaches to care coordination; 2) MCOs have no authority over many of the services and service systems used by their enrollees; and, 3) in some there are a lack of organized service systems with which the MCO can readily identify and coordinate. In their role of purchaser of health care, State Medicaid agencies can take steps to address these problems in two ways as discussed below.

### *Define Realistic Responsibilities of MCOs*

States need to define realistic responsibilities for MCOs in their managed care contracts. Although recognizing that continuity of care can best be achieved when a single point of accountability and funding integration exists, State contract provisions should reflect the extent to which this has occurred. At present, the practice is not widespread. Contract requirements should explicitly identify the components of care coordination, (such as risk screening, assessment, care planning, service coordination, transition planning, and monitoring and reassessment as components of care management) that the MCO or PHP is required to perform. Contract provisions also should explicitly describe the expected relationship between the MCO and other Medicaid service providers, including Medicaid carve-out PHPs.

### *Foster Development of Coordinated Systems of Care*

MCO attempts to develop linkages to service providers outside its own network are constrained if rational systems of care do not exist outside the MCO. Many different State and local, public and private agencies provide services required by an enrollee with special health care needs, and each agency often has separate rules governing eligibility, reimbursement and access to services. It is possible that each agency provides a care manager to the enrollee, thereby creating a situation in which a Medicaid enrollee with special health care needs might have multiple care managers but none with overall responsibility for total care coordination. Although linking medical and nonmedical

services is critical to effective care, MCOs are challenged to effectively link these myriad providers because of time and resource constraints.

State Medicaid agencies also are limited in their capacity to create linkages between MCOs

and community agencies when services are provided by non-Medicaid programs. However, State Medicaid agencies can take steps to facilitate this process by:

- C creating and promoting rational systems of care external to the MCO that support the provision of social, educational, and specialized services;
- C strengthening partnerships with State health agencies who have statutory responsibilities for developing systems of care for populations with special health care needs; e.g., Title V agencies for children with special health care needs and State Units on Aging for older Americans;
- C communicating with other State agencies to develop consistent, coordinated policies and information systems / sharing to identify and serve populations with special health care needs; and,
- C coordinating State-administered resources to support integrated delivery of services.

### **Integrated Service Delivery**

The National Long Term Care Channeling Demonstration of the 1970s and the growth of Medicaid Home and Community Based Waivers since the 1980s have provided States with the opportunity to use case management to coordinate acute and long term care for populations with special health care needs. Both programs targeted those who were likely to require institutional care, and sought to arrange comprehensive home and community services that extended beyond the typical medical model. While these programs were generally successful at postponing or preventing institutional placement, both had limits on the extent to which services were truly integrated. Moving from an institutional setting where all medical, social support, nutritional, and rehabilitative services were covered under a single roof and payer (Medicaid), States struggled to create similar environments in the community with multiple payers, agencies and settings of care. However, case managers were often limited in their authority and capacity to bridge these various systems of care. For example, a beneficiary who was receiving personal care services in the home under the Medicaid waiver program may have required hospitalization for an acute illness. Since hospital stays are covered under Medicare, the case manager would often lose contact during the stay, after which the beneficiary may be placed in a Medicare reimbursed home health program. Limited freedom to coordinate care across programs and the lack of flexibility to redesign benefits specific to the needs of beneficiaries prompted States to think of new models for service delivery to populations with special health care needs (Manton, 1993). The issue of care coordination can be partially resolved when systems of

care are created that bring together many of a beneficiary's service needs under a single accountable entity; i.e., an integrated service system.

Several states, with HCFA approval, have designed integrated systems of care for beneficiaries who are dually eligible for Medicaid and Medicare. These programs seek to integrate services (primary, acute and long term services) and coordinate financing (Medicare and Medicaid):

- C The Minnesota Department of Human Services has developed a program called Minnesota Senior Health Options (MSHO) which coordinates Medicaid and Medicare financing and acute and long term care delivery systems. This demonstration project required both Medicaid and Medicare waivers from HCFA to test the integration of primary, acute and long term care services for individuals ages 65 and older who are eligible for both Medicare and Medicaid. The waivers allow the State to combine the purchase of both Medicaid and Medicare services into one contract managed by the State. Minnesota is the first State to be granted such a combination of waivers. MSHO began enrolling Seniors in February 1997. The five-year demonstration will be implemented in a seven county metropolitan area. As of January 1999, it had 2,777 enrollees (Cashore, et al., 1999).
- C Texas Star+Plus also combines acute and long term care services but through an incentive program that offers an unlimited drug benefit to beneficiaries who choose to receive their Medicare services under the plan.
- C The Program for All-Inclusive Care for the Elderly (PACE), provides medical, social support, educational and housing services under one umbrella. Physician, nurses, nurse clinicians, social workers, personal care aides, home help, therapists, transport drivers, rehabilitation specialists, nutritionists, and pharmacists are all on staff and have frequent opportunities to discuss service options and implications with the beneficiary and with each other. Several PACE programs are provided within resident housing, further facilitating the integration of a beneficiary's home environment with the care planning and treatment process. However, most MCOs are not so equipped and the model may not be easy to replicate.

While the term integration is often broadly applied to these and other models of care, no model completely overcomes the problems of coordinating the myriad of services not otherwise covered under Medicaid or Medicare, but critical to the care needs of these populations. These are services that remain outside the direct control of the MCO and are accessed via multiple case managers and eligibility criteria. Because of this, improvement in care coordination at every level is needed - within the MCO benefit package, within Medicaid services not a part of the MCO or PHP benefit package, and with service providers of other systems or providers of care outside of Medicaid.

## CHAPTER SEVEN

### Increase Quality Monitoring

**Summary:** *Quality monitoring of MCO performance is used to avoid adverse outcomes and promote continuous quality improvement. For a general population, some dimensions of quality (e.g., enrollee satisfaction and the use of primary and preventive services) have been found to be similar or better in capitated MCOs than in fee-for-service (FFS). However, studies assessing MCOs performance in caring for enrollees with special health care needs show mixed results. This greater level of uncertainty about MCOs' performance in delivering quality health care to enrollees with special health care needs is of particular concern because the health of these individuals could be more susceptible to decline without receipt of quality health care.*

*Despite this concern, quality monitoring activities generally have not specifically focused on enrollees with special health care needs. While MCOs, States and HCFA use a variety of mechanisms to monitor health care quality for the Medicaid population overall, only a few efforts specifically address care provided to enrollees with special health care needs. The complexities associated with measuring health care quality are compounded by several challenges unique to enrollees with special health care needs, including the difficulty of identifying individuals with special health care needs, the large number of different conditions causing disability, and the existence of multiple conditions and risk factors. These challenges limit the usefulness of existing quality monitoring tools that were developed to assess quality of care delivered to general commercial and Medicaid populations without special health care needs.*

#### **Actions to be taken by the Department of Health and Human Services:**

*DHHS, in partnership with States, advocacy organizations, MCOs and other stakeholders, will play a leadership role in developing and/or adapting performance measures, quality standards, and clinical practice guidelines that are necessary for monitoring and improving the quality of care provided to populations with special health care needs. Further, HCFA will monitor implementation of State Quality Assessment and Improvement strategies, States' fair-hearing systems, and State oversight of internal MCO grievance and appeal systems, with specific attention to how well they address the needs of enrollees with special health care needs.*

#### **Recommendations for action by others:**

**Recommendation 18:** *States should require MCOs to undertake, as part of their*



*internal quality assessment and performance improvement programs, initiatives that assess and improve the quality of care specific to populations with special health care needs.*

***Recommendation 19:*** *States, as part of their Quality Assessment and Improvement Strategies required by the BBA, should monitor, and take action to improve, care specific to populations with special health care needs.*

***Recommendation 20:*** *States should monitor MCOs' internal grievance and appeal systems for access and timeliness, and ensure that all aspects of the State fair-hearing system, including notice to enrollees, access to records, and continuation of benefits until the impartial hearing is held, are provided to enrollees with special health care needs in an accessible and timely manner.*

### **Managed Care Raises Hopes, Expectations, and Concerns for Quality**

Health care purchasers, including State Medicaid agencies, are attracted to MCOs because of their potential to provide high-quality health care while controlling costs. Because MCOs have a defined set of patients and providers and are a “point of accountability,” many believe they present an opportunity to measure and improve the quality of care provided to enrollees (Sofaer, Woolley, Kenney et al., 1998; Booth, Riley and Mitchell 1998). However, concerns have been raised that when MCO providers are paid a fixed monthly amount for each member, they have a financial incentive to deny or reduce the amount of service. Yet, in several studies comparing managed care to FFS arrangements on the quality of care provided to the general population, researchers found similar or better levels of care for primary and preventive services as well as patient satisfaction (Miller and Luft, 1994; Sisk, Gorman and Reisinger et al., 1996; Brown, Clement, Hill et al., 1993; Rowland, Rosenbaum, Simon et al., 1995; Piper and Bartels, 1995).

Research on the quality of care provided to individuals with special health care needs has shown mixed results. For example, a study comparing the treatment of AIDS patients in an HMO and a FFS plan found that functional outcomes and patient satisfaction were similar (Wilson, Sullivan and Weissman, 1998). However, in a comprehensive review of studies of MCO performance, Miller and Luft noted that “two studies with the most carefully designed prospective methodologies--the Medical Outcomes Study and the Medicare home health study--provided evidence that at least some ill, elderly HMO enrollees had worse quality-of-care outcomes than did their fee-for-service counterparts” (1997). Although the authors note that the studies are based on somewhat dated data and limited sample sizes, they conclude that “much more research and reporting are needed on quality-of-care process and outcomes measures for vulnerable groups.”

Such findings have heightened concern among public purchasers regarding the quality of care provided to individuals with special health care needs, because they generally have more costly and complex needs and their health may be more susceptible to decline if they do not receive necessary care. This uncertainty about quality of care for individuals with special health care needs suggests that States should pay particular attention to these populations in designing Medicaid managed care initiatives. However, monitoring the quality of care for populations with special health care needs remains a challenge for several reasons.

## **Challenges of Measuring Quality for Populations With Special Health Care Needs**

### *Definition of Quality*

The Institute of Medicine (IoM) defines quality as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (IoM, 1990). Over the past decade, many organizations have used this definition to develop and refine tools that measure and monitor MCO performance in delivering care to a general population.

Measuring quality generally is assumed to rely on three interrelated elements: structure, process and outcomes (Donabedian, 1980). Structural measures evaluate whether a MCO or provider has the capacity to provide care. These measures include such indicators as the types of services and facilities available and the qualifications of practitioners. Process measures address the actual provision of services for the prevention, diagnosis, and treatment of disease. They typically include such measures as immunization rates, number of prenatal visits and retinal exams for diabetics. Outcome measures look at the results of care provided and often include changes in functional and/or health status and patient satisfaction with care.

Because each of these elements, by itself, has limitations, quality monitoring systems often rely on a combination of structure, process and outcome evaluation. Although structural measures indicate what features should be present in an MCO, they do not indicate whether the care provided is appropriate. These measures generally are used by purchasers to assess quality prospectively; i.e., before signing a contract to enroll individuals (Sofaer, Woolley, Kenney et al., 1998). In contrast, process and outcomes measures address the rates at which certain services are used and their effectiveness in addressing the patient’s condition. They are used to assess MCOs retrospectively and identify areas for improvement.

