

Legal Protections and Advocacy Strategies

For People with
Severe Mental Illnesses
in Managed Care Systems

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Disclaimer

This publication is intended as an overview of legal rights and advocacy strategies in public and private managed care systems. The authors have attempted to ensure that all information presented is accurate and complete as of the date of publication. However, this information is being provided at a time of rapid changes in health care delivery systems. The laws and legal strategies that apply to individuals' rights within those systems are also undergoing considerable change. This publication should not be used as a substitute for legal or other expert advice.

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NAMI is a grassroots, family and consumer, self-help, support, education, and advocacy organization dedicated to improving the lives of people with severe mental illnesses. Severe mental illnesses are biologically based brain disorders that can profoundly disrupt a person's ability to think, feel, and relate to others and their environment.

**This report is available on the NAMI Web site:
www.nami.org.**

Executive Summary

Introduction

Managed care evolved from concerns about out-of-control health care costs. Originally confined to the private health care sector, managed care has now expanded to the public health care sector as well, including state Medicaid programs. Critics of managed care argue that hard-to-serve populations with complex needs, such as persons with severe mental illnesses, are particularly vulnerable to being denied necessary care in managed care systems driven by the desire to contain costs. Unfortunately, these concerns have often proved valid in public and private sector managed behavioral health care systems.

Individuals with severe mental illnesses and their families are frequently unaware of their rights in managed care systems and how to assert them. This guide is intended to provide consumers, family members, and advocates with an overview of their rights in public and private sector managed care systems. It is also intended to provide advocates with practical information they can use to influence the design and implementation of managed behavioral health care systems and programs.

Consumers have different rights and protections in managed care programs, depending on whether the managed care arrangement originates through the public sector (usually state Medicaid programs) or through private health insurance.

Legal Rights in Public Sector Managed Care

The 1997 federal Balanced Budget Act (BBA) led to changes in federal Medicaid law that included a number of protections for persons with mental illnesses enrolled in Medicaid plans. These changes include the following:

- ❖ *Disclosure of information*—Upon request, each Medicaid managed care organization (MCO) and managed behavioral health organization (MBHO) must make available information in easily understandable form on
 - ✓ Provider identity, location, qualifications, and availability.
 - ✓ Enrollee rights and responsibilities.
- ❖ *Scope of covered services*
 - ✓ Grievance and appeals procedures.

- ✓ Benefits covered and cost-sharing imposed by the MCO.
- ✓ Service areas of the MCO.
- ✓ Quality and performance of the MCO.
- ✓ Information or benefits available under Medicaid law that are not available through the MCO.
- ❖ *Emergency Services*—Emergency services must be covered by Medicaid MCOs without prior authorization.
- ❖ *Gag clauses*—Clauses are not permitted that prohibit physicians from advising their patients about MCO policies that have the effect of denying or limiting care.
- ❖ *Internal grievance procedures*—Medicaid MCOs must establish procedures to allow enrollees and providers to challenge denials of coverage and payment for services.
- ❖ *Adequate capacity and services*—Medicaid MCOs must have adequate capacity to offer and maintain an appropriate number, mix, and geographic distribution of services.
- ❖ *Parity*—Medicaid MCOs must comply with the provisions of the 1996 Federal Mental Health Parity Act.

Mechanisms for Challenging Denials or Limits on Care in Public Sector Managed Care

Filing internal grievances—Federal law requires Medicaid MCOs to establish internal procedures whereby subscribers who feel that they have been unfairly denied care can file grievances.

Medicaid fair hearings—Federal law requires state Medicaid agencies to provide consumers with a Fair Hearing process before an objective, impartial arbiter. Unfortunately, a recent report issued by the National Health Law Program concludes that many state Medicaid agencies have been slow to establish mechanisms for this process.

Filing a lawsuit—Consumers who are unable to get satisfaction through internal grievances or the fair hearing process may consider filing a lawsuit against state Medicaid agencies or against MCOs. These lawsuits may be filed either under state tort laws or under federal Medicaid law.

Influencing the Design and Implementation of Your State's Medicaid Managed Care Program

Advocates who want to influence the design or implementation of state Medicaid managed care programs should start by obtaining and reviewing certain key documents. These documents are public, and states are therefore required to make them available to citizens upon request. These documents include

- ❖ *Requests for information (RFIs)*—In the first step toward designing a managed care system, these documents are often used by states to elicit information from stakeholders on key issues.
- ❖ *Requests for proposals (RFPs)*—These documents are used by states to solicit proposals from MCOs based on the state’s outline for the managed care system.
- ❖ *Medicaid contract*—The actual contract between the state or county and the MCO. A second contract frequently exists between the MCO and individual providers serving the targeted population.
- ❖ *Medical necessity documents*—These documents define the clinical standards used by MCOs to guide decision making on whether a service is necessary and therefore covered by the plan in individual cases.
- ❖ *Other key documents include the MCO’s utilization review guidelines, practice guidelines, mechanism* for reimbursing providers, and internal and external review processes.

Unfortunately, the BBA may have weakened the rights of consumers and family members to provide direct input into the design and development of Medicaid managed care contracts by eliminating the need for states to obtain a waiver from the Federal Health Care Financing Administration (HCFA). However, important sources of rights for consumers and family members may still exist, including the following:

- ❖ *Federal Medicaid law* and the requirement that states establish medical care advisory committees, which must include consumers of Medicaid services.
- ❖ *State Medicaid laws*, some of which may require public notice and input into the process of amending state Medicaid plans.
- ❖ *State contract procurement laws*, some of which encourage consumer participation in the public contracting process.

Medical Necessity

Medical necessity is the means by which MCOs and MBHOs determine whether and for how long to cover specific services for specific populations. Consumer and family advocates should ensure that Medicaid managed care contracts for people with severe mental illnesses include

- ❖ Precise definitions of medical necessity that are sufficiently broad to cover the comprehensive services required by persons with severe mental illnesses over time.
- ❖ Language specifying that medical necessity determinations will be made only by licensed psychiatrists, psychologists, or other

qualified clinicians experienced in the treatment of people with severe mental illnesses.

- ❖ Language requiring that medical necessity decisions be made in a timely fashion, without undue delay.
- ❖ Language defining suicidal ideation and suicide attempts as medical emergencies.
- ❖ Language specifying that court-ordered treatment is included in the definition of medical necessity.

Drug Formularies

Two methods are typically used by MCOs and MBHOs to limit access to the newer, more effective but more expensive medications often needed by people diagnosed with a severe mental illness. These are

- ❖ *Restrictive drug formularies*, which may not include some of the newer atypical antipsychotic medications.
- ❖ *Fail-first policies*, which require persons to fail first on one or more older medications before they can have access to newer medications.

Consumer and family advocates should work to

- ❖ Ensure that Medicaid managed care contracts do not impose undue restrictions on access to atypical antipsychotic medications.
- ❖ Advocate for state laws prohibiting unnecessary barriers to effective medications.
- ❖ Advocate for inclusion of a separate pharmacy rate in the Medicaid managed care contract, not one that co-mingles pharmacy into the general capitation rate.

Other Necessary Features of Medicaid Managed Care Contracts

Medicaid managed care contracts that affect persons with severe mental illnesses should also include

- ❖ Programs for assertive community treatment (PACT) and other intensive services that are available on a 24-hour, 7-day-a-week basis.
- ❖ Integrated treatment programs for individuals with co-occurring severe mental illnesses and addictive disorders.
- ❖ Comprehensive crisis services, including mobile crisis response teams to respond to persons in urgent need of help.
- ❖ Meaningful consumer and family participation in monitoring the performance of managed care systems, such as consumer satisfaction teams and facility monitoring teams.

- ❖ Separate and distinct criteria for the treatment of children and adolescents with mental illnesses (if they are covered in the managed care system).
- ❖ Adequate and accessible provider networks.
- ❖ Direct access to mental illness specialists (without requiring enrollees to go through a gatekeeper).
- ❖ Accountability measures that are available to consumers, family members, and other advocates.

Legal Rights in Private Sector Managed Care

All states and the District of Columbia require MCOs operating in the private sector to have internal grievance procedures in place. Additionally, 36 states and the District of Columbia require health plans to participate in independent external reviews available to consumers when they have exhausted the plan's internal grievance process.

Information about external reviews and how to initiate them can be obtained from your state's Department of Insurance. Grievance and appeals mechanisms may also be available through other state agencies such as the Department of Health or the Department of Consumer Affairs.

Filing a Lawsuit

While filing a lawsuit is always a last resort, this sometimes may be the only option when other methods for obtaining redress have failed. In general, private insurance policies are subject to state laws and regulations. However, insurance plans provided by employers who self-insure are preempted from state law compliance by the federal Employee Retirement Income Security Act (ERISA). The legal rights and remedies available to consumers under ERISA often are far more limited than the rights and remedies available under state law.