### *Challenges*

Although the use of structure, process, and outcome measures to monitor health care received by the general population is widespread, this has not been the case with respect to populations with special health care needs for several reasons:

**Difficulty identifying individuals with special health care needs.** As discussed in Chapter 2, identifying all individuals with special health care needs is challenging and not currently done by most MCOs. The New England SERVE project found that MCOs generally were unable to report the numbers of children with special health care needs enrolled (New England SERVE, 1997). A recent study of individuals with disabilities in Medicaid managed care found that despite receiving higher capitation rates for individuals with disabilities, most MCOs probably do not know whether a new enrollee has a disability or chronic condition (Regenstein and Schroer, 1998). A study of six Medicaid managed care programs found that, even when given a financial incentive, many providers are reluctant to identify individuals with HIV because of confidentiality and other concerns (Rawlings-Sekunda and Kaye, 1998). Individuals who are homeless, by definition, are often difficult to locate and may find it disadvantageous to identify themselves as homeless. For some children in foster care, the foster care eligibility category may not be entered into the Medicaid eligibility system for weeks or months as other pressing issues take precedence (Dreyfus and Tobias, 1998).

In a study conducted by the Economic and Social Research Institute, fewer than half of the 58 State capitated and primary care case management programs<sup>8</sup> require their MCOs to contact a new enrollee (with or without a disability) within a given time period (Regenstein and Schroer, 1998). HCFA's proposed rule implementing the BBA Medicaid managed care provisions would require MCOs to conduct an initial health assessment of each enrollee within 90 days of enrollment. The proposed rule would require States to ensure that MCOs have in place procedures to identify individuals with complex and serious medical conditions in a timely manner, and that an appropriate treatment plan is implemented. The proposed rule notes that complex and serious medical conditions may be "physical-health, mental-health or substance-abuse-related." Thus, States and MCOs will need to develop or adopt screening mechanisms to identify beneficiaries with complex and serious conditions in a timely manner.

**Populations with special health care needs are small and heterogeneous.** Measures used to assess quality often focus on a specific condition, such as asthma, or a particular health service, such as immunizations. Because determinations of a MCO's performance is best made by determining how a MCO performs routinely, and not in a few isolated events, a larger study population increases the ability to use and have confidence in the results of

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<sup>8</sup> Of the 58 systems, 36 are capitated and 22 are primary care case management.

quality measurement. In the case of enrollees with special health care needs or uncommon conditions, this is problematic, due to the relatively small numbers of individuals who have a particular health condition.

In a study of six Medicaid managed care initiatives, the National Academy for State Health Policy (NASHP) found that, because of the small number of enrollees identified, special focus generally is not taken in monitoring the quality of care received by enrollees with HIV (Rawlings-Sekunda and Kaye, 1998). However, despite the small numbers, two sites have initiated monitoring activities. Massachusetts is evaluating network physician compliance with new clinical guidelines developed for prescribing protease inhibitors. CalOPTIMA requires MCOs to collect specific quality indicators in HIV identification, prevention and treatment, if they want to receive an AIDS-adjusted capitation rate (Rawlings-Sekunda and Kaye, 1998).

The diversity of individuals with special health care needs makes it difficult to group individuals together and measure quality of care. Measures that are important for one segment of a population are not necessarily meaningful for another. For example, what constitutes quality care for a person who is physically disabled could be different for an individual who is mentally disabled.

**Multiple conditions and risk factors can make interpretation of quality measures difficult.** Many individuals with special health care needs have multiple health conditions and other risk factors. For example, although approximately 12 percent of the SSI population has diabetes, it most often is not the reason for disability (Tobias, 1997). Many are disabled as a result of mental retardation, serious mental illness or other physical disability. Other characteristics, such as age, diagnosis, and comorbidities also can influence the outcome or effectiveness of care.

Because of this, when comparing the performance of different MCOs in improving or maintaining health, it is necessary to use statistical approaches to analyze the results of quality measures that can account for any other conditions (co-morbidities) or characteristics (risk factors) that can influence the health of enrollees. These approaches involve either “stratifying” or “adjusting” for risk. Opinions differ about when to stratify (reporting separately on quality for certain subpopulations within a larger population) or adjust (keeping all populations together but calculating the measures in a way that “controls” for the differences caused by certain characteristics such as age or comorbidity). Stratification and risk adjustment can be methodologically difficult to do, and require agreement (that may be difficult to obtain) on certain assumptions that underlie the stratification or adjustment.

**Some health and social services outside of the MCOs’ control can influence quality**

**outcomes.** For individuals with special health care needs, service needs might extend beyond health care to rehabilitative and support services known as wraparound or enabling services (IoM, 1997). As discussed in Chapter 6, these may be provided not by the MCO, but by community and social support agencies. As a result, it is difficult to gauge the quality of a service provided by an MCO, if a population under study also depends on other organizations for related services that are outside the scope of benefits provided by the MCO. For example, outcomes of care for stroke patients depends in part on patient participation in care. However, strokes are often accompanied by depression. If the MCO's benefit package does not include coverage of mental health services, it may not be appropriate to measure some aspects of MCO performance on restoring function to a stroke victim because the MCO does not control all the services needed to treat depression and improve patient functioning.

**Lack of information systems.** The absence of comprehensive health information systems is a barrier to high quality care. This is not just a problem with MCOs, but is a problem throughout the health care industry. Creating and using valid measures of quality sometimes requires obtaining data that are not routinely collected for patient care or payment purposes, such as information about patient perspectives on care or measures of functional status. Quality measures can also require detailed clinical data often available only from a patient's record (e.g., patient reports of improved health, clinical observations of practitioners such as clarity of lungs, air flow measurements, observations of skin breakdown, blood pressure and blood profiles) (The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998). Often, such information often is not automated, recorded inconsistently, or accessed easily. Under FFS medicine no economic incentive existed to develop information systems to provide information on quality (Kleinke, 1998). Under managed care, MCOs are held accountable for measuring and improving the quality of care delivered to a defined population, and thus are accountable for having the information to do so. However, MCO information systems sometimes do not obtain detailed information on all services delivered to all enrollees. Detailed clinical information is not always obtained from primary care providers reimbursed on a capitated as opposed to FFS basis. Detailed clinical data may not be available on pharmacy or laboratory data. Even when data are available, information systems do not always link data across service systems such as primary care, laboratory, hospital, and pharmacy. Audits of MCO data used to produce performance measures have found a number of data quality problems including: missing encounter data, "homegrown" coding systems (i.e., coding systems developed internally by an individual MCO and that do not always produce comparable data), missing information in patient records, and inaccessibility of mental health records (NCQA, 1997).

Two approaches could be used to ensure that MCOs have information systems adequate to

measure, monitor, and improve quality. The first approach is to require MCOs to have in place information systems with specific program specifications. The second approach is to set expectations that MCOs must meet concerning quality standards, monitoring, and improvement. MCOs will then need to acquire information systems adequate to fulfill these expectations. HCFA has chosen the latter approach; the proposed rule to implement the Medicaid managed care quality provisions of the BBA calls for States to require each MCO to maintain a health information system that collects, analyzes, integrates, and reports data needed to calculate performance measures and implement an ongoing quality assessment and performance improvement program. The proposed rule specifies required basic elements for MCO information systems.

### **Limited Applicability of Existing Quality Monitoring and Improvement Mechanisms**

Mechanisms for measuring, monitoring, and improving MCO provision of quality care to a general population include: 1) determining compliance with structural standards; 2) using performance measures; 3) using practice guidelines; 4) establishing clear contract specifications; 5) using independent external quality review organizations to conduct reviews, validate data, evaluate quality studies, and assist the MCOs with quality improvement activities; 6) conducting focus groups and quality studies; and, 7) ensuring that beneficiaries have an adequate grievance and appeals system. States generally approach their quality oversight activities by using a combination of these complementary mechanisms (OIG, 1998).

Nevertheless, States' ability to use these mechanisms to monitor MCO performance in caring for enrollees with special health care needs is a challenge. A recent study of 58 Medicaid managed care initiatives that serve beneficiaries with disabilities in 36 States found that all of the capitated initiatives include a quality assurance component in their contracts. Yet, they rarely require MCOs to address issues unique to enrollees with disabilities (Regenstein and Schroer, 1998). Another study found that only 3 of the 21 States enrolling beneficiaries with disabilities in 1995 and 1996 knew of any MCOs with programs that targeted quality improvement in any indicator of disability care (Landon, Tobias and Epstein, 1998). A 1996 GAO study of 17 States with prepaid initiatives that include Medicaid enrollees with disabilities found that only 8 of the States had specific monitoring efforts designed to assess quality of and access to care of these populations (GAO, July 1996). Evaluations of States with section 1115 waivers indicate that information is lacking about the quality of care received by MCO enrollees through these waivers (Coulam, Irvin and Teitelbaum, et al., 1998; Ammering and Mitchell, 1998; Mitchell, Haber, Lee et al. 1998; Mitchell and Saucier 1998; Long, Zuckerman, Rangarajan and Berkowitz, 1998; Marstella, Coughlin, Long and Rangarajan, 1998; Ku and Hoag, 1998).

States are engaging (and requiring their MCOs to engage) in some activities to ensure that enrollees with special health care needs receive quality care in a managed care environment. A study tracking the impact of State managed care reforms on children and adolescents (and their families) who have behavioral health disorders found that seven of the 10 State participants have “some efforts to assess the quality of services” for this population (Stroul, 1997). The study noted that several States reported that behavioral health care goals are incorporated into contracts with MCOs - with bonuses or fiscal penalties attached to performance. Other States monitor care by requiring specific structural components and operational procedures: collecting performance data, conducting quality improvement studies and reviewing encounter data on use of services.

HCFA’s proposed rule implementing the BBA Medicaid managed care provisions supports the need for States’ ability to monitor MCO performance and improve quality for Medicaid managed care enrollees. For example, for the first time in Medicaid law, each State Medicaid program would be required to implement an overarching quality assessment and performance improvement (QAPI) strategy designed to address the effectiveness of its managed care program. In addition, the BBA stipulates that the strategy must be consistent with standards established by DHHS. These standards, specified in the proposed rule, and HCFA’s monitoring of State strategies, will help ensure quality care for Medicaid enrollees. HCFA’s proposed rule further specifies that the State strategy must assess the quality and appropriateness of care to “all” Medicaid enrollees covered under each MCO’s contract. Therefore, the State’s strategy must also include “procedures for monitoring and evaluating the quality and appropriateness of care and services to enrollees that reflect the full spectrum of populations enrolled under an MCO’s contract.” Although the proposed rule does not explicitly state that the quality of care for populations with special health care needs must be addressed separately in the State’s strategy, this is HCFA’s intent.

**Predetermined structural and operational standards for MCOs.** Predetermined standards typically are used to assess structural and operational aspects of an MCO’s performance. For private MCOs, structural and operational standards have been developed and used by accrediting organizations such as the National Committee on Quality Assurance (NCQA) and the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO). In order to protect and improve the health and satisfaction of Medicaid and Medicare enrollees, HCFA developed a Quality Improvement System for Managed Care (QISMC) in 1998. QISMC standards are mandatory for Medicare+Choice MCOs and serve as a model for States to use at their discretion to develop requirements for Medicaid MCOs. If a State chooses to adopt these standards and to require compliance by MCO contractors, the State would have a greater likelihood of compliance with HCFA’s proposed Medicaid managed care rule implementing the BBA provisions pertaining to quality requirements for MCOs.