Potential legal theories available under state laws against managed care plans that are not exempted from ERISA include the following:

- ❖ *Negligence lawsuits*—Historically, negligence lawsuits have been available only to remedy inappropriate care by physicians. However, state legislatures and courts are increasingly recognizing the rights of consumers to file negligence lawsuits against MCOs, when denials of care can be directly attributed to the MCO.
- ❖ *Breach of contract*—Legal remedies for breach of contract are traditionally available only to those who are considered parties to the contract; for example, MCOs and employers. Consumers often are not considered parties. However, some courts may consider

consumers as “third-party beneficiaries” and therefore allow them to file breach of contract lawsuits against MCOs.

- ❖ *Americans with Disabilities Act (ADA)*—For the most part, courts have been very cautious in applying the ADA to private insurance arrangements. However, ADA remedies may be available in certain circumstances under Title I (employment) or Title III (public accommodations). Additionally, remedies may be available against state or county agencies under Title II of the ADA.
- ❖ *Confidentiality of medical information*—New protections against unauthorized breaches of confidential medical information by health care providers or insurance companies are contained in federal rules issued on December 20, 2000, by former President Clinton.

The information contained in this report should not be construed as personal legal advice. If you feel that your rights have been violated by a managed care organization or insurance company, it is important to consult an attorney who is familiar with your state’s laws.

Introduction

The landscape of our health care delivery system continues to undergo dramatic changes, evolving from primarily a fee-for-service system into a managed care delivery system. Health care in the fee-for-service system involved health care professionals providing services to consumers and billing the payer (the state Medicaid agencies, consumers, and/or private insurance companies), who in turn submitted payment to the treating provider.

In the managed care system, managed care organizations (MCOs) and health care providers are paid a fixed dollar amount, known as the “capitation rate,” for each person who is enrolled in the managed care plan. In developing the capitation rate, managed care organizations estimate what they believe the health care service costs will be for participating health plan members and assume the risk of providing service and treatment to consumers in excess of the capitation rate. Managed care organizations also factor in administrative overhead and profit in establishing the capitation rate. The primary purpose of the managed care system is to control the cost of providing health care. Managed care organizations require review and approval for most health care services and require services to meet their definition of medical necessity in order to cover the cost of the services.

Unlike managed care, the fee-for-service system involved consumers going to see a medical provider of their choosing, who provided care and/or referred the consumer to a specialist for additional care. The bill for the medical services was then submitted to and paid by either health insurers or employers. Many complained that health care costs were growing at an uncontrolled rate under the fee-for-service system because it included little or no oversight of medical providers and some providers consequently ordered unnecessary services and drove up overall health care costs. Architects of the managed care system expressed concern over rapidly rising health care costs.

A health care system that focuses primarily on reducing costs presents a threat to the health and well-being of one of our most vulnerable populations—people with severe mental illnesses. There are documented cases of managed care organizations imposing barriers to consumers receiving necessary care and treatment in the interests of cutting costs and maximizing profit. For example, a managed care organization may refuse to pay for more expensive medications or assertive community treatment (ACT) services.

Despite the real concern that managed health care will continue to impede access to necessary care and treatment, it has also presented

the opportunity for positive change in the health care delivery system that may actually benefit people with serious brain disorders. The advent of managed health care has brought the opportunity for documented performance and accountability standards for treatment outcomes. Accountability in treatment outcomes was generally not part of the traditional fee-for-service system. Also, managed care favors treatment in the least costly setting, with its goal to minimize health care costs. This may raise visibility and awareness of the tremendous need for far more community-supported and -based services, all of which could increase the quality of life for persons with serious mental illnesses.

Despite the opportunity for accountability presented in a managed care delivery system, the system's tendency to favor cost cutting over providing critically needed care raises real concerns for mental health consumers and advocates. **Unfortunately, state and federal legislatures have not kept pace with the managed care revolution by enacting adequate consumer protection laws.** Although some federal and state laws and regulations offer limited consumer protections, there are signs that state and federal lawmakers and policymakers have grown increasingly concerned with managed care practices and the lack of regulation. Politicians, whether responding to a sense of what is right or to polls showing that people are being increasingly frustrated and harmed by managed care practices, seem willing to work on managed care reform. Family members and consumers need to keep the pressure on by advocating for better access, accountability, and improvements in the existing and future health care delivery systems.

This publication provides a summary of your existing legal rights in the managed care system and advocacy points to consider in working for positive change in our health care delivery system.

Glossary

The following are commonly used terms in the managed care delivery system:

Adverse selection: Adverse selection “occurs when plan enrollees include a higher percentage of high risk individuals than in the average population, resulting in the potential for greater health care utilization and therefore increased costs.”¹

Any willing provider: Most managed care plans operate with a limited number of mental health providers who must apply to and be accepted into the plan’s network of providers to receive referrals from the managed care plan. Many providers who were excluded from plan networks advocated for any willing provider protection to permit them to participate in managed care plan provider networks. States responded with “any willing provider” (AWP) laws that require health plans to allow “qualified providers” to participate on the plan’s network. “Qualified providers” includes those who are willing to accept the health plan’s terms and conditions for participation and have the necessary experience and credentials to participate in the provider network. Managed care plans have opposed enactment of AWP laws because of the administrative expense associated with keeping multiple health care providers in the network.

Capitation: In managed care systems, capitation is a form of payment made for the delivery of a defined set of services to a designated population for a specified time period. Capitation is essentially a flat fee paid to managed care organizations for each individual enrolled in the plan to cover the health care costs incurred by those enrollees. It is not based on the actual cost of services that are provided. Instead it assumes and estimates the anticipated utilization of services given the characteristics of the given population and the benefit plan design. A capitated payment is typically made by a payer (e.g., state Medicaid agency or private employer) to a managed care organization, which then may *subcapitate* payment to health care providers or facilities. Capitation is an example of a financial incentive used by managed care plans to control health care costs, because the plan assumes the risk that the cost of care for individuals enrolled in the plan will not exceed the capitated rate paid by the payer. Capitation presents a real risk to consumers because it estimates the average costs for the average

¹ SAMHSA, *Partners in Planning: Consumers’ Role in Contracting for Public Sector Managed Mental Health and Addiction Services* (1988).

enrollee and fails to account for the cost of the intensive services often needed by individuals with serious mental illnesses, which may result in those individuals not receiving critically needed services.

Carve-out: Mental health and addictive disorder services may be provided to consumers by a full-service MCO or by a specialty carve-out managed behavioral health care organization (MBHO). MBHOs provide clinical management and/or administrative services for payers and manage services for individuals requiring mental health and/or addictive disorder services. In contrast, a full-service MCO provides a comprehensive health benefit package for primary and specialized health services and integrates the clinical management of mental illnesses and addictive disorders into its management of all conditions and illnesses. Full-service MCOs may also contract or carve out services for mental illnesses and addictive disorders to MBHOs. *Despite the fact that there are significant differences between MCOs and MBHOs, this report will discuss legal rights and advocacy strategies as they pertain to managed care in general, and any reference to MCO and/or managed care system applies to both MCOs and MBHOs.*

Drug formulary/drug coverage: Pharmacy costs are the single most significant cost increase in health care today. Managed care organizations, with policies and procedures that focus on controlling costs, have responded by developing drug formularies, which are essentially a list of specific medications covered by a managed care organization in a benefit package.

An “open formulary” is a managed care organization list of medications that includes FDA-approved drugs. Although “open,” these formularies often include other cost-control measures to encourage the use of less expensive medications. For example, a managed care plan may require a higher out-of-pocket payment (copayment) by the enrollee for a brand-name drug than for a generic drug.

A “closed formulary” is a plan that denies reimbursement for specific drugs or requires higher enrollee copayments for specific drugs, but not all drugs. Forty percent of MCOs use closed formularies.²

As part of their formulary policies, MCOs may require **pre-approval** before an enrollee can obtain specific drugs. MCOs may permit a formal appeal if an enrollee’s request for coverage of a medication is denied. Appeals and grievances require enrollees to convince the managed care plan administrators to make an exception to approve a medication not included on the formulary. Depending on the plan, the process may be rapid and straightforward, or it may be convoluted, time-consuming, and futile. (For more detailed information on drug formularies, see NAMI’s publication *Omnibus Mental Illness*

² “Getting the Drug You Need,” *Newsweek*, April 26, 1999.

Recovery Act—Access to Effective Medications: A Critical Link to Mental Illness Recovery.)

Financial incentives: Managed care contracts with health care providers may include provisions that serve as a financial inducement to limit necessary services that would otherwise be covered by the plan. For example, such an arrangement exists when MCOs provide a bonus or additional compensation to psychiatrists for not exceeding a certain budgeted dollar amount in treating individuals. Clearly, this type of agreement gives providers an incentive to reduce or limit medically necessary care for consumers, because the providers receive additional compensation for coming in under budget. Financial incentives in compensation arrangements with health care providers are one method managed care organizations use to reduce and control costs. Twenty-nine states have enacted legislation to ban financial incentives that compensate providers for providing less than medically necessary and appropriate services.³

Gatekeeper: Many managed care organizations require enrollees to receive a referral from either a primary care physician (PCP) or an MCO plan physician for services for mental illness and/or addictive disorders. MBHOs also often require, in lieu of PCP evaluation, a telephone contact and discussion with an MBHO administrator before the consumer may receive a referral to a network provider. The PCP or other plan administrator is known as the gatekeeper because that individual decides whether or not to approve a referral to a specialist. Managed care plans may also require enrollees to obtain prior authorization for other types of services, such as emergency care, and/or may require treatment providers to receive authorization from a gatekeeper for continued services.