When enrolling populations with special health care needs into MCOs, Medicaid programs also could have specific structural and operational requirements for these populations. Standards could include requirements for a certain number and type of providers; a system for linking primary, specialty, rehabilitative, and support services; and particular programmatic aspects, such as case management. To assess compliance with standards, State Medicaid staff (or a State-designated organization) may conduct onsite reviews (Booth, Riley and Mitchell, 1998). For example, Oregon's Office of Medical Assistance Programs conducts on-site evaluations of organizations participating in the Exceptional Needs Care Coordination Program to determine compliance with the requirement to provide specialized case management services to enrollees that are aged, blind or disabled (Oregon Office of Medical Assistance Programs, 1998). Proposed regulations implementing the BBA specify that each State strategy must include standards on MCOs' structure and operation as well as standards for quality measurement and improvement.

**Performance measures for MCOs.** These measures provide a numeric rate (percent) expressing how frequently an MCO (or a hospital, nursing home, medical group, etc.) provides care that is desirable, e.g., childhood immunization rates. Some well-known performance measurement tools for a general population are the Health Plan and Employer Data Information Set (HEDIS), the Consumer Assessment of Health Plan Study (CAHPS), and Performance-Based Measures for Behavioral Health Care Programs (PERMS). The original HEDIS measures were designed to assess care provided to commercially insured populations enrolled in MCOs (NCQA, 1993). Over time, HEDIS has evolved to include measures targeted to Medicaid and Medicare populations. As a measurement system, the current version of HEDIS (3.0/1999) addresses a cross section of the American people (Sofaer, Woolley, Kenney, et. al., 1998). Although a few HEDIS measures address quality care for certain populations with special health care needs, such as diabetics, clinically depressed individuals, and the elderly, most of the HEDIS effectiveness of care measures assess preventive care services (NCQA, 1998). Given appropriate sampling and over sampling, HEDIS measures can be used to assess preventive services provided to populations with special health care needs (Sofaer, Woolley, Kenney, et al, 1998). However, many of the HEDIS specifications (e.g., continuous enrollment requirements and the sample size that is required to make plan-to-plan comparisons) limit the utility of HEDIS as a tool for monitoring care provided to populations with special health care needs.

CAHPS is a collection of surveys that asks consumers about their experience with their health insurance plan, both FFS and managed care. The surveys gather information about enrollees' (and/or their families') experiences with FFS and MCOs. CAHPS contains core surveys that address: 1) adults who are privately insured; 2) adults who are enrolled in Medicaid; 3) children who are privately-insured; 4) children who are enrolled in Medicaid; and, 5) Medicare beneficiaries enrolled in FFS or HMOs. CAHPS also has supplemental questions that can be added at the discretion of the survey's sponsor. CAHPS has also



developed, or is in the process of developing, surveys or supplements that address the following:

- C individuals with chronic conditions and disabilities;
- C behavioral health services;
- C children with special health care needs;
- C adults with special health care needs;
- C Medicaid SSI; and,
- C disenrollment from health plans by Medicare beneficiaries.

PERMS, sponsored by the American Managed Behavioral Healthcare Association (AMBHA), is a data assessment tool developed to assess care provided by managed behavioral health organizations. PERMS is a mechanism to test and validate behavioral health performance measures. The AMBHA hopes that quality measurement organizations which operate on a national level will use PERMS to incorporate valid, reliable behavioral performance measures into their data sets (Sofaer, Woolley, Kenney, et al, 1998).

A recent study showed that States are interested in adding chronic care measures to their list of required comparative performance measures (McManus, Graham and Fox, 1999). However, with a few exceptions (such as asthma, diabetes, and mental health), measures for populations with special health needs are lacking (McGlynn, 1996; Kuhlthau, 1998; Perrin, Kuhlthau, Walker et al., 1997; Ireys, Grason and Guyer, 1996). Even when measures are available, States may not require MCOs to report them because of the small numbers of enrollees to which they apply in each MCO and the resulting cost implications. Although all 39 States participating in a recent study reported that they monitor satisfaction, less than one in four ask, or require MCOs to ask, questions specific to the care of children with chronic conditions (McManus, Graham and Fox, 1999).

A number of tools have been developed, or are in the process of being developed, to assist States and MCOs to measure and monitor MCO performance in caring for populations with special health care needs, including the following:

- C The George Washington University's Center for Health Policy and Research issued a resource guide that provides: 1) an overview of issues to be considered when measuring the performance of MCOs enrolling individuals with disabilities; and, 2) information about measures (both prospective and retrospective) that exist, or are about to be made available, that will support efforts to measure and improve care provided by MCOs to individuals with disabilities. The guide also identifies areas in which technically strong measures do not exist (Sofaer, Woolley, Kenney, et al, 1998).
- C Through their Stakeholder's Initiative, the Center for Health Care Strategies (CHCS)

sponsored an effort to adapt existing measures to populations with special health care needs. CHCS also is sponsoring a coordinated effort that seeks to describe the elements of appropriate care coordination. The group hopes that these elements can be used to develop quality indicators for care coordination.

- C The Agency for Healthcare Research and Quality (AHRQ), is sponsoring an effort to develop a child and adult CAHPS questionnaire for populations with special health care needs. Through their Expansion of Quality Measures (Q-SPAN) initiative, AHRQ provides funding to develop “ready-to-use” performance measures. Current projects include developing measures for patients with asthma and cardiovascular conditions, assessing functional status as a measure of health care quality for patients with hip fractures and developing an adult global quality assessment tool (AHCPR, 1998a).
- C The Foundation for Accountability and the NCQA are working collaboratively on The Child and Adolescent Health Measurement Initiative. This effort, funded by The David and Lucile Packard Foundation, The Robert Wood Johnson Foundation, The Commonwealth Fund and the AHRQ seeks to: 1) develop an MCO accountability framework for child and adolescent health; 2) develop and test child and adolescent measures; and, 3) translate the data into consumer-friendly reports.

By requiring MCOs to measure performance, achieve minimum performance levels established by the State, and demonstrate sustained improvement, HCFA’s proposed rule to implement the BBA would promote use of performance measures in MCO quality improvement programs.

**Practice guidelines.** There is increasing interest in the use of practice guidelines as tools to improve the quality and cost-effectiveness of health care. The IoM defines clinical practice guidelines as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” (IoM, 1992). Practice guidelines provide direction to staff and shape provider behavior. Many believe that use of guidelines will make medical care more reliant on evidence-based recommended practices and less a function of where a patient receives care. Numerous organizations develop practice guidelines, including professional organizations, government bodies and expert panels. A National Guidelines Clearinghouse sponsored by the AHRQ in partnership with the American Medical Association (AMA) and the American Association of Health Plans (AAHP) is available on the Internet.

Practice guidelines based on scientific knowledge or current professional judgment clearly describe appropriate care for clinical conditions. Monitoring compliance with guidelines detects over- and under-use of services as well as poor performance, and is instrumental to quality improvement programs.

A U.S. General Accounting Office (GAO) study found that many MCOs customize guidelines to fit their clinical and financial objectives or develop their own guidelines, which could undermine the goal of making care more reliant on evidence-based practices (GAO, May 1996). An IoM Committee on Practice Guidelines found that guidelines development is not always systematic and that the guidelines are not always linked to empirical findings (IoM, 1997). Responses to a NAMI survey by nine of the largest managed behavioral health care organizations in the United States revealed that treatment guidelines for schizophrenia used by the behavioral health care organizations are out-of-date and do not mention the newest antipsychotic medication, or address the full range of care people with severe psychotic illness require (Hall, Edgar and Flynn, 1997). Further, clinical practice guidelines do not exist for all clinical conditions. This is especially true for low prevalence conditions, and certain health conditions for which information on the comparative effectiveness of alternative treatments is inconclusive.

**Contract specifications.** It generally is agreed that contracts are the most appropriate vehicle for States to express expectations of MCO performance. States can define in their contracts with MCOs; for example: structural and operational standards, performance measures MCOs must report, the type of survey they must use to assess enrollee satisfaction, and topics for quality improvement studies (Moss, 1998). Standards also frequently relate to the adequacy and appropriateness of provider networks, provider credentialing, linguistic and cultural competency, appointment availability and telephone systems, hours of operation, consumer appeal structures, and internal quality control procedures (Moss, 1998; Rosenbaum, Smith, Shin et al., 1998; Holahan, Zuckerman, Evan and Rangarajan, 1998). At the contracting stage, States generally require MCOs to show that their strategy to serve Medicaid enrollees meets some minimum standards (Holahan, Zuckerman, Evan and Rangarajan, 1998). After contracting with the MCOs, States ensure compliance by conducting, or requiring that another organization conducts, on-site reviews.

A study of Medicaid managed care contracts by The George Washington University's Center for Health Policy Research found that, "As States gain managed care experience and enroll higher risk populations, they are moving toward greater inclusion and specificity in their contracting practices" (Rosenbaum, Smith, Shin et al., 1998). When researchers compared 1996 contract specifications to those used in 1995, they found more detail in access, coverage, and quality specifications. They attributed the change to an increase in enrollment of individuals with disabilities, States' experience in trying to enforce prior contracts, and pressure from stakeholders to improve clarity in contracts (Rosenbaum, Smith, Shin et al., 1998). The George Washington University's Center for Health Policy Research has developed a number of sample purchasing specifications for States to refer to in constructing their contracts with MCOs.

**Independent external quality review.** The Omnibus Budget Reconciliation Act of 1986

(OBRA 1986) requires that each State agency that contracts with an MCO use an independent external quality review organization (EQRO) to conduct an annual review of the quality of each MCO's services. States use EQROs for a variety of activities, including focused studies, individual case reviews, performance and encounter data validation, administration of satisfaction surveys and monitoring contract compliance (OIG, 1998; NASHP, 1998). The BBA also contains an additional requirement for review of "the quality outcomes and timeliness of, and access to" the services included in the contract between the State agency and the MCO (BBA section 4705(a)). HCFA published proposed regulations on these external quality review requirements in the Federal register on December 1, 1999.

**Focused quality studies.** Undertaking focused quality studies (conducted either by the MCO, an EQRO, or the State) is a method States can use to obtain information when the number of individuals meeting the study criteria is small. A study conducted by the DHHS Office of Inspector General (OIG) revealed that the most frequent activity performed by EQROs in the seven study States was focused quality studies (DHHS, OIG, 1998). For these studies, EQROs generally review medical records to obtain information on services delivered to a group of individuals with the same health care needs. The OIG study notes that States are aware that focused studies do not offer broad assessment of care delivered to everyone enrolled in a State's Medicaid managed care programs, but can "capture a slice of care delivered to one or two subpopulations." The ESRI study found that 15 initiatives in 13 States include external QA studies for enrollees with disabilities as part of their overall QA strategy (Regenstein and Schroer, 1998).

**Grievance, appeal, and State fair-hearing procedures.** Partly due to the lack of mechanisms to adequately monitor quality of care for populations with special health care needs, many view a fair and efficient dispute resolution system as an essential safeguard to ensure that MCO enrollees receive timely and appropriate services (NAIC, 1996; Karp and Wood, 1997; American Arbitration Association, American Bar Association and AMA Commission on Health Care Dispute Resolution, 1998). The Consumer Bill of Rights and Responsibilities states:

"All consumers have the right to a fair and efficient process for resolving differences with their health plans, health care providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review" (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997).

Since enrollees with special health care needs frequently require more costly and complex services (which usually require an approval from the MCO), a fair and efficient grievance system is of particular importance to these individuals.

Under Federal regulations (42 CFR 434.32), Medicaid MCOs are required to have State-approved internal grievance processes that provide prompt resolution of issues and ensure participation of individuals with authority to take corrective action. Some States either require or encourage Medicaid enrollees to first seek resolution of a grievance or appeal through the MCO's internal dispute resolution system prior to accessing external review of the issue (Families USA, 1998; Rawlings-Sekunda, 1999). In an effort to ensure timely and efficient systems, States establish requirements for MCOs' internal grievance and appeal systems. The New England SERVE Project found that all MCOs participating in their survey have multilevel grievance and appeals procedures that appear to follow NCQA grievance and appeals standards. In addition, HCFA's Quality Improvement System for Managed care (QISMC) has several standards that relate to the structure and process of MCO grievance and appeals systems, data collection and reporting of grievances and appeals, and the use of the data for quality improvement purposes.

Medicaid enrollees have a right to contest MCO decisions through an external State fair-hearing process required in Medicaid regulations incorporating the requirements of the landmark court case, *Goldberg v. Kelly*, 397 U.S. 254 (1970). Federal regulations ensure that before services are reduced, suspended, or terminated, Medicaid beneficiaries must be given written notice explaining the reason for the decision. If the enrollee disagrees with the decision, he or she has the right to a hearing before an impartial decision maker. In preparation for the hearing, the enrollee (or representative) has the right to review all records that will be used at the hearing in support of the decision to deny coverage. If the enrollee has requested the hearing in a timely manner, the State must ensure that the enrollee continues to receive the services until the impartial hearing is held (42 CFR 431 Subpart E).

Both internal MCO grievance and appeal processes and the external State fair-hearing procedures are complex and can be confusing (Families USA, 1998). Because of the educational levels of many Medicaid enrollees and their limited experience with managed care, they might lack the skills necessary to advocate for themselves. In addition, Medicaid enrollees may be more intimidated by, and need more assistance in filing a grievance, appeal, or State fair-hearing request. A number of States have implemented systems that give enrollees other ways to express dissatisfaction, such as toll-free

consumer complaint hotlines, consumer assistance, and ombudsman programs (Rawlings-Sekunda, 1999).

The National Academy for State Health Policy's 1998 Survey of Medicaid Managed Care programs revealed that 43 States (96 percent) with capitated (risk) initiatives require MCOs to report on grievances and appeals on a regular basis (Kaye, Pernice, and Pelletier (ed), 1999). Although some Medicaid capitated initiatives specify standard reporting

categories, other initiatives allow MCOs to decide how to categorize complaints (Rawlings-Sekunda, 1999). Also, since Medicaid enrollees often have several avenues through which to register problems, States must use an array of information sources to track enrollees grievances, including MCO and State-sponsored hotlines, ombudsman programs, and internal MCO logs. Although States use grievance and appeal data to track and monitor MCO performance, use of different definitions and reporting categories as well as differences in the manner of data collection make plan-to-plan comparison difficult (Rawlings-Sekunda, 1999; GAO, 1998). Stratifying the data by population (e.g., such as chronically ill adults or children with special health care needs) would be a challenge. The New England SERVE project found that although all MCOs in their study collect and report grievance data, 50 percent of them could not estimate the percent of grievances from children with special health care needs or their families (New England SERVE, 1997).

States with section 1115 waiver programs are required to collect and review each MCO's grievance reports on a quarterly basis and then report the data to HCFA in their quarterly reports. The BBA directs States to: 1) ensure that managed care enrollees receive information about the procedures available to an enrollee and a health care provider to challenge or appeal the failure of the organization to cover a service; 2) include an examination of MCO grievance procedures in their quality assessment and improvement strategy; and, 3) require that each Medicaid MCO have internal grievance procedures to allow challenge to a denial of coverage of or payment for services.

### **HCFA's Quality Monitoring**

HCFA reviews, approves and monitors quality under each of four distinct approaches that States may use to implement Medicaid managed care strategies: 1) voluntary managed care enrollment; 2) mandatory enrollment under the State plan; 3) section 1915 (b) waiver authority; and, 4) section 1115 waiver authority. States may use one or a combination of these approaches in their Medicaid managed care initiatives. The process and mechanisms HCFA uses to review and monitor these initiatives are discussed below.

**Voluntary managed care enrollment strategies.** HCFA monitors State voluntary managed care enrollment initiatives through two primary mechanisms. First, HCFA is required by statute to review (and prior-approve) all contracts between a State and each of its MCOs. When reviewing these contracts, HCFA assesses the quality improvement and monitoring requirements that States place on their MCOs to ensure that they fulfill Federal statutory requirements regarding quality. The BBA includes an explicit requirement that quality be monitored for the "full spectrum of populations enrolled under a contract." HCFA is placing new emphasis on quality for populations with special health care needs as a result of this statutory requirement.

After contracts are executed, HCFA uses standardized protocols contained in the “Monitoring Guide: Medicaid Managed Care Initiatives” (Monitoring Guide) to determine State compliance with Federal laws pertaining to quality and States’ use of other quality guidelines disseminated by HCFA (e.g., “A Health Care Quality Improvement System for Medicaid Managed Care”). The Monitoring Guide contains six quality-of-care topic areas:

- C the State quality improvement framework;
- C internal quality assurance programs;
- C external quality review for risk contracting organizations;
- C quality measurement and focused studies;
- C enrollee and provider satisfaction; and,
- C quality issues specific to PCCM programs.

The Monitoring Guide which has been disseminated as a draft that has not yet been finalized, is used for State monitoring across HCFA’s Regional Offices. HCFA will revise this monitoring tool when final rules implementing the BBA are published.

Further, all States contracting with MCOs must make provisions for an annual, independent, external review of the quality outcomes, timeliness of, and access to care and services delivered by the MCO. On December 1, 1999, HCFA published a proposed rule which defines the components of external quality review.

**Mandatory managed care under a State plan option.** The BBA established the option for States to require certain Medicaid beneficiaries to enroll in managed care through a provision of the State plan. As of December 1, 1999, seven States have been approved under this option. Of these seven States, only North Carolina enrolls a population with special health care needs - the adult SSI population. Previously this population was required to enroll in managed care under a section 1915(b) waiver program. MCOs contracting with a State under the State plan option must meet all the quality requirements for voluntary managed care initiatives.

**Section 1915(b) waiver programs.** States generally submit proposals to HCFA under section 1915(b) of the Social Security Act to obtain a waiver to limit beneficiary “freedom of choice” of Medicaid provider when implementing a mandatory capitated MCO initiative.

In addition to meeting all the requirements for voluntary managed care initiatives, in order for section 1915(b) waivers to be approved, States must make assurances to HCFA about the quality of care provided under the waiver program. In May 1999, HCFA introduced a revised State guide entitled “Proposal for a Section 1915(b) Capitated Waiver Program.” The document contains specific questions about populations with special health care needs.

One section specifically pertains to populations with special health care needs. The revised application guide details the beneficiary protections HCFA expects States to address in waiver applications, such as State assessment of MCO skill and experience in serving enrollees with special health care needs, and how the State plans to include traditional providers when developing managed care networks. In developing the new waiver application guide, HCFA used its 1998 document entitled, “Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs,” developed in collaboration with a variety of organizations, including State Medicaid agencies, State health departments, MCOs, consumer and advocacy groups, provider organizations, and other DHHS agencies including the Health Resources and Services Administration. HCFA currently is strengthening its review of State waivers and demonstrations that seek to mandatorily enroll children with special health care needs.

HCFA’s Regional Offices monitor section 1915(b) programs by performing on-site reviews every two years, checking for problems related to access and quality. Should a problem develop, the Regional Office arranges calls with State officials and requires corrective action plans. Quality of care also is assessed by an independent contractor, who assesses the State’s performance at least twice over the first two “cycles” of a section 1915(b) waiver (i.e., over the first four years). HCFA reviews this information before renewing waivers.

**Section 1115 waiver demonstrations.** MCO initiatives conducted under a section 1115 waiver must meet the same quality monitoring requirements as voluntary managed care initiatives. In addition, as with section 1915(b) waivers, HCFA reviews a State’s section 1115 waiver request to ensure that the program proposed by the State can be expected to deliver quality services. For section 1115 waivers, HCFA attaches “terms and conditions” to the waiver approval. These terms and conditions require States to develop internal and external quality audits to monitor the performance of their MCOs, and to cooperate with independent evaluators who review the section 1115 demonstrations for quality of care provided to Medicaid beneficiaries. Before a demonstration program is implemented, the

State must submit to HCFA for approval an “Operational Protocol,” which provides specific information on quality monitoring activities and processes.

Historically, the terms and conditions generally have not focused on populations with special health care needs. Now that States are proposing to use section 1115 authority for programs for populations with special health care needs, HCFA will address the unique needs of these populations in the terms and conditions of new demonstrations and amendments to existing demonstrations. Terms and conditions specific to enrollees with rare and expensive health conditions are in place for one State. Another State has applied for a waiver to enroll in Medicaid HIV/AIDS individuals who do not meet the statutory



definition of “disabled.” When reviewing proposals for waiver programs including populations with special health care needs, and when developing terms and conditions, HCFA plans to apply the concepts found in this document to ensure that Medicaid enrollees with special health care needs are protected.

## CHAPTER EIGHT

### Align Payment Incentives

***Summary:** Populations with special health care needs often generate higher than average health care costs. Approaches to paying MCOs that acknowledge these costs are an important safeguard to prevent financial incentives to underserve these populations or threats to MCO solvency. In addition to adjusting payments based on health, alternative payment approaches such as risk-sharing, withholds or bonuses can be used as incentives to MCOs to encourage appropriate resource use for populations with special health care needs. However, there are difficult issues in designing and implementing such payment approaches, including: the need for additional investments, planning for and addressing the differential effects on MCOs, and monitoring for effects on quality of care. Limitations in the accuracy and reliability of claims and encounter data, and historical requirements for Medicaid managed care ratesetting will all affect approaches to payment.*

**Action to be taken by DHHS:**

*HCFA will commit resources to procure technical support to States in developing risk-adjusted payment methodologies related to populations with special health care needs.*

**Action to be taken by others:**

***Recommendation 21:** States should use reimbursement mechanisms that reflect the costs of the beneficiaries they enroll. Such mechanisms include risk-adjusted capitation and risk-sharing arrangements.*

***Recommendation 22:** States should collect and validate MCO encounter data to assist in the management of their Medicaid managed care initiatives. These data can be used, for example, to assist in the identification of enrollees with special health care needs, in matching services to enrollees' needs, and in developing payment rates, as appropriate.*

#### Higher Costs of Populations with Special Health Care Needs

Because of their more intensive health care needs, populations with special health care needs often have higher average health care costs in comparison to the general Medicaid

population.