Medicaid: Medicaid is a jointly funded, federal–state health care insurance program for people who qualify under income guidelines or as a result of meeting other criteria. Medicaid covers approximately 36 million people, including children, elderly people, people with disabilities, and those who are eligible to receive federally assisted income maintenance payments.

³ The Health Policy Tracking Service of the National Conference of State Legislatures reports that 29 states prohibit managed care plans from using financial incentives to compensate a health care provider for providing less than medically necessary and appropriate services. Those states are Alabama, California, Delaware, Florida, Georgia, Idaho, Illinois, Kansas, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Ohio, Pennsylvania, Rhode Island, South Dakota, Texas, Vermont, and West Virginia. Health Policy Tracking Service of the National Conference of State Legislatures, *Issue Brief on Bans on Financial Incentives* (August 16, 2000).

Medical necessity: This concept is most critical because it constitutes the fundamental way that MCOs deny or restrict services to consumers. MCOs review provider and enrollee requests for services using a “medical necessity” standard. If services are deemed medically necessary, then, pursuant to the benefit contract, the MCO is required to cover the cost of the services. Most managed care organizations develop their own definition of “medical necessity,” and the troubling reality is that the definition often provides MCOs with broad discretion to deny or restrict services. *Many states have enacted laws that define the term “medical necessity” in the context of determining whether services are covered by the plan.* The most detailed, specific, and comprehensive medical necessity protocols available to the public are those of a few state Medicaid managed mental health programs.

Magellan Behavioral Health, the nation’s largest managed behavioral health care organization, defines medical necessity as services by a provider to identify or treat an illness that has been diagnosed or suspected. The services must be (i) consistent with the diagnosis and treatment of the condition and the standards of good medical practice; (ii) required for other than convenience; and (iii) the most appropriate supply or level of service. When Magellan considers the medical necessity of inpatient care, it defines the term medical necessity as meaning that “the needed care can only be safely given on an inpatient basis.”⁴

Most managed behavioral health care organizations also use more detailed clinical guidelines to determine the appropriate level of care. Often managed care organizations employ utilization management techniques, including a requirement of prior authorization before services are provided, concurrent reviews after an admission, and retrospective reviews after discharge, to determine whether or not services are medically necessary. MCOs have repeatedly been criticized for failing to employ qualified health care professionals to make medical necessity determinations and to participate in the utilization review process.

Network providers: Most MCOs contract with a limited number of health care professionals to provide services for individuals enrolled in the plan. Those professionals are the “network providers” for the MCO, and enrollees are often restricted to those providers in obtaining referrals for care and treatment. A frequent criticism is that MCOs maintain limited provider networks in the interests of keeping administrative costs down at the expense of offering consumers a meaningful choice of mental health care providers.

⁴Magellan “medical necessity” definition and criteria obtained from the Magellan National Provider Handbook available on the Magellan Web site, www.magellan.com, accessed April 27, 2000.

Point-of-service plans: A point-of-service (POS) plan allows enrollees to obtain care and treatment from out-of-network health care providers. Some MCOs offer POS plans. Most often, individuals enrolled in an MCO offering a POS plan must pay a higher out-of-pocket cost for that plan. The benefit of a POS plan is that consumers may obtain and/or continue care and treatment with a trusted provider who may not be part of the managed care organization's provider network. Some states have enacted laws requiring MCOs in the private sector to offer a POS plan to enrollees. Those laws typically allow the MCO to charge higher out-of-pocket costs for the POS plan.

Regulations: Regulations are state and/or federal rules, issued by the executive branch of government, that managed care plans may be required to comply with. Regulations are enforced either through complaints filed with the state or federal agency that has oversight of the managed care industry or through litigation. Often state or federal laws require the executive agency with oversight responsibility for the managed care/health insurance industry to issue health care regulations.

Tardive dyskinesia: A neurological condition characterized by involuntary movements of the mouth and tongue, and sometimes the arms, legs, head, or trunk, tardive dyskinesia is associated with prolonged exposure to some medications, particularly the older, conventional antipsychotic medications.

Treatment outcome data: Treatment outcome data measure the health status of individuals enrolled in MCOs resulting from treatment and services received or denial of services requested. Treatment outcome data should include factors such as general health status, level of functioning, quality of life, and measures reflecting consumer and family member satisfaction or dissatisfaction with the managed care plan and treatment provided or denied.

Utilization review: A utilization review is an evaluation, most often conducted by the managed care plan, of the appropriateness and medical necessity of treatment and/or the need for continuation of treatment, based on clinical criteria developed by the managed care organization. Managed care plans use utilization review as a strategy to control costs. Many managed care plans perform the utilization review functions themselves. Others contract with independent third-party utilization review agents. Although utilization reviews should be conducted exclusively by qualified medical professionals, MCOs have reportedly used case managers or other unqualified individuals to perform these functions. A handful of state legislatures have considered legislation that would limit the utilization review function to medical professionals who have the same qualifications as the treating provider requesting approval for the services.

Waivers: Medicaid waivers are available to states when the Health Care Financing Administration (HCFA), the federal agency responsible for oversight of state Medicaid programs, allows or grants states permission to waive certain federal requirements in order to operate a specific kind of program. In general, federal law allows states to apply for two types of Medicaid waivers: Program Waivers (referred to as section 1915 Freedom of Choice waivers), which allow states to waive the federal requirements of state-wideness, comparability of services, and freedom of choice; and Research and Demonstration Waivers (referred to as section 1115 waivers). States use section 1915 waivers to create carve-out delivery systems operated by managed behavioral health care organizations to provide services for persons with mental illnesses and addictive disorders.

Legal Rights in Public Sector Managed Care

Federal and state Medicaid laws and regulations provide limited protection to consumers with serious mental illnesses. The 1997 Federal Balanced Budget Act resulted in changes to federal Medicaid law that include several consumer protection provisions summarized below. Federal Medicaid law also dictates certain services that must be provided by states that receive federal matching funds for participating in the Medicaid program. However, most Medicaid services are optional, and the state decides on the scope of the services.

There are two ways for consumers participating in the Medicaid managed care system to challenge a decision denying services and/or coverage of services short of commencing a lawsuit. Consumers may file a grievance with the managed care organization or may request a fair hearing before the state Medicaid agency. If neither of these options produces a satisfactory result, then consumers may consider filing a lawsuit, which is frequently costly and time-consuming.

Federal Medicaid Law

1997 Balanced Budget Act (BBA)

The BBA includes provisions that require state Medicaid agencies to provide consumers in the Medicaid program with the following rights and/or protections.

- ❖ Enrollment in Medicaid MCOs—States may enroll Medicaid-eligible persons in managed care entities on a mandatory basis without HCFA-approved waivers under sections 1915(b) or 1115 of the Medicaid law; however, HCFA-approved waivers are required when placing children with special needs and dually eligible Medicaid–Medicare persons. States must submit a state Medicaid managed care plan to HCFA for approval.
- ❖ Consumer choice—The BBA requires that individuals be given a choice of at least two MCOs, with certain limited exceptions such as in rural areas. This provision of the act proved contentious and appeared to be at cross-purposes with its intent.

The “consumer choice” provision of the BBA appeared to be included to benefit consumers by providing them with choice in their Medicaid managed care plans. However, consumer and advocacy groups expressed great concern to HCFA because the most important

consumer choice in a health care system is a meaningful choice of *providers* and choice of different *types of services*, not choice of managed care plans. The concept of a choice of specialized managed behavioral health care plans is extremely difficult for state Medicaid programs to implement effectively, and as a result few states have attempted to have more than one Medicaid managed behavioral health care contract.

The difficulties with a choice of managed care plans include the fact that there are typically small numbers of individuals who use specialized services, making it difficult to have economies of scale if there is more than one managed care organization. Also, having two or more managed care contracts leads either to individual consumer choice (which significantly increases the risk of adverse selection and plan actions to discourage the most seriously ill from signing up) or to assignment from the state Medicaid program (which negates the whole notion of choice).

The provision has the effect of imposing unnecessary administrative burdens and costs on the state Medicaid programs without conferring a significant benefit on consumers. Currently, most states are still operating Medicaid managed care under an HCFA-approved waiver and have not yet had to provide a choice of managed care plans.