**Children with special health care needs.** Although significant variability exists within diagnostic categories, studies suggest that Medicaid expenditures for children with special health care needs are from two to 20 times higher than costs for all Medicaid children (Ireys et al., 1997). In the State of Washington in 1993, the average cost of care for a child with special health care needs was more than \$5,000 versus approximately \$1,500 for a child without special health care needs (Washington State Health Care Policy Board, 1997). Data from 1992 show that health expenditures for children with mental retardation averaged \$4,000 - four times that of a healthy child (Ireys, Grason, Guyer, 1996). However, within the population of children with special health care needs, costs vary significantly depending on the individual and nature of the illness. For example, in one study the costs of care for children with heart defects ranged from \$69,000 to \$209,000 (Ireys, Grason, Guyer, 1996).

**Children in foster care.** The average per capita health care costs of children in foster care are higher than the average per capita costs of children not in foster care and without special health care needs. Washington, Colorado and Tennessee documented that the costs of children in foster care during different years in the 1990s were at least four times greater than the average cost for children eligible for Aid to Families with Dependent Children (AFDC). This difference was nearly six times greater in Washington, at \$3,075 versus \$543 (Dreyfus and Tobias, 1998). In New Mexico, in Fiscal Year 1999, monthly capitation rates for foster care children varied by age from \$131 (age two to eleven months) to \$2,134 (age 15 to 21 years). This compared to rates for AFDC children of \$65 (for one to five year olds) to \$216 (age 15 to 21 years). Children in the New Mexico foster care system between 15-21 years of age required the second highest capitation rate in the State (surpassed only by infants under eleven months old who are blind and disabled). Some of the differential in expenditures may be explained by higher utilization of mental health services. Use of mental health services by children in foster care in some cases is 10 to 20 times higher than for other children (Halfon, Berkowitz and Klee, 1992).

**Individuals who have serious and persistent mental illness/substance abuse.**

Individuals with conditions pertaining to mental health/substance abuse (MH/SA) exhibit longer lengths of stay than others in hospitals. Based on the State Medicaid Research Files (SMRF), average lengths of stay for MH/SA claimants in Washington and Michigan in 1993 were approximately 70 percent higher than for non-MH/SA claimants. Disparity of service needs also can be seen in average inpatient costs. The average inpatient cost of MH/SA claimants was more than double the average cost for non-MH/SA claimants. For example, Michigan's average MH/SA cost was \$1,726 compared to the population average of \$583; New Jersey's average MH/SA cost was \$3,143 versus \$1,301; and the State of Washington's average MH/SA cost was \$1,119 versus \$570 (Larson, Farrelly, Hodgkin et

al., 1998).

**Individuals who are homeless.** Advocates and providers who work with individuals who are homeless report that the health status of many is markedly inferior to that of the average managed care enrollee, often characterized by complex, interrelated conditions exacerbated by living on the streets (Care for the Homeless, 1998). Further, because individuals who are homeless often have decreased access to care, when they are hospitalized there may be multiple conditions to treat. Individuals who are homeless are difficult to identify and few estimates of expenditures exist for this group. However, a study of New York City inpatient hospital stays from 1992 -1993 comparing a sample of adults who are homeless and adults who are not homeless showed that patients who were homeless exhibited lengths of stay 4.1 days (36 percent) longer than those of other low-income adult patients. The average cost of additional hospital days for patients who were homeless was \$2,414. Moreover, this population accounted for 26 percent of public hospital expenditures for inpatient mental health and substance abuse treatment, even though they only accounted for 10 percent of the discharges (Salit, Kuhn, Hartz et al., 1998). Other studies show higher instances of acute care and psychiatric care hospitalization, as well as more emergency visits, for homeless women (O'Connell, 1999).

**Disabled and elderly.** Expenditures for the disabled and elderly are more than three times greater than those of other children and adults. The average health care cost of adults with disabilities was found to be \$7,956 compared to \$2,067 for other adults (GAO, 1996). The disparity in costs is even greater for certain disabilities, such as AIDS or quadriplegia. Compared to the average cost of Supplemental Security Income (SSI) Medicaid beneficiaries, care for individuals with AIDS or quadriplegia are approximately four times more costly. The annual cost for individuals with AIDS and quadriplegia exceeds \$22,000 while the cost for the average SSI individual is approximately \$5,800 (Dreyfus, Kronick, and Tobias, 1997; Health Resources and Services Administration, 1997).

### **Appropriate Payment is a Critical Safeguard**

Capitated forms of managed care provide States and MCOs with increased flexibility in approaches to health care delivery. Appropriate payment levels from States to MCOs can also provide MCOs with the ability to give effective financial incentives to providers in their network (GAO 1996; Kronick, Tollen, Grgurina, et al, 1998). Little scientific evidence exists to suggest that, *on average*, payments to MCOs are inadequate to cover the varying degrees of expenditures for individual enrollees. MCOs that enroll sufficient numbers and a random mix of enrollees are able to balance the higher cost of enrollees with special health care needs with larger numbers of enrollees who are healthy and thereby lower-cost, so that on average, payments are sufficient. However, if an MCO has a higher

than average proportion of enrollees with special health care needs, and if capitation rates are not set appropriately, then MCOs may experience pressure to limit services or may lose money on these enrollees.

### *Adverse Selection*

Approaches for establishing insurance or capitation payment rates rely on predicting, and then spreading, the financial risk for the costs of health care across a large and diverse population. The most successful predictions of costs are found in groups that are large because larger groups of enrollees will likely include a balance of individuals with higher costs and lower costs, and will be statistically more representative. In contrast, when MCOs have small numbers of enrollees, predicting “average” costs is difficult. Within small groups, relatively few very high (or very low) cost individuals can lead to a significant deviation from predicted health care expenditures. When MCOs unintentionally enroll populations whose health care costs significantly deviate from the average, the population is said to be “biased;” i.e., they do not require an average level of health care expenditures. Selection bias refers to an MCO having a disproportionate number of enrollees with high (or low) cost conditions. “Adverse selection” refers to an MCO or insurer having a greater than average proportion of enrollees with high health care costs. If this type of selection bias is not accounted for by the payment method used, the actual payments made may not be appropriate for the care delivered.

For example, research on the enrollment of SSI beneficiaries in TennCare found that “There was substantial risk selection among the managed care plans in TennCare. In particular, according to several measures of risk selection, blind and disabled SSI beneficiaries with higher than average health care needs disproportionately enrolled in seven plans while beneficiaries with relatively low needs disproportionately enrolled in four other plans (one plan appears to have enrolled an average mix of beneficiaries)” (Mathematica Policy Research, 1999). Further, the research suggests that the overall financial performance of participating plans was associated with risk selection. The report goes on to suggest that the methods used by the State during the initial enrollment of beneficiaries into TennCare may have caused the selection bias.

Because of the higher costs of certain groups enrolled in Medicaid MCOs, it is essential that payment methodologies be analyzed and tested to determine their relative ability to provide appropriate payments to MCOs that might experience adverse selection. In selecting and implementing payment methods, States should consider the characteristics of various payment methods, such as health-based risk-adjusted capitation, risk-sharing, withholds and bonuses, carve outs, and other program design features used to discourage adverse selection.

## *Health Based Risk-Adjusted Capitation*

**Rationale.** The goal of risk-adjusted capitation is to use information to predict expected health care costs. The premise is that selected variables are correlated with different levels of expenditures. Applying risk adjustment to capitated payment systems can result in rates that relate more closely to costs (Ash, Ellis, Yu et al, 1997). Although it is not feasible to expect that predictions from any model will be precise for each individual, the goal in capitation is to predict, on average, health care costs for particular groups -- even groups that are biased (Greenwald, Esposito, Ingber, et al. 1998). Even very basic risk-adjustment methods, such as those using only demographic factors such as age and sex, address the variability among MCO enrollees more effectively than merely paying the same average rate for all of an MCO's enrollees.

For some populations, adjusting rates solely by using demographic factors such as age and sex is sufficient. This is true for large, random groups such as some commercial populations and portions of the Medicaid population, particularly most AFDC-related Medicaid beneficiaries. But many experts in payment methodology have concluded that adjusting for demographic characteristics alone is insufficient to appropriately pay MCOs that have high proportions of individuals with special health care needs (Kronick, Dreyfus, Lee, et al, 1996; Kronick, Tollen, Grgurina, et al, 1998).

**Issues in health-status-based risk adjustment.** Research has produced a number of risk-adjustment models using various measures of health status in addition to demographic factors. Many of these models combine conditions (such as diagnoses) into cost categories or groups. Using these categories or groupings, average expenditures are estimated and used as the basis for payment to MCOs or other providers that enroll individuals with the conditions included in the groupings. The average rates can be calculated either on a prospective or concurrent basis. Prospective models estimate future expenditures based on data in prior years. Concurrent models use current year data to "look back" at current year rates (Greenwald, Esposito, Ingber, et al, 1998). Each approach has advantages and disadvantages. Concurrent methodologies by their nature capture more of the variability in individual expenditures; they do not attempt to predict future costs. Concurrent data factor for acute and unexpected conditions, which may not be relevant when predicting systematic differences in expenditures for different groups. Prospective models are most useful when payments must be predicted for future years.

Health status or diagnostic information is found in FFS claims and encounter data, and sometimes is supplemented with self-reported health information obtained through surveys or clinical assessments. Using both sources of information can better predict future health expenditures, but surveys are expensive to design and conduct, and raise issues related to data integrity (Lee and Rogal, 1997). The data integrity issues can be addressed through

cognitive and field testing, but at substantial costs. FFS claims data are available for use by States and researchers, although the reliability and completeness of these data vary widely across States. These historical data contain diagnostic codes and costs of treating particular illnesses. Risk adjustment using diagnosis-based health status essentially examines the available diagnostic codes (e.g., ICD-9 codes) in an administrative database. By grouping diagnostic codes according to resource use, utilization or necessary services, a model is developed of homogeneous groups of medical conditions and a payment rate established for each group (Lee and Rogal, 1997).

When selecting from among the various available risk-adjustment models, attention needs to be given the potential to game or upcode. “Gaming” refers to the tendency of the entity receiving payments to maximize payments. This is an issue HCFA has faced in virtually all its payment systems, and is not a concern specific to capitated or risk-adjusted systems. Rather, the potential for any payment system to be “gamed” or “maximized” is an issue that needs to be considered when making payment design and methodology decisions. A tradeoff occurs between higher levels of predictive power and greater opportunities for coding manipulation. Generally, models based on demographic information lend themselves to less coding manipulation, while models based on diagnosis or health status present more opportunities for coding manipulation (HCFA, 1999a). In the past, HCFA has identified issues with “DRG creep” (e.g., upcoding of hospital diagnostic coding) in the Medicare FFS program. State Medicaid agencies should consider the level of sensitivity they require in payment rates, and then balance this with opportunities more precise payments present for upcoding.

Typically, if risk-adjustment models have fewer and broader categories, they are less sensitive to upcoding practices. For example, if all ICD-9 codes relating to a particular condition, such as diabetes, are included in a single payment grouping, no incentive exists to code one particular diabetes ICD-9 code over another. However, this type of model may not allow for significant predictive accuracy for different levels of severity for a given disease. In this case, compromise exists between gaming and predictability. Also, models that base future payment levels on prior services or procedures rendered (versus diagnosis) may provide incentives for either higher levels of utilization or coding that reflects higher than actual utilization. Implementation of risk-adjustment models based on health status should include methods to either audit MCOs or identify significant changes in coding patterns that might reflect gaming activities.