- ❖ Termination rights—Enrollees may terminate their enrollment in an MCO for cause at any time, and without cause during a 90-day period following initial enrollment, and at least every 12 months thereafter. States are required to inform all Medicaid enrollees of their termination rights at least 60 days before each annual enrollment season.
- ❖ Enrollment priorities and default enrollment—States must establish enrollment priorities for MCOs that do not have sufficient capacity to enroll all individuals seeking enrollment. Under these priorities, individuals already enrolled with the MCO are given priority in continuing enrollment.
- ❖ Default enrollment—States must also establish a default enrollment process under which people who fail to enroll with an MCO during the enrollment period will be enrolled by the state with several factors taken into consideration, including attempts to continue existing provider-consumer relationships.
- ❖ Disclosure of information—Information distributed to Medicaid enrollees must be easily understood, and each Medicaid MCO must, upon request, make available to enrollees and prospective enrollees the following information:
 - ◆ Provider identity, locations, qualifications, and availability
 - ◆ Enrollee rights and responsibilities
 - ◆ Scope of covered services
 - ◆ Grievance and appeal procedures

Note—A provision that would have required MCOs to disclose to enrollees the proportion of premiums and revenues spent for non-health care items and services was amended out of the enacted version of the BBA. Advocates should still request that information from their state Medicaid agency and/or MCO. It is also critical that advocates request a copy of the “medical necessity” definition used by the MCO to deny or restrict care and a copy of its clinical guidelines.

- ❖ Comparative information—States must annually make available and provide upon request a list identifying the MCOs that are (or will be) available and must provide the following comparative information, presented in a chart-like form:
 - ◆ Benefits covered and cost-sharing imposed by the MCOs
 - ◆ Service area of the MCOs
 - ◆ Quality and performance of the MCOs
- ❖ Information on benefits not provided by the MCO—States must inform Medicaid enrollees of any benefits to which they may be entitled under Medicaid law that are not available through the MCO, and also must inform them of where and how they may access those benefits.
- ❖ Emergency services—Medicaid MCOs must cover emergency services *without prior authorization*, regardless of whether a person obtains the services in or out of network. The BBA defines “emergency services” in relevant part as—

...inpatient and outpatient services that are needed to evaluate or stabilize an emergency medical condition, which is defined in relevant part as a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that a prudent layperson, who possesses an average knowledge of health and medicine, could reasonably expect the absence of immediate medical attention to result *in placing the health of the person in serious jeopardy, serious impairment to bodily functions or serious dysfunction of any bodily organ or part.*

The BBA added important consumer protections. However, advocates and consumers with serious mental illnesses must persuade HCFA and state Medicaid agencies of the critical need to *always classify suicide attempts and suicidal ideation as medical emergencies.*

- ❖ Gag clauses—Medicaid MCOs are prohibited from including gag clauses in provider contracts. The law makes clear that Medicaid beneficiaries are entitled to receive the full range of medical advice and counseling that is appropriate for their care.
- ❖ Grievance procedures—Medicaid MCOs must establish an internal grievance procedure under which enrollees and providers may challenge the denial of coverage of or payment for services. Unfortunately, the BBA did not include provisions requiring Medicaid MCOs to provide external independent reviews of denial

of care decisions and did not provide detailed requirements related to coverage determinations, reconsideration, and appeals, all of which were addressed in the BBA for Medicare. (Despite the failure to include external review requirements in the BBA, Medicaid recipients are entitled to a fair hearing, as described below.)

- ❖ Adequate capacity and services—MCOs must assure the state that they have adequate capacity to offer an appropriate range of services in the service area and must maintain a sufficient number, mix, and geographic distribution of providers. A provision that would have required MCOs to assure the state that they have an appropriate range of services (which differs from the capacity to offer services described above), including transportation and translation services, was amended out of the enacted version of the BBA.
- ❖ Compliance with the Federal Parity Law—Medicaid MCOs must comply with the provisions of the 1996 Federal Mental Health Parity Act (MHPA), which provides that insurers may not impose annual or lifetime limits on mental health benefits if the same limits are not imposed on other physical health benefits.

Efforts were under way in Congress in 2000, and will most likely continue in 2001, to expand the MHPA to ensure full parity for individuals with severe mental illnesses.

Unfortunately, the MHPA does not ensure full parity because it only requires equal coverage for annual and lifetime limits. It is still perfectly legal for insurers to impose on individuals enrolled in their plans higher copays and deductibles and to restrict the number of hospital days and outpatient visits.

Also, the law applies only to employers with 50 or more employees, and employers are not required to comply with the law if they can show that compliance with the law results in an increase in costs of 1 percent or higher.

Efforts were under way in Congress in 2000, and will most likely continue in 2001, to expand the MHPA to ensure full parity for individuals with severe mental illnesses.

- ❖ Quality assurance standards—States must develop and implement quality assessment and improvement strategies that include access standards to ensure that covered services are available within reasonable time frames, ensure continuity of care, and include adequate primary and specialized services and monitoring procedures for evaluating quality and appropriateness.

Also, MCOs with Medicaid contracts must have an annual external independent review of the quality outcomes and timeliness of, and access to, the items and services for which the MCO is responsible

under the contract. The review results must be made available to the public.

The BBA also requires follow-up studies by the U.S. General Accounting Office (GAO) and the Secretary of Health and Human Services to address Medicaid MCO quality, accountability, and access.

A provision that would have required HCFA to develop public participation guidelines for states with Medicaid managed care systems was amended out of the enacted version of the BBA.

Scope of Health Care Services Required by Federal Medicaid Law

Federal Medicaid law requires states to provide benefits to individuals who qualify for the program. The law includes a comprehensive list of services that must be provided to individuals who qualify as “categorically needy.” Most people with serious mental illnesses who are Medicaid eligible fall under the “categorically needy” criterion.

To qualify as categorically needy, individuals must—

- ❖ meet the financial requirements of the Medicaid program;
- ❖ be disabled and receiving federal Supplemental Security Income (SSI) or qualify for a state SSI program; and/or
- ❖ qualify under a less strict standard developed by the states for individuals with disabilities.

Federal Medicaid law requires states to provide the following benefits to individuals who qualify as categorically needy:

- ❖ Inpatient and outpatient hospital services
- ❖ Physician services
- ❖ Medical and surgical dental services
- ❖ Nursing facility services for individuals 21 years or older
- ❖ Home health care for persons eligible for nursing facility services
- ❖ Rural health clinic services and other ambulatory services offered by a rural health clinic that are otherwise covered under the state plan
- ❖ Laboratory and x-ray services
- ❖ Pediatric and family nurse practitioner services
- ❖ Early and periodic screening, diagnosis, and treatment (EPSDT) services for individuals under age 21

Some states also provide the following *optional* Medicaid services:

- ❖ Rehabilitation services
- ❖ Clinical services
- ❖ Targeted case management

- ❖ Prescription drugs
- ❖ Institutions for mental diseases for individuals under age 22
- ❖ Institutions for mental diseases for individuals over age 64

In a June 7, 1999, letter to state Medicaid directors, HCFA emphasized that programs of assertive community treatment (PACT) could be financed through the use of Medicaid optional services.

Despite what appears to be a comprehensive list of services required by federal Medicaid law, the reality of managed care is that the actual scope of Medicaid services provided to consumers with serious mental illnesses may be much narrower, depending on how managed care systems use medical necessity and clinical guideline reviews to limit care.

Coverage for Individuals Qualifying as “Medically Needy”

States have the option of covering persons other than those who qualify as “categorically needy,” including individuals who are “medically needy” (individuals who would qualify as categorically needy, except that they earn more than the threshold). The federal Medicaid law requires states that decide to cover the “medically needy” to provide an additional minimum level of services.

Despite what appears to be a comprehensive list of services required by federal Medicaid law, the reality of managed care is that the actual scope of Medicaid services provided to consumers with serious mental illnesses may be much narrower, depending on how managed care systems use medical necessity and clinical guideline reviews to limit care.

For that reason, consumers and family members need to advocate for strong consumer protections in grievance and appeal procedures to counter the tendency of managed care to narrow the scope of services available to consumers.

Challenging Managed Care Decisions to Deny Services and/or Coverage

Federal Medicaid law provides two ways for consumers to challenge managed care decisions to

deny services and/or coverage of services short of filing a lawsuit. Consumers may participate in the MCO’s internal grievance process or request a fair hearing from the state Medicaid agency.

Managed Care Organization Internal Grievance Process

In the public mental health system, federal law requires state Medicaid contracts with managed care organizations to include internal grievance procedures that allow consumers to file complaints on denial of care decisions. Consumers may file a grievance or appeal denial of care decisions for many reasons, including denial of hospital

admissions, failure to authorize coverage for continued care in a hospital, restrictions in the number of psychotherapy visits, and denials of coverage of medication necessary to treat a severe mental illness effectively and safely.

Internal grievance procedures usually, but not always, lead to rubber-stamped decisions by managed care organizations. However, these procedures may be necessary before an external review can be sought.

An independent external review is not required under federal Medicaid law. However, state laws may require Medicaid programs to provide enrollees with an external review process.