**State practices.** Although the majority of State Medicaid agencies use traditional factors such as age, sex, geography, and basis of eligibility in their methodology for developing rates, significant progress has been made in developing and using more refined health-based risk adjustment models. The number of State Medicaid agencies incorporating health status into setting capitation rates grew from four in 1996 to 13 in 1998. Six of these (Colorado,

Indiana, Maryland, Michigan, Ohio, and Oregon) reported using a particular risk-adjustment system based on health status, and the Commonwealth of Massachusetts is developing a methodology for future use (National Academy for State Health Policy, 1999). The more commonly used health-based reimbursement models include the following.

- C Principal Inpatient Diagnostic Cost Groups (PIPDCGs).** This methodology uses the variables of age, gender, welfare status, diagnosis, and prior utilization. The original model was designed for the Medicare population age 65 and older and uses the principal inpatient diagnosis to categorize individuals into diagnostic cost groupings. The newer model replaces the Medicare Adjusted Average Per Capita Cost (AAPCC) HMO rate setting methodology which uses a base rate set at 95 percent of the FFS expenditures in a geographic region and adjusts them for age, sex, institutional status, and Medicaid eligibility. PIPDCGs is relatively easy to administer because it does not rely on ambulatory codes. However, it could encourage more inpatient admissions and it does not incorporate the health conditions of individuals who have not been hospitalized. Payment amounts depend on the assignment of the person to the diagnosis group with the greatest future cost implications from among his/her inpatient stays. Individuals who are not hospitalized during the data-collection year are assigned payments based on demographic and eligibility factors. Gaming is a potential issue in the PIPDCG model because of the opportunity to reorder diagnoses on an inpatient hospital claim (Ellis, Pope, Iezzoni, et al, 1996).
  
- C All Diagnosis Diagnostic Cost Group (ADDCG)** is an enhanced version of the preceding model, which uses secondary inpatient diagnoses and ambulatory diagnoses. This model captures more individuals and lessens incentives for hospitalizations, but is more difficult to administer because of the need to obtain the necessary ambulatory data (Ellis, Pope, Iezzoni, et al, 1996).
  
- C Hierarchical Coexisting Conditions Diagnostic Cost Group (HCCDCG)** further enhances the PIPDCG model by using hierarchical coexisting condition (HCC) groups that include related conditions within these hierarchies. Individuals are assigned to as many HCCs as appropriate (individuals may have a wide range of health conditions). This payment model allows for the degree of severity and multiple conditions to be reflected in the payment (Ellis, Pope, Iezzoni, et al, 1996).
  
- C Ambulatory Care Groups (ACGs)** use outpatient and inpatient diagnostic information, age, and sex. The ACG model is based on Ambulatory Diagnosis Groups (ADGs), age and gender. These ADGs are groupings made up of ICD-9 codes based on service need. The ADGs categories are based on criteria that include factors such as life expectancy, likelihood of disability, and likelihood of



hospitalization. ACGs ultimately are combinations of ADGs. The ADGs are used in an additive way with extra payments for coding of additional conditions. They are used so that a person is assigned to only one cost group, and they are less sensitive to coding practices because the groupings are broader than ADGs. However, ADGs are more powerful and can predict better (Weiner, Dobson, Maxwell, et al., 1996). Maryland uses the ACG methodology to set rates for its mandatory managed care program (Medicaid Managed Care TAG, 1999).

- C Disability Payment System (DPS).** Costs associated with individuals with disabilities and chronic conditions are more predictable than the general Medicaid population as a whole, mainly because of the recurring nature of needed services. The DPS was specifically developed for Medicaid populations who are disabled. It uses historical Medicaid FFS claims data to count diagnoses and estimate the cost in a given year for a person with a specific disability in a previous year. DPS uses 18 groupings that correspond to either body system, types of illness, or disability. These groupings are further allotted to 43 subcategories according to relative costs. In this model, individuals can be assigned to several groups (Kronick, Dreyfus, Lee, et al, 1996). A disadvantage of this model is the counting of diagnoses, which may encourage increased coding or frequencies of conditions. Colorado and Oregon use this methodology to set their capitation rates.
  
- C Condition-specific Risk Adjustment.** Six States (Arizona, California, New York, Oklahoma, Utah and Wisconsin) adjust payments for particular conditions (National Academy for State Health Policy, 1999). Utah adjusts its capitation rates to reflect the diagnosis of AIDS (Regenstein and Schroer, 1998). State Medicaid agencies have used diagnostic information, pharmacy data, or State AIDS registries to identify enrollees with AIDS (Dreyfus, Kronick and Tobias, 1997; Rawlings-Sekunda and Kaye, 1998). In addition to paying special rates for enrollees with AIDS, States pay special rates for enrollees with serious or persistent mental illness and poverty-level pregnant women.
  
- C Other approaches.** The National Association of Children's Hospitals and Related Institutions' (NACHRI) Classification System is a unique model for children with special health care needs. This model incorporates diagnoses and functional status of children with chronic physical, mental, emotional, behavioral or developmental disorders expected to last 12 months or longer (Health Resources and Services Administration, 1996; Lee and Rogal, 1997). In addition, States have developed other risk-adjustment models unique to their programs. For example, Utah incorporates health information in its rate setting through a "Marker Diagnoses" methodology used by the Health Insurance Plan of California, which includes a list of inpatient diagnoses. Individuals admitted to a hospital for these diagnoses are

"marked" and the MCO capitation payment is weighted to reflect the higher costs of these enrollees (Medicaid Managed Care TAG, 1999). Indiana has calculated average expenditures by Major Diagnostic Class (MDC) to set MCO rates, with annual adjustments that reflect the consumer price index. Michigan has established its own unique system for the Children's Specialty and Children's Comprehensive Health Care program based on the costs of diagnoses that are placed into four groups reflecting varying levels of resource intensity. In addition to using various risk-adjusted capitation models, 11 States also use other risk adjusters. Examples include adverse selection adjustments in Nebraska and Tennessee, and adjustments based on resource use in Colorado (Regenstein and Schroer, 1998).

### *Risk-Sharing*

Because no health-based risk adjustment methodology addresses all potential policy needs when setting capitation rates, States may choose to use additional safeguards to limit the amount of financial risk MCOs, face and thereby protect enrollees from being underserved (Dreyfus, Kronick, and Tobias, 1997). These protections can take several forms:

**Reinsurance/stop-loss.** The most common form of risk sharing used by State Medicaid agencies is reinsurance or stop-loss protection. This mechanism is designed to insure against catastrophic expenses for enrolled individuals over a particular period of time and to offset projected losses from claims exceeding a predetermined threshold (GAO, 1996). Risk sharing/stop loss can be used in conjunction with a risk-adjusted capitated payment system, but is more frequently used when States do not risk-adjust their capitation rates.

In a typical reinsurance arrangement, a State establishes a "threshold" of costs for an enrolled individual in a given year. Once this threshold is reached, the State pays the MCO for the cost of claims exceeding the amount. This type of risk sharing can be provided either by a commercial reinsurance company or by the State Medicaid agency. The State can establish reinsurance pools by reducing the capitation amount paid to the MCO. In some State Medicaid programs, reinsurance is mandatory. In 10 States (Arizona, Iowa, Maryland, Missouri, Nebraska, Nevada, New York, Ohio, Pennsylvania and Utah) State-sponsored stop loss/reinsurance is required, while another 15 States require commercial stop loss/reinsurance. Optional State-sponsored stop loss/reinsurance is available in an additional six States (California, Massachusetts, Minnesota, Montana, Vermont and Wisconsin) (National Academy for State Health Policy, 1999). This is an

effective method to ensure that the financial viability of MCOs is protected when the costs of care are higher than expected.

A negative consequence of reinsurance is that it reduces the incentive for providers to

manage utilization of services once the threshold is crossed, because the MCO is not financially responsible beyond this point. One solution is for the MCO to share responsibility for a portion of the costs beyond the established threshold (Dreyfus, Kronick, and Tobias, 1997). Although the adverse risk of catastrophic losses to a MCO can be substantially reduced through reinsurance, these arrangements alone are not sufficient to protect MCOs with high proportions of enrollees with special health care needs groups or high cost case-mixes. If a MCO manages a large number of enrollees with chronic illnesses, financial losses can be substantial without reaching the level at which catastrophic protection becomes available.

**Risk corridors.** Risk corridors set parameters that limit the amount of profits and losses MCOs realize. Depending on its purchasing strategy goals, a State can choose to provide protection to MCOs through risk corridors when a risk-adjusted system is new and untested. This is done by establishing a limit on profits or losses, such as 10 percent. Eight States (California, Hawaii, Massachusetts, Nevada, Ohio, Oklahoma, Utah, and Wisconsin) reported using risk corridors in 1998 (NASHP, 1999).

Risk corridors can be flexible in their make-up and may be vehicles for sharing risk between purchasers and providers (Actuarial Research Corporation, 1996). However, risk corridors can also be detrimental to State Medicaid agencies, because they place the State at risk for losses shared with MCOs. These unexpected costs, which may exceed the upper payment limit (UPL), would not be paid by HCFA through the Federal share, and thus, State Medicaid agencies would incur these losses.

**Risk pools.** Risk pools are established by reducing the capitation amount the State pays the MCO. This reserve fund is then later divided among all MCOs based on the proportion of costly incidents within each MCO. The State can redistribute funds to a MCO that may have experienced higher utilization of high-cost services relative to the other participating MCOs. Five States (California, Hawaii, Pennsylvania, Tennessee, and Wisconsin) use risk pools (National Academy for State Health Policy, 1999).

**Condition-specific risk sharing.** Under this method the State shares the cost of providing services to an enrollee who has a specific health care condition. This is commonly used for special health care conditions or needs such as AIDS or neonatal infants. Seven states (Kentucky, Massachusetts, Oklahoma, Pennsylvania, Rhode Island, Utah, and Wisconsin) use this methodology for certain health care conditions (NASHP, 1999).

**Retrospective adjustments.** Depending on the complexity of the payment method, retrospective or year-end adjustments are also an option to address the lack of experience with a new payment method, the inadequacy of data, or unexpected catastrophic expenses. Utah phased in its capitation system over two years, with cost settlements at the end of the

year (Actuarial Research Corporation, 1992).

### *Carve-outs*

Another practice used by many State Medicaid agencies is that of deleting, or “carving out,” certain Medicaid benefits from the services that an MCO is to provide to enrollees under its contract with the State. Sometimes Medicaid services are carved out because the State prefers to enter into a special arrangement with another prepaid capitated entity for the provision of that service only; e.g., behavioral health services or dental services. When a prepaid, capitated managed care organization contracts with a State to provide a less than comprehensive array of services, it is referred to in the Medicaid program as a “Prepaid Health Plan (PHP)” as opposed to an MCO. Nineteen State Medicaid agencies, or 42 percent of those with risk programs, use specialized plans, or carve-outs, for special populations (NASHP, 1999). (See Chapter 6, for a discussion of PHPs.) Adverse selection can occur in PHPs just as it does in comprehensive MCOs. For example, Tennessee experienced significant funding problems after implementing its behavioral health carve-out program, TennCare Partners. This program was designed to serve the behavioral health care needs of all TennCare beneficiaries. The two behavioral health organizations under contract to TennCare Partners were to provide the full spectrum of behavioral health care services to enrollees who were severely mentally ill as well as those in need of a moderate level of services. After implementation of the program, a substantial number of enrollees with moderate service needs either left the program or were no longer eligible for enrollment. The capitation payments were inadequate to cover the needs of the remaining, more costly, enrollees. This example emphasizes the need to reexamine risk-adjusted capitation payments when changes occur in the composition of MCO enrollees (Chang, Kiser, Bailey, et al, 1998).

Alternatively, a service might be carved out because the State prefers to pay for it on a FFS basis; e.g., medications. This is one way to reimburse for a particular service that may contain certain higher costs; e.g. antiretroviral drugs for the treatment of HIV/AIDS. Most State Medicaid agencies also exclude from capitation rates the costs of intermediate care facilities for the mentally retarded (ICFs/MR), nursing homes, and home- and community-based waiver services (GAO, 1996; Regenstein and Schroer, 1998). These costs are excluded from capitation rates because of the higher level of financial risk when establishing capitation rates for high-cost services such as nursing home confinements, as well as the inexperience of MCOs in long term care (GAO, 1996).

### *Withholds and Bonuses*

Financial incentives can be further strengthened to help ensure delivery of appropriate care

through use of performance-based rewards or penalties (Glied, 1998). Some States use direct financial incentives when contracting for populations with special health care needs, such as withholds, bonuses, or a combination of both. In a withhold situation a State might pay an MCO 95 percent of the total capitation and withhold the remaining five percent which is paid at the end of the contract period if a set of quality performance or utilization standards have been met. With a bonus, the total capitation rate is paid to the MCO and additional funds are paid if a set of performance standards is met or exceeded. Both of these mechanisms can greatly influence MCO behavior and quality of care. Withholds and bonuses also are used by some MCOs as a component of their reimbursement strategies for providers.

Massachusetts bases bonuses or penalties on specific performance criteria. Examples include: 1) a bonus of \$400,000 for convening at least two forums that address identification and treatment of depression, substance abuse, and other disorders for children and adolescents; 2) a bonus of \$500,000 for improving service linkages and continuity of care for children and adolescents; 3) a bonus of \$250,000 for reducing future hospitalizations of children in foster care; and, 4) either a \$360,000 penalty for noncompliance or a \$450,000 bonus for collaborating effectively with the homeless advocacy community in educating providers on identifying and tracking individuals who are homeless (Massachusetts Behavioral Health Partnership, 1999).

The effectiveness of withholds and bonuses for Medicaid MCOs depends greatly on the MCO's total enrollment size and the proportion of that enrollment which is Medicaid. For a withhold or bonus to influence behavior, the MCO needs to enroll a sufficient portion of Medicaid enrollees relative to its total enrollment so that obtaining the additional payment at the end of the contract period is significant. Medicaid-only MCOs are most influenced by these payments, while MCOs whose revenue base is largely non-Medicaid are less influenced.

### *Program Design to Discourage Adverse Selection*

State Medicaid agencies can do a number of things to prospectively discourage adverse selection in their managed care initiatives. For example, State Medicaid agencies often require standard benefit packages across MCOs, which helps to reduce adverse selection. Uniformity in services offered by MCOs lessens the likelihood that any particular MCO will offer significantly more services, thus becoming more attractive to Medicaid enrollees with special health care needs (Mathematica Policy Research, 1999). However, many believe that MCOs with unique provider network characteristics also will attract higher proportions of enrollees with chronic conditions. For example, an MCO known for having physicians who specialize in AIDS care will attract a disproportionate share of individuals with HIV/AIDS. State Medicaid agencies may choose to address this potential for adverse

selection when establishing MCO contracts by requiring a certain mix of specialists for all participating MCOs. When the number of specialists in an area is small, multiple MCOs may need to contract with the same providers.

Other program strategies to discourage adverse selection include: mandatory enrollment processes, limiting the number of MCOs (and thus, competition) and controlling MCO marketing activities (Medicaid Managed Care TAG, 1999). Mandatory enrollment eliminates the choice between managed care and FFS, thus allowing for less disparity in the types of MCO enrollees. In addition, limiting the number of participating MCOs increases the likelihood that all MCOs will have a large number of Medicaid enrollees, thus spreading risk over a large population (Saucier, 1995). Through State review of marketing materials and monitoring of marketing practices, the State can help ensure that MCOs do not market selectively to lower-cost populations. Arizona has used these strategies to ensure an average mix of enrollees in its MCOs (Medicaid Managed Care TAG, 1999).

However, a key element that contributes to selection bias is beneficiary choice. Differences in MCO expertise in providing health care to populations with special health care needs, including maintaining provider networks that have experienced specialized providers, attract more enrollees with chronic illnesses. Beneficiaries will disproportionately enroll in these MCOs and States might auto-assign beneficiaries with special health care needs into MCOs that traditionally have served these vulnerable groups. The length of the lock-in period of the enrollee in the MCO is another factor related to adverse selection. A short lock-in period allows enrollees to make short-term selections and MCOs to encourage movement (Greenwald, Esposito, Ingber, et al., 1998).

As a result, States could find that beneficiary choice, existing provider networks, and the geographic distribution of risk make it very difficult to prevent adverse or favorable selection. These difficulties suggest the need to revise capitation rate setting methodologies to ensure that the amount paid to any given MCO appropriately addresses the costs of the beneficiaries they enroll.

### **Issues in Designing and Implementing Payment Approaches**

The critical first step in designing and implementing a risk-based payment system for populations with special health care needs enrolled in managed care is to identify individuals with special health care needs and their conditions, and the costs of services needed to adequately meet their health care needs. States should consider what is the best payment methodology to use (Boland, 1996) along with a number of other important considerations as discussed below:

### *Additional Investments*

State Medicaid agencies need to consider resources necessary to implement health-based risk-adjustment systems. State Medicaid agencies using these models have invested significant time and money in external consultants and gathering data essential for this process (Conviser, Gamliel, and Honberg, 1998; Kronick, Tollen, Grgurina, et al, 1998; Kronick and Dreyfus, 1997). When considering models that incorporate health status, it is important to include certain stakeholders. These include physicians or other clinical experts, administrators, information systems experts, and actuaries.

### *Differential Effects on MCOs*

Before implementing a more complicated payment system, it is necessary to understand the potential impact on MCOs. Medicaid purchasers should consider that some level of risk is important to control expenses and facilitate greater efficiency, but too much risk may cause MCOs to suffer financial losses and lead to their withdrawal from the program (Actuarial Research Corporation, 1992). The number, size, and experience of MCOs needs to be assessed before implementing a new payment methodology. Newly established MCOs likely will have higher administrative costs, due to startup costs and the inability to spread costs across established product lines. Smaller MCOs will have less than average membership levels, which will contribute to the difficulty in spreading risk (Ku, Hoag, 1998). MCOs with less experience serving Medicaid beneficiaries or with small enrollment may need additional protection through reinsurance or risk sharing (Dreyfus, Kronick, and Tobias, 1997).

The financial viability of MCOs should be monitored closely. State Insurance Departments historically have examined the financial solvency and viability of HMOs. HCFA's proposed rule implementing the BBA Medicaid managed care provisions would require MCOs to make provision, satisfactory to the Medicaid agency, against the risk of insolvency. State Medicaid agencies and Insurance Departments should collaborate when evaluating MCOs' financial solvency (Actuarial Research Corporation, 1996).

Another important criterion is the protection of providers within MCO networks. Existing Federal and State laws, as well as contracts between MCOs and providers, are designed to ensure that providers are not put at unreasonable levels of financial risk. Note that additional protections for individual providers are not within the scope of this study.

### *Quality Monitoring Essential*

When implementing a payment system based on the health status of enrollees, States should monitor the effects of the payment system on the delivery of health care. They

should look for signs of adverse risk selection, MCO dissatisfaction, and enrollee dissatisfaction. In order to monitor the impact of payment methods for populations with special health care needs, States may want to evaluate MCOs' marketing techniques, the number of MCOs leaving the Medicaid market, and levels of enrollee disenrollment (Kronick, Dreyfus, Lee, et al, 1996; Kronick, Tollen, Grgurina, et al 1998; Medicare Payment Advisory Commission, 1998).

### *Long Term Care*

Several efforts have been undertaken to integrate long term care into managed care. Michigan has a waiver of both freedom of choice (under section 1915(b)) to require enrollment of beneficiaries in managed care) and a home- and community-based services waiver, under section 1915(c), for behavioral health needs, substance abuse problems, and developmental disabilities. ICF/MR payments in facilities are not included in capitation payments under this program. Pennsylvania has a combined waiver for beneficiaries with symptomatic HIV or AIDS. Texas STAR+PLUS has mandated managed care for all Medicaid services, including home and community based services. Arizona implemented two long term care programs under capitation in 1988 - one for elderly and physically disabled (EPD) and one for populations with developmental disabilities. Individuals are eligible to receive these long term care services if they meet screening criteria for any one of the conditions. Minnesota is conducting a demonstration which integrates long term care and acute care services for approximately 3,000 elderly beneficiaries who are dually eligible for Medicaid and Medicare. For beneficiaries who select this option, the MCO receives a capitated payment from HCFA for Medicare plus a capitated payment from the State for Medicaid.

Because only a few initiatives from State Medicaid agencies integrate long term care into managed care, future evaluations are needed to allow for a more thorough understanding of challenges, successes, and how populations with special health care needs are being served in long term care programs.

### *Underlying Issues Affect Adequacy of Payment Rates*

**Need for more accurate and reliable data.** The future development of risk-adjustment methodologies depends on reasonably accurate and complete diagnostic information. Reliable data are essential for all types of payment mechanisms (GAO, 1996). This is perhaps the biggest obstacle to implementing health-based risk adjustment.

Although progress continues to take place, State Medicaid agencies have not been able to rely entirely on receiving complete and accurate encounter data from MCOs (Regenstein and Schroer, 1998). As capitation payments become the norm and the FFS claims data



diminishes, MCOs will need to collect improved encounter data and make it available to State Medicaid agencies for rate setting purposes. Increased reliance on encounter data for payment purposes should lead to greater incentives for accurate collection and reporting, both for MCOs and for their providers (Newhouse, 1994; Kronick, Dreyfus, Lee, et al, 1996). When establishing capitation rates, the use of both inpatient and ambulatory diagnostic information is preferable. Even if diagnostic information for ambulatory services is not readily available in the short term, inpatient diagnostic data often is available and can be used. This approach is being tested by the Health Insurance Plan of California for small employee groups, and also is an interim strategy in the Medicare program in moving toward a comprehensive health-based, risk-adjusted payment methodology for Medicare+Choice entities (Kronick, Dreyfus, Lee, et al, 1996; Medicare Payment Advisory Commission, 1998).

Efforts are underway to improve Medicaid encounter data. The Balanced Budget Act (BBA) of 1997 provides new directives for Medicaid health information systems. HCFA's proposed rule would require that "The State must ensure that each MCO maintains a health information system that collects, analyzes, integrates and reports data." More specifically, a State would be required to ensure that data elements in an MCO system include information on services provided through encounter data or other mechanisms the State defines. The proposed rule also would require the MCO to ensure the accuracy and integrity of data received from providers.