Consumers and family members should familiarize themselves with the grievance and appeals mechanisms available to them in their state's Medicaid managed care system.

Medicaid Fair Hearing Process

Consumers also have important rights to file complaints challenging adverse coverage and payment decisions outside the managed care plan. These rights are particularly important because independent third parties review these complaints. Federal Medicaid law requires states to provide consumers with a "fair hearing" to resolve complaints related to care. Consumers should file a written request for a fair hearing with the state Medicaid agency. *The fair hearing is held before an impartial officer and outside of the MCO's internal grievance system.*

To date, HCFA has not issued regulations to clarify the interplay between an MCO's internal grievance process and the statutorily available fair hearing process. This issue is extremely problematic for individuals enrolled in Medicaid, for MCOs, and for health care providers because many state Medicaid agencies have failed to properly inform and educate MCOs on the fair hearing process and how it differs from the MCOs' internal grievance process. One issue that has led to much confusion is whether a Medicaid enrollee must exhaust a managed care organization's internal grievance process before filing a grievance under the fair hearing process. HCFA has indicated that some states require Medicaid enrollees to exhaust an MCO's internal grievance process before commencing the fair hearing process, while others do not and allow enrollees to participate in the MCO's grievance process and the fair hearing process simultaneously.⁵

HCFA is expected to issue regulations to clarify the requirements, if any, to exhaust the MCO grievance process before participating in the fair hearing process.

The following rules apply to the federal Medicaid fair hearing process:

- ❖ *Managed care decisions subject to fair hearing reviews:* Federal law defines the types of managed care decisions that may be reviewed

⁵ Telephone interview with Tim Roe of HCFA (August 22, 2000), clarifying the interplay between MCO internal grievance process and fair hearing process.

in a fair hearing, including denials of care, terminations of care, suspensions or reductions in covered services, and plan disenrollment (including disenrollment of consumers who do not accept or follow a treatment plan). The law provides that Medicaid beneficiaries have a right to a hearing before an impartial decisionmaker.

- ❖ *Informing beneficiaries of their right to a fair hearing:* Medicaid beneficiaries must be informed in writing of an adverse action taken by the MCO, generally at least 10 days before the date of the proposed termination or reduction of services. Beneficiaries must also be informed in writing of their right to a hearing, of the method by which they may obtain a hearing, and that they may either represent themselves or use legal counsel, a family member, a friend, or other spokesperson to assist them at the hearing. Adequate and timely notice is crucial because Medicaid enrollees may forfeit their right to be heard in opposition to the adverse action if they fail to follow the required procedures.
- ❖ *Continuation of services:* The fair hearing notice must include an explanation of the circumstances under which benefits will continue pending the outcome of the hearing. If an enrollee requests a hearing before the date of the adverse action, then the Medicaid agency may not terminate or reduce services until a decision is made after the hearing. An exception is made when it is determined at the hearing that the sole issue is one of federal or state law or policy, **and** the Medicaid agency promptly informs the enrollee in writing that services are to be terminated or reduced pending the hearing decision.
- ❖ *Expedited review:* Many states require MCOs to make available an expedited review process and to notify enrollees of the availability of the expedited review.
- ❖ *Hearing decision:* The Medicaid agency must provide a written decision within 90 days of the hearing request, summarizing the facts and setting forth the reasoning behind the decision.
- ❖ *Additional rights for Medicaid beneficiaries:* Individuals filing appeals are allowed to examine all documents before the hearings, bring witnesses to hearings, present their own arguments, and cross-examine any witnesses.

A recent report on Medicaid managed care and due process pointed out many areas in which MCOs and state Medicaid agencies have failed to comply with the fair hearing provisions of federal Medicaid law and have violated enrollees' constitutionally protected due process rights.⁶ The report points to many instances in which MCOs fail to provide Medicaid enrollees with proper notice of a decision to deny, limit, or terminate services and fail to notify enrollees of their right to request a fair hearing. The report recommends that states develop a uniform written notice of adverse actions to send to enrollees that

includes a form for requesting an internal grievance and a state fair hearing.⁷ The report also recommends that the uniform written notice be developed with the assistance of Medicaid enrollees, consumer advocates, and health plans. Overall, the report stresses the need for states to do a better job of educating and informing MCOs on federal Medicaid law covering all aspects of the fair hearing process and to work with MCOs to clarify the relationship between the MCO internal grievance process and the separate fair hearing process.

Consumers, family members, and advocates should become familiar with the state fair hearing process and should insist that state Medicaid agencies monitor whether MCOs are following the federal law on the process and observing Medicaid enrollees' constitutionally protected due process rights.

Medicaid Liability

Individuals enrolled in a Medicaid managed care plan may proceed with a lawsuit against the state Medicaid agency and/or the managed care organization. Filing a lawsuit requires significant time and financial resources. However, if managed care organizations engage in a pattern of denying medically necessary services, assistance in filing lawsuits may be available from legal services organizations.

Options exist under the following legal theories:

- ❖ State tort laws (e.g., negligence or malpractice)—Action may be filed against managed care plans based on the theory that the managed care organization is acting as an agent of the state and its actions represent state action.
- ❖ Coverage decisions—Decisions to deny, limit, or terminate care may be challenged by a lawsuit against the managed care plan **and** the state on the grounds that individuals are entitled to coverage or on the grounds that the managed care plan is not providing adequate coverage for mandated benefits, such as the EPSDT required by federal law for children.

Summary: Legal Rights in the Public Sector

The 1997 Balanced Budget Act amended federal Medicaid law to include additional rights and protections for enrollees:

⁶ K. Olson and J. Perkins, *Medicaid Managed Care and Due Process: The Law, Its Implementation, and Recommendations* (Center for Health Care Strategies and National Health Law Program, November 2000). There is a companion report entitled *Medicaid Managed Care and Due Process: A Guide for Health Plans and State Administrators*. Both reports may be ordered online at www.chcs.org or by calling the Center for Health Care Strategies, Inc., at 609-279-0700.

⁷ *Id.*, p. 34.

- ❖ Mandatory managed care is permitted without waivers, except in limited circumstances.
- ❖ Consumers must be provided with a choice of at least two managed care plans.
- ❖ MCOs must follow new provisions related to Medicaid enrollees' termination rights, enrollment priorities, and default enrollments.
- ❖ Medicaid MCOs must disclose certain information to enrollees.
- ❖ States must make available comparative information on Medicaid MCOs.
- ❖ States must disclose benefits not provided by MCOs but required by federal Medicaid law.
- ❖ Medicaid MCOs must cover emergency services without prior authorization.
- ❖ Gag clauses are prohibited.
- ❖ Medicaid MCOs must establish and provide an internal grievance procedure.
- ❖ Medicaid MCOs must have an adequate capacity to provide the services included in the contract.
- ❖ Medicaid MCOs must comply with the Federal Mental Health Parity Act.
- ❖ States must develop and implement quality assessment and improvement standards.

Federal Medicaid law requires states to provide certain minimum services to individuals who qualify as categorically and/or medically needy. States may also choose to offer optional Medicaid services above and beyond those required by federal law.

There are three ways to challenge an adverse Medicaid managed care decision:

1. *MCO internal grievance process:* Often not effective because of the lack of impartiality involved in an MCO reviewing its own decision to limit or deny care.
2. *Medicaid fair hearing process:* May be more effective because fair hearings are filed with the state Medicaid agency and held before an impartial officer, outside of the MCO's internal grievance process.
3. *Commencing a lawsuit against the state Medicaid agency and/or the MCO:* May be time-consuming and expensive, but may also be effective.

Advocacy in Public Sector Managed Care

Managed care in the public mental health system typically evolves through state Medicaid programs. The federal government shares responsibility with the individual states for funding and regulating Medicaid programs. While states are today more free to develop their Medicaid programs as they see fit, federal law still protects consumer rights as states shift to Medicaid managed care. In addition, state laws and regulations may provide some protections for consumers.

States are not required to participate in the federal Medicaid program; however, all states participate in Medicaid and are entitled to receive federal matching funds to cover the health care costs for eligible Medicaid enrollees. As a condition for drawing down federal Medicaid funds, states must comply with the federal Medicaid law and regulations (with the exception of Arizona, which operates under special rules).

The movement of state Medicaid systems from primarily fee-for-service to Medicaid managed care presents the potential threat that managed care will focus on controlling costs at the expense of the health and well-being of persons with serious brain disorders. Although the hope is for greater accountability in health care delivery, the reality is that few, if any, state Medicaid managed care systems are measuring treatment outcomes, which is critical to determine the effectiveness or ineffectiveness of managed care services.

The number of Medicaid managed behavioral health care systems in the states has increased dramatically. In 1996, 14 states implemented Medicaid managed care programs.⁸ In 1999, 41 states and the District of Columbia operated some form of managed behavioral health care.⁹ Given the prevalence of managed care systems operating in the public sector, it is critical that consumers and

The movement of state Medicaid systems from primarily fee-for-service to Medicaid managed care presents the potential threat that managed care will focus on controlling costs at the expense of the health and well-being of persons with serious brain disorders.

managed behavioral health care.⁹ Given the prevalence of managed care systems operating in the public sector, it is critical that consumers and

⁸ Substance Abuse and Mental Health Services Administration, *State Profiles, 1999, on Public Sector Managed Behavioral Health Care* (May 2000): 1.