State Medicaid agencies should be proactive in assuring complete and accurate data submission. Strategies to consider include: 1) developing MCO contract language regarding encounter data submission; 2) providing positive financial incentives for adequate submission of encounter data; 3) using negative incentives or penalties for failure to submit adequate encounter data; and, 4) auditing encounter data to ensure compliance.

**FFS data as the basis for rate calculation.** Historically, State Medicaid agencies have used trended FFS claims data to establish capitation rates. Continuing this approach assumes that historical data reflect the desired treatments for all chronic illnesses. However, the FFS system may reflect overutilization of some services or poor access to others. Considerable debate exists about the extent to which either the FFS or managed care systems include the right incentives to produce the optimal level of care for populations with special health care needs. New medical treatments continue to evolve, making more current information necessary (Newhouse, 1998). FFS data will decline as

more Medicaid beneficiaries are enrolled in MCOs, making encounter data the primary source of information for risk-adjusting payments.

Risk-adjustment models need to be recalibrated periodically to reflect modifications to

coding systems, patterns of medical practice, and changes in coding practices by MCOs. Recalibrating a risk-adjustment model's weights using (at least in part) MCO data is important to compensate for diagnostic drift or upcoding (i.e., gaming). Should a trend exist toward coding at a higher severity level over time, recalibration will detect the lower service level associated with the higher codes, and lower the payment weights appropriately (HCFA, 1999).

State Medicaid agencies might wish to consider certain interim strategies for implementing risk-adjustment models. Minnesota is using an interim strategy to implement a prospective ACG risk-adjustment methodology by January 2000. Through use of a "mock" system to test this model before implementation, Minnesota found that noncontinuous eligibility contributed to a significant degree of error in the model. The State is now testing a more concurrent model, in which expenditures are predicted on one year of data, versus the original two years of data. Results will be shared with MCOs that will be reimbursed through this method. The goal of testing and sharing with MCOs is to promote buy-in through open communication before implementing the model (Minnesota Department of Human Services, 1998).

**Upper payment limit.** Capitation payments to MCOs are affected by HCFA's "upper payment limit." The upper payment limit can be described as the FFS equivalent cost of providing services to an actuarially equivalent non-enrolled group. In other words, capitation payments can be no higher than the FFS equivalent cost of services to be delivered under the contract. Because capitation payments are linked to the FFS cost equivalent, a State's Medicaid FFS payment levels and utilization rate of medical services in large part determine the approximate level of capitation payments. HCFA is attempting to identify potential reforms to the upper payment limit requirement that would address the problems of the eroding FFS baseline in State Medicaid programs and insufficient payment and utilization levels in FFS, as well as other concerns.

**END OF REPORT**

# APPENDIX A

## List of Acronyms

AAHP	American Association of Health Plans
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
AFDC	Aid to Families with Dependent Children
APHSA	American Public Human Services Association
BBA	Balanced Budget Act of 1997
CAHPS	Consumer Assessment of Health Plan Study
CBoR	Consumer Bill of Rights
CDC	Centers for Disease Control and Prevention
CHCS	Center for Health Care Strategies
DHHS	Department of Health and Human Services
GAO	General Accounting Office
HCFA	Health Care Financing Administration
HEDIS	Health Plan Employer Data and Information Set
HRS	Health Research and Services Administration
IADL	Instrumental Activities of Daily Living
IoM	Institute of Medicine
MCO	Managed Care Organization

NAIC	National Association of Insurance Commissioners
NAMI	National Alliance for the Mentally Ill
NARD	National Association for Rare Disorders
NASHP	National Academy for State Health Policy
NCQA	National Committee for Quality Assurance
NGA	National Governors Association
NPRM	Notice of Proposed Rulemaking
OBRA	Omnibus Budget Reconciliation Act
OIG	Office of the Inspector General
PCCM	Primary Care Case Management
PERMS	Performance-Based Measures for Behavioral Health Care Programs
QAPI	Quality Assurance and Performance Improvement
QuICCC	Questionnaire for Identifying Children with Chronic Conditions
QISMC	Quality Improvement System for Managed Care
SAMHSA	Substance Abuse and Mental Health Services Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TANF	Temporary Assistance to Needy Families
UM	Utilization Management
WHO	World Health Organization

# APPENDIX B

## **Medicaid, MCOs, Providers and The Americans with Disabilities Act**

The American with Disabilities Act (ADA) applies to Medicaid managed care programs as States, managed care organizations and health care providers are covered by its requirements. Although the bulk of this report addresses individuals with special health care needs, it is important to note that ensuring access for all Medicaid enrollees is preeminent. Whether disabled individuals require a greater diversity or intensity of health care services than nondisabled individuals, they are still protected by the ADA.

Barriers to accessing public-funded health care services, such as poorly planned transportation services, inaccessible medical response systems, and inaccessible physician offices, have imposed staggering economic and social costs on Americans with disabilities and undermined efforts to educate, rehabilitate and employ individuals with disabilities. Titles II and III of the ADA are helping to eliminate barriers, the removal of which will benefit society through the skills and talents of individuals with disabilities, and help individuals with disabilities participate more fully in society.

### **ADA Requirements for the Medicaid Program and Other Public Health Programs**

Title II of the ADA prohibits State and local governments from discriminating against qualified individuals with disabilities in any of their programs, activities, or services. This requirement applies to health care services provided under a State's Medicaid program. A few of the requirements of Title II are highlighted here (States should refer to the ADA and to the regulations at 28 CFR Part 35). For example, Medicaid program eligibility criteria for participation may not screen out or tend to screen out individuals with disabilities unless such criteria are proven necessary for the provision of the Medicaid program, activity or service.

Title II also requires State officials to complete a self-evaluation of the services, policies and practices, including the Medicaid program, to determine compliance with ADA requirements. The self-evaluation is designed to identify policies and practices inconsistent with Title II requirements. States also are required to have a transition plan to correct inconsistencies.

Title II addresses the accessibility of existing facilities and of newly constructed or altered facilities. Each state program, such as Medicaid, when viewed in its entirety, must be readily accessible to individuals with disabilities. Known as "program accessibility," this standard applies to facilities that existed on January 26, 1992. Every existing facility that

provides services need not necessarily be fully accessible to comply with the law. Program accessibility may be provided by a number of methods, including alteration of existing facilities, acquisition or construction of additional facilities, relocation of a service or health care provider to an accessible facility or provision of services at alternate accessible site. Title II also requires the provision of effective communication for individual with disabilities.

### **State Models – Nebraska and Pennsylvania**

Nebraska and Pennsylvania provide two examples of actions taken by States to assure “program accessibility” and meet other ADA requirements.

The State of Nebraska developed the following contractual language to help assure that its program, and program providers, meet the State’s requirement under Title II of the ADA:

HMOs must demonstrate, among other things, that the location of facilities and proximity to and availability of transportation will enhance accessibility of service to the reasonably anticipated enrollees, including aged and handicapped individuals; that facilities will not present architectural barriers to aged and handicapped individuals; and that continuity of service to enrollees will be enhanced by providing a means to ensure that enrollees receive the proper level and type of care and that provision of services is coordinated, within and outside the HMO.

Disability advocates filed suit against the State of Pennsylvania, claiming the Medicaid managed care program did not assure adequate access to care for individuals with mobility and visual impairments. The State’s Medicaid administrators settled the suit with an agreement that features the following provisions:

- The State will ensure that provider offices are inspected for accessibility and that reasonable efforts are made to ensure that “the office is architecturally accessible to persons with mobility impairments.”
- “Informational material about providers will be made available, upon request, in Braille, large print, and audiotape formats.”
- Provider directories and other provider supplements will contain information about which providers are accessible to persons with mobility impairments.
- The State will analyze the geographic distribution of accessible providers and address issues of inadequate geographic access.
- Providers or the State will assist (phone calls) enrollees to locate an accessible provider if requested.

### **ADA Requirements for Private Providers, and Managed Care Organizations**

Title III of the ADA delineates requirements for MCOs and private providers similar to those delineated for States and local governments under Title II. Title III covers places of public accommodation, including medical offices. Under this Title, health care providers may be required to make changes in the delivery, organization, and practice of health care services, where necessary to serve individuals with disabilities, unless they can demonstrate that making such changes would fundamentally alter the nature of their programs or services. Examples of Title III requirements follow. (Covered entities should refer to the ADA and Regulations 28 CFR Part 36 regarding these provisions.)

- Health care providers and MCOs must provide their services in the most integrated setting appropriate to the needs of persons with disabilities. Separate programs or services for persons with disabilities may be necessary to ensure the equal opportunity to receive services. Where such programs or services are necessary, individuals with disabilities cannot be forced to participate in separate or different programs or services.
- Health care providers and MCOs may not impose or apply eligibility standards or rules that exclude individuals with disabilities from receiving health care benefits or health care services unless such criteria can be shown to be necessary for the provision of the services being offered. (For example, it would not be discriminatory for a physician specialist who treats only burn patients to refer a deaf individual to another physician for treatment of a broken limb or respiratory ailment. To require a physician to accept patients outside of his or her specialty would fundamentally alter the nature of the medical practice. On the other hand, it would be a violation for an MCO to exclude all persons with cerebral palsy from its services.)
- Health care providers and MCOs must make reasonable modifications in policies, practices, and procedures that exclude individuals with disabilities, unless doing so would fundamentally alter the service. (For example, a physician's office may not be required to purchase new examination tables at a different height provided that the physician's office can provide an equally effective modification such as assistance for individuals with disabilities to transfer on and off tall examination tables even if that assistance is not provided to other patients.)
- Health care providers and MCOs are required to provide effective communication to disabled persons through auxiliary aids when necessary, unless an undue burden (i.e., significant difficulty or expense) or fundamental alteration would result.
- Health care providers and MCOs must remove architectural and communication barriers that are structural in nature in existing facilities where readily achievable. (For example, a managed care plan may have to build a wheelchair ramp, rearrange

furniture, install grab bars in a bathroom, or lower telephones to allow individuals with disabilities access to physician offices in the MCO's building.)

- Health care providers and MCOs must maintain accessible features of facilities and health care and other equipment that are required to provide access to individuals with disabilities; e.g., if a wheelchair lift is installed to meet ADA requirements, the lift needs to be maintained in working order.)

### **Office for Civil Rights (OCR) Activities**

OCR receives hundreds of complaints each year regarding disability discrimination. DHHS has jurisdiction to investigate and resolve complaints against State and local government health and human service agencies as well as against any entity receiving funds, such as Medicaid funds, from DHHS. Most of these complaints are resolved through negotiations either before or after a letter of finding is issued.

States developing managed care programs for individuals with special health care needs should, especially in mandatory programs, ensure that MCOs and providers are as accessible as possible to populations they will serve. Further, if all providers or plans are not accessible, the State should assist disabled individuals in finding providers or MCOs capable of meeting their unique needs. These activities in no way diminish each provider's and plan's existing obligations under the ADA to take reasonable steps to ensure that the health care services or programs they make available are accessible and accommodate the unique needs of individuals with disabilities wherever possible.

OCR gives technical assistance to providers, MCOs, and State Medicaid agencies about ADA requirements. These efforts should continue to be strengthened to encourage more States, MCOs, and providers to seek technical assistance.



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