⁹ *Id.*, p. 2.

family members advocate for greater consumer protections for persons with severe mental illnesses.

What Can Consumers and Family Members Do to Influence Public Sector Managed Care Systems?

Review Existing and/or Proposed Medicaid Contracts with MCOs

Consumers and family members should obtain copies of state Medicaid documents relevant to managed care systems. The following documents should be made available to you by the state agency in charge of administering the Medicaid program:

Requests for information (RFIs): RFIs are typically the first step states take in designing their managed care systems, asking stakeholders to provide information on key issues related to the delivery of health care services. States use the information obtained in the RFI process to develop specifications for the request for proposal (RFP), described below. Some states skip the RFI stage and move directly to the RFP stage.

Requests for proposals (RFPs): RFPs are written requests to managed care organizations to submit specific and detailed proposals to provide health care services based on the state's outline for the managed care system.

Medicaid contract: There are typically two types of Medicaid contracts. The first is a contract between a state or county and the MCO designated to administer services to Medicaid recipients. The second is the contract between the MCO and health or behavioral health care providers serving the targeted population.

Medical necessity document: Consumers and advocates should request a copy of the document that includes the managed care organization's operational definition of "medical necessity." It is critical that consumers and advocates become familiar with the medical necessity standard because it is used to determine the actual access to health care services afforded to consumers.

Other documents: The following documents should be available either from the state or directly from the managed care organization: (i) the managed care organization's utilization review guidelines, (ii) the managed care organization's practice guidelines; (iii) the managed care organization's reimbursement of provider mechanisms; and (iv) the managed care organization's and/or the state's internal, external, and/or independent review processes and clinical review processes.

Importance of the Documents

Although the materials listed above may be lengthy and technical, they are important because they establish the framework for the Medicaid managed care system. The documents define who is to be served by the program, the financial resources to be invested, the specific services available to consumers, legal protections for consumers in these systems, and other critical information.

Obtaining the Documents

The documents are public and states are required to make them available to citizens. Document disclosure laws in each state establish procedures for obtaining public documents from agencies, which may be slow or resistant to providing these documents voluntarily. NAMI advocates should familiarize themselves with these laws and procedures to follow in filing requests for information under state document disclosure laws. States may require you to request the documents directly from the MCO. If the MCO fails to comply with your request, promptly notify the state agency charged with administering the Medicaid plan (preferably in writing with a copy of the letter sent to the managed care organization).

What to Do with the Documents

After obtaining these materials, consumers and advocates should work with their state NAMIs and with NAMI National to understand the documents and to provide feedback on the managed care system. Assistance may also be available from legal services organizations in the states, many of which have specific experience in reviewing Medicaid managed care documents and assisting advocacy organizations in asserting their rights in Medicaid managed care systems. Some state protection and advocacy organizations are also developing expertise in reviewing and having an impact on state Medicaid managed care systems. (See appendix A.)

Consumer advocates may also wish to review the following publication: *Partners in Planning: Consumers' Role in Contracting for Public-Sector Managed Mental Health and Addiction Services*, developed by the Judge David L. Bazelon Center for Mental Health Law and the Legal Action Center with significant input from a stakeholder council representing those who use mental health and/or drug and alcohol treatment services. The publication is a technical assistance guide to empower consumer and family groups' participation in the design and selection of public contracts for public sector managed mental health and addiction services. It is available free from SAMHSA (call 800-729-6686) or for \$5.00 from the Bazelon Center (Web site: www.bazelon.org, or call 202-467-5730, ext. 41).

Provide Input to the State on the Medicaid Managed Care Contract

The following laws may provide consumers and family members with an opportunity for input on state Medicaid managed care contracts:

Federal Medicaid law: The Federal Medicaid Act was amended significantly in 1997, with enactment of the BBA. Before enactment of the BBA, federal law allowed states to impose mandatory enrollment in Medicaid managed care only if HCFA had granted the state either a section 1915(b) or section 1115 waiver of Medicaid rules. The law required states to provide notice and seek public input into the waiver process.

The BBA eliminated the need for states to obtain a waiver from HCFA for mandatory managed care, except for protected classes, such as children with special needs. It also eliminated the need for states to provide public notice and a comment period for state Medicaid managed care plans developed outside the waiver process. Under the BBA, states that are interested in mandating Medicaid managed care must submit a state plan amendment to HCFA. After a review process, states may receive approval for the Medicaid managed care plan.

Although the waiver process for mandatory managed care involved a formal opportunity for public input, under the state plan amendment process, the public may still be permitted to provide input because state Medicaid agencies are required to establish Medical Care Advisory Committees. The committees must include consumer members and the state Medicaid agency must consult with the committee on policy decisions. Also, Medical Care Advisory Committee meetings are open to the public and represent a forum for consumer and family member input into the design and operation of Medicaid managed care plans.

State Medicaid law: States that participate in the Medicaid program must comply with federal laws and regulations. However, states may also enact stricter laws for their Medicaid programs.

State laws may require public notice and input into the process of amending state Medicaid plans. Since states are increasingly adopting Medicaid managed care systems, advocates should familiarize themselves with their rights under state laws to have an impact on these procedures.

NAMI, as part of its model legislation—Omnibus Mental Illness Recovery Act (OMIRA)—advocates for consumer and family member participation in mental illness services planning, including involvement in accountability measurements (the factors that should be used to hold managed care organizations accountable for their performance in providing public sector services to persons with serious mental illnesses and/or addictive disorders) and public reporting of such data. Consumers and advocates should participate in designing and amending Medicaid plans as they relate to mental health systems.

Federal procurement laws: Court cases decided in Iowa¹⁰ and Ohio¹¹ make clear that a state awarding a contract for Medicaid managed behavioral health care services must comply with the Federal Procurement Act when it undertakes the process of contracting for those services. Although this process does not address public input, it requires states to be evenhanded in awarding Medicaid managed care contracts.

State procurement laws: There are specific provisions in nearly all of the state statutes establishing state contract procurement procedures and processes. Some states, such as Florida, encourage public participation in the public contracting process. Knowledge of your state's procurement procedures and requirements may be advantageous as you advocate for active participation of consumers and family members in developing Medicaid managed care RFPs and in selecting qualified managed care plan vendors.

State administrative procedure laws: Medicaid managed care RFIs, RFPs, contracts, or state plan amendments may be considered "rule-making" under the state's Administrative Procedures Act in certain states. If so, these acts may require notice, comment, and participation by interested members of the public in the process of selecting a contractor for Medicaid managed care.

What Managed Behavioral Health Care Organizations Are Saying about Medicaid Managed Care Contracts

Representatives of four MBHOs that have a significant share of the state Medicaid contract business participated in a one-day focus group meeting during which they discussed contracting for public mental health services. The Center for Mental Health Services convened the

¹⁰ Colette Croze and Wendy Krasner, *Public Sector Procurement of Managed Behavioral Healthcare*, An AMBHA Commissioned Study (December 1997) citing *Medco Behavioral Care Corp. of Iowa v. State Department of Human Services*, 553 N.W.2d 556 (Iowa 1996), a case in which the court reversed the Department of Human Services' decision awarding a contract for Medicaid managed behavioral health care to a bidder, finding that the winning bidder had a conflict of interest and the state erred in its scoring of proposals and in the introduction of additional information outside of the bidding documents.

¹¹ *Id.*, *Value Behavioral Health, Inc. v. Ohio Department of Mental Health*, Case No. C2-97-395 (S.D. Ohio July 30, 1997), in which the court found that the state failed to follow lawfully mandated bidding procedures when it attempted to award a contract for Medicaid managed behavioral health care services to a bidder. The court ruled that the state violated federal law and regulations by attempting to award the contract for Medicaid services to a bidder whose offer was not responsive to the RFP and did not conform to the RFP requirements.

focus group meeting and issued a special report summarizing the opinions and comments of the four MBHOs.¹²

MBHOs have been involved in a number of lawsuits related to Medicaid contracts and have pulled out of several state Medicaid contracts in which either their performance fell well below expectations or they were suffering significant financial losses. The report indicates that fewer MBHOs are responding to RFPs for public sector/Medicaid managed care contracts. MBHOs expressed the following concerns about and recommendations on Medicaid managed care contracts:

- ❖ State and local governments with which MBHOs contract fail to provide necessary information and data and fail to resolve design issues before the procurement process begins, leading to unnecessary confusion for MBHOs. Also, MBHOs expressed concern over the cost of responding to RFPs with an increasing number of program design specifications.

MBHOs recommended that states clearly define the requirements for providing services and ask how MBHOs intend to operate their systems to comply with those requirements. MBHOs also recommended that states avoid requirements that redefine an MBHO's mode of operation.

- ❖ MBHOs are unlikely to find RFPs attractive that include excessive financial requirements and limit profits without recognizing potential financial and performance risks for the MBHO.
- ❖ MBHOs expressed concern that benefit levels in RFPs may be vague, resulting in ambiguity and the potential for administrative and legal battles over coverage. Also, RFP benefit levels may represent an unrealistic "wish list" requested by stakeholders and not reflected in the amount the state is willing to pay for the services. MBHOs recommended that the benefit package be clear in the contract because ambiguity may lead to litigation and unrealistic expectations.
- ❖ MBHOs said that states sometimes attempt to micromanage MBHOs that are awarded public sector contracts and fail to appropriately define the role of the state and its relationship to the MBHO in providing an array of services to consumers.

MBHOs recommended that states avoid micromanagement and clearly state their expectations for service coordination across health care and other state social service programs.

¹² T. Savelle, G. Robinson, and S. Crow, *Contracting for Public Mental Health Services: Opinions of Managed Behavioral Health Care Organizations* (Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 2000). The report is available online at www.mentalhealth.org or by calling the CMHS Knowledge Exchange Network, 800-789-2647.

- ❖ Although MBHOs agreed with the use of performance measures, they expressed concern that states require compliance with performance measures that are beyond the MBHO's ability to measure and require measures that may not be consistent with the goals of the Medicaid program.

MBHOs recommended that performance measures be tied to program objectives and reflect factors that MBHOs can track.

- ❖ MBHOs commented that consumers should play an active role on advisory committees addressing service delivery and member service issues; however, the MBHOs do not believe that contracts should require consumer representation on MBHO governing boards.

Clearly, states should be concerned if fewer MBHOs are responding to RFPs for Medicaid managed care contracts. Fewer competitors bidding on a contract may negatively affect the quality and cost of services. On the other hand, states must maintain adequate oversight of MBHO performance and must continue to refine the RFP and contracting process to ensure that, ultimately, Medicaid enrollees (particularly people with serious mental illnesses and/or addictive disorders) receive critically needed services.

Advocacy Points for Consumers and Family Members

There is considerable variation in the extent to which consumer protections that may benefit consumers with serious mental illnesses have been incorporated into existing state Medicaid managed care systems. One thing is clear: Most states transitioning from a primarily fee-for-service program to Medicaid managed care have fallen far short of providing adequate protections for consumers with serious mental illnesses.

In reviewing existing and proposed Medicaid managed care contracts, consumers and family members should consider the following issues as they relate to the managed care system and consumer protections. If problems are identified, family/consumer advocates should consider presenting them to HCFA, the federal agency that maintains oversight of state Medicaid programs and approves state Medicaid plans. Advocates may also present concerns directly to the state Medicaid agency and/or state legislators who sponsor consumer protection legislation.

These advocacy points present suggestions on how to help build a health care delivery system that properly serves consumers with serious mental illnesses.

Medical Necessity

Medical necessity determinations dictate the scope of services individuals with serious mental illness will receive under managed care. The term is not defined in federal Medicaid law. Instead, federal law authorizes states to develop and apply medical necessity criteria. Federal law provides some guidance to states by establishing that services to Medicaid beneficiaries must be “sufficient in amount, duration and scope to reasonably achieve their purpose” and by prohibiting state agencies from discriminating in providing care on the basis of a

Consumers should ask state Medicaid agencies and MCOs participating in Medicaid for the criteria and definitions they use in making decisions on medical necessity.

person’s diagnosis or condition. Consumers should ask state Medicaid agencies and MCOs participating in Medicaid for the criteria and definitions they use in making decisions on medical necessity.

Key terminology, such as “actual benefits” (how benefits are actually accessed) and “medical necessity,” should be precisely defined in public sector managed care systems. When those terms are not precisely defined, the ambiguity may result in managed care organizations denying or limiting services in the interest of holding down costs.

MCOs are frequently criticized for narrowly interpreting the scope of medically necessary services to minimize the cost of more intensive services that may be required by individuals with serious mental illnesses. Consumer advocates have also criticized MCOs for allowing plan administrators

(individuals who work for MCOs and respond to health care provider and/or enrollee requests for approval of a specified treatment or service) who lack clinical expertise in treating severe mental illnesses to make medical necessity determinations for services related to those illnesses. Advocates should seek to ensure that MCOs either employ plan administrators who are clinically qualified and licensed mental health experts to make medical necessity determinations or pay for a second opinion by an independent professional with appropriate credentials.

Administrative Delay

Managed care organizations may erect administrative barriers to making timely medical necessity decisions, particularly for the intensive care (i.e., extended inpatient care and/or extended community-based placement) often required for consumers with serious mental illnesses. For example, they may fail to advise consumers of proper procedures, or they may delay decisions. For this reason, it is critical that consumer advocates work together to monitor unnecessary administrative delays or barriers in coverage decisions and report any such

problems to the appropriate state Medicaid agencies and/or HCFA. (See appendix B.)

Suicide

Unfortunately, MCOs do not always consider suicide attempts and suicidal ideation as a medical emergency. Advocates should ensure that **suicide attempts and suicidal ideation are always viewed as a medical emergency.**

Public vs. Private Managed Behavioral Health Care Systems

Medical necessity protocols used in public managed mental health care systems (most often state Medicaid programs) should be modified from the protocols used in the private managed mental health care system (most often health care available through private employment benefit plans). Iowa is a case in point. The central source of turmoil in Iowa's initial Medicaid managed mental health care implementation in 1995 to 1996 was the difference between the private sector medical necessity criteria, which tended to restrict or limit care, and the public sector safety-net functions, which tended to provide broader care.¹³

As a result of those differences, the state and its managed care vendor, with the involvement of consumers, families, and providers, negotiated the following three changes to the vendor's typical private insurance model of medical necessity:

- ❖ Up to five days of coverage for court-ordered mental health inpatient services and one day of coverage for court-ordered substance abuse inpatient services is covered under the Iowa Medicaid plan.
- ❖ Children may not be discharged from inpatient settings until a safe living arrangement and a plan for the necessary follow-up for mental health treatment have been arranged. As a result, 194 children were retained in inpatient care for an average of 17.6 days each, and for the first time a wide array of alternatives became available.
- ❖ Psychosocial necessity was added to the operational definition of medical necessity. Psychosocial necessity is defined as an expansion of medical necessity that examines environmental factors that inhibit or hamper the effectiveness of treatment and explicitly includes rehabilitation and support services. Managed care case managers are instructed to specifically consider the potential for services/supports to allow the enrollee to maintain functional improvement attained through previous treatment.

Advocates should push for these types of creative changes, which help to ensure that the public mental health system continues to

¹³ James E. Sabin and Norman Daniels, "Public Sector Managed Behavioral Health Care V: Redefining 'Medical Necessity'—The Iowa Experience," pp. 445–446, 449, in *Psychiatric Services* (Washington, DC: American Psychiatric Association, 2000).

function as a comprehensive system of care and a safety net for those most in need of services—individuals with severe mental illnesses.

One other critical issue that pertains to medical necessity in the public and private sectors is *who pays for court-ordered involuntary civil commitment* in the managed care system. In general, unless the contract between the payer (state Medicaid agency or private entity) and the managed care organization specifies that the MCO is financially responsible for court-ordered services, then such services are **not** paid for by the MCO unless the MCO determines that the services are medically necessary.¹⁴

At least one state has addressed this issue in its public managed mental health contract. In its Medicaid managed care contract, Iowa requires that medically necessary services include those that are court ordered.¹⁵

Communication between the courts and MCOs may decrease court-ordered civil commitments if MCOs are willing to provide coverage for an array of previously unavailable community interventions and services (such as the programs of assertive community treatment, or PACT). This has occurred in Colorado, where Colorado Health Networks, the Medicaid MCBO, has successfully reduced court-ordered treatment by working with the court.¹⁶

Grievance Procedures (Internal and External Appeals)

Internal Grievance Procedures

Federal law requires state Medicaid managed care contracts to provide an internal grievance procedure, which gives consumers an opportunity to be heard when managed care organizations deny services or coverage of services. Internal grievances give the MCO an opportunity to review and either affirm or reverse its initial decision to deny or limit services. The obvious drawback of internal grievance procedures is the lack of objectivity or independence involved in an MCO reviewing its own decision to deny or limit care, which is why an external grievance procedure process can be extremely valuable. Some managed care contracts require consumers to file internal grievances before they can file external grievances.

¹⁴ Center for Mental Health Services Forum, *Mental Health Services Under Managed Care: What Have We Learned So Far?* Presented by Garrett Moran Westat (CMHS contractor), May 8, 2000.

¹⁵ *Id.*

¹⁶ *Id.*

External Grievance Procedures

Consumers should be entitled to an independent external review of MCO denials of care and/or coverage because of the obvious bias built into the internal grievance procedure. Federal Medicaid law does not require MCOs to offer consumers an independent external review. Advocates should work to persuade their state legislatures to mandate that MCOs participating in Medicaid programs provide consumers with both an internal and independent external clinical review of denial of service/coverage decisions with prompt and strict timelines for binding decisions.

Consumers should be entitled to an independent external review of MCO denials of care and/or coverage because of the obvious bias built into the internal grievance procedure.

Components of effective internal and external grievances include the following:

- ❖ The overriding priority is for managed care organizations to develop grievance procedures and systems that are user friendly and easy for consumers to navigate, which they can do by incorporating the recommendations listed in the bullets below.
 - ❖ Either the MCO or the state should provide an ombudsperson program to assist consumers with the internal and external review processes.
 - ❖ All information must be culturally sensitive to ethnically diverse populations and must be accessible to those who do not speak or read English.
 - ❖ All notices, decisions, and correspondence should be written simply, in plain and understandable language.
- ❖ Consumers should receive timely written notice of decisions denying services and/or coverage of services that give rise to the internal grievance process.
 - ❖ Notice should include a clear and understandable explanation of the reason for the denial, including the clinical rationale for the denial, and a detailed description of the internal grievance process.
 - ❖ Timelines for both internal and external grievances should provide for prompt access to services and immediate access for emergency care. However, timelines within which consumers must commence the appeal process should not be so strict that they are unrealistic for consumers to meet. This is especially important for consumers who may be undergoing care and treatment for serious mental illnesses.
 - ❖ Qualified mental health providers who were not involved in the initial adverse decision should be required to review it and render a decision on the grievance. The external independent review panel should include clinical specialists in the treatment of people with severe mental illnesses.

- ❖ A written decision should be issued to the consumer that clearly states the reason for the grievance decision and the options available for pursuing an external review of the decision.
- ❖ Both the internal and external review processes should require the MCO to continue to provide the services at issue pending the outcome of the grievance process.
- ❖ Managed care contracts may be written to include broad exclusions that permit a managed care organization to deem a request for treatment *excluded* rather than *denied on the grounds of medical necessity*. Consequently, the MCO grievance system should cover denials of care on the grounds that the treatment is excluded as opposed to the narrower category of decisions denying services as not medically necessary.
- ❖ Consumers should not be charged a fee for participating in the external review process, because the fee may serve as a barrier to consumers participating in an appeal.
- ❖ Both MCOs and state Medicaid agencies must provide a clear statement to consumers on the requirements and procedures for consumers to participate in the MCO grievance process and the right to participate in a fair hearing (federal Medicaid law requires states to provide enrollees with due process guarantees through the fair hearing process, including notice of an adverse action and the opportunity to be heard); the fair hearing process, including an explanation of how it differs from the MCO grievance process; and what consumers must do to ensure that their grievance is heard in both systems.

Drug Formulary/Drug Coverage

New Medications—New Opportunities

Since 1990, remarkably effective medications have become available for the treatment of mental illnesses. New medications offer exciting new opportunities for full and productive lives for people with schizophrenia, bipolar disorder, major depression, and other severe mental illnesses. These treatments can mean the difference between hope and despair, recovery and struggle, even life and death. Despite the newer medications' unparalleled promise, an insidious tragedy is unfolding in this country. Far too many people with chronic mental illnesses are being denied access to the newer, life-changing treatments.

The Cost of Medicaid Managed Care Restricting Psychiatric Medications

Some states are stepping up efforts to restrict access to the newer medications. State Medicaid agencies and their managed care agents have implemented or are considering cost-cutting measures that deny

or delay access to the newer, most effective medications for treating serious mental illnesses.

The risks of these cost-cutting measures to the health of millions of Americans who have severe mental illnesses, and to the welfare of society overall, are great. Moreover, such measures could produce even greater economic burdens associated with hospitalizations or incarcerations. Advocates need to fight against unnecessary restrictions on access to medications that treat severe mental illnesses. Advocates should alert state legislators, health care payers, the media, and the general public about the dangers inherent in such restrictions.

The use of newer antipsychotic and antidepressant medications makes sound fiscal sense. The greater initial cost of the medications is more than recovered in the decreased cost of clinical care, particularly because fewer days of hospitalization are necessary.

Professional judgment and informed consumer choice, not economics, should determine consumer access to medications to treat mental illnesses. Choice should be based on current knowledge of effectiveness and potential side effects and should be consistent with existing treatment guidelines.

A Clear Case for the Use of Newer Medications

The newer antipsychotic and antidepressant medications are the first choice of medical experts. Most psychiatric treatment guidelines established by the nation's leading medical societies recommend the newer medications as the drugs of first choice in most situations for most consumers. The newer medications are more effective in managing the symptoms of devastating brain disorders such as schizophrenia and offer more hope of recovery. Also, the side effects of the newer medications are generally less severe than those of older drugs, so it is less likely that consumers will stop treatment because of adverse side effects.

The use of newer antipsychotic and antidepressant medications makes sound fiscal sense. The greater initial cost of the medications is more than recovered in the decreased cost of clinical care, particularly because fewer days of hospitalization are necessary.

Newer atypical antipsychotic medications (such as Clozaril and Zyprexa, used to treat persons with schizophrenia) have been proven effective in enabling persons with severe mental illnesses to return to the workforce as well as live more independently. Public and private payers risk legal costs and liability for tardive dyskinesia and other damaging side effects associated with the older medications.

In the case of newer antidepressants, the total treatment costs of newer antidepressants and older antidepressants are similar. Medication costs are higher, but costs of office visits and other medical

care are reduced because dosage adjustments are simpler and side effects are less problematic.

The Incentives for Managed Care Systems to Make Effective Medication Accessible

Left untreated, mental illnesses can have terribly destructive and costly effects, including unemployment, poverty, homelessness, criminalization, social isolation, and premature death.

Concerned about escalating costs, both private and public sector managed care plans have developed a variety of ways to restrict access to medications. Sometimes these policies may be appropriate to avoid the inappropriate use of drugs or to encourage the use of generic equivalents. But often the limitations are designed to discourage the use of more expensive, but frequently more effective, medications. The two major cost-cutting measures used by managed care plans are *restrictive drug formularies* and *fail-first policies*.

❖ *Restrictive drug formularies.* A drug formulary is a list of specific medications covered by a managed care plan. If a drug is not included on a managed care plan's formulary, an enrollee cannot get it unless he or she pays for it out of pocket. Managed care plans use either a closed formulary, in which they deny reimbursement for specific drugs or require higher enrollee copayments for certain drugs, or an open formulary, which includes all FDA-approved drugs, but which contains other cost-control measures such as copayments to encourage the use of less expensive medications.

There are two other considerations related to managed care drug formularies. First, managed care plans may require pre-approval before an enrollee can get specific drugs. Second, managed care plans may permit a formal appeal for excluded drugs. The enrollee must convince the plan administrators to make an exception to approve a medication not included on the formulary. Depending on the managed care plan, the process may be rapid and straightforward, or it may be convoluted, time-consuming, and ultimately futile.

❖ *Fail-first policies.* Fail-first policies, also known as "step therapy," require a person to take an older, less expensive medication first. Only after that drug fails, which might trigger a serious relapse, will a newer, more expensive drug be approved. Controlling costs through fail-first approaches conflicts with most clinical treatment guidelines for mental illnesses. It is poor clinical care to delay the start of effective treatment and expose a person with mental illness to increased risks.

Managed Care and Capitation Rates

Combining a pharmacy managed care capitation with a mental illness treatment capitation should be prohibited. Nearly all capitations are

inadequately financed. Combining the two forces a trade-off: medication, other clinical care, or support services. Such a trade-off frequently results in treatment failures.

Proposed State and Federal Legislation

Consumers, family members, and advocates should push for state and federal legislation that would require the following:

- ❖ Ideally, managed care plans should offer unrestricted access to all effective and medically appropriate medications and should not deny access to specific medications for mental illness.
- ❖ If unrestricted access is not possible, managed care plans that use formularies should allow exceptions when a nonformulary alternative is medically indicated.
- ❖ Managed care plans should establish procedures for members to quickly appeal a medication decision and receive prompt reconsideration.
- ❖ Third-party, independent, clinical review appeals of medication denials should be mandated.
- ❖ An enrollee's previously prescribed and newly prescribed medications should be maintained until the entire appeals process is completed. Further, managed care plans should not be permitted to require enrollees to switch from medications that have been effective for them.
- ❖ Managed care plans should inform the public and potential enrollees about the plan's pharmacy benefit, restrictions that may apply to the pharmacy benefit, and any other plan procedure that affects access to medications before anyone enrolls in the plan or the plan's contract is renewed.

For more information on access to medications, see NAMI's publication *Omnibus Mental Illness Recovery Act—Access to Effective Medications: A Critical Link to Mental Illness Recovery*. (Available on the NAMI Web site at www.nami.org or by contacting the NAMI office at 703-524-7600.)

Financing the Medicaid Managed Care Contract

Adequate financing of the Medicaid managed care system is critical. Underfunding always causes the most harm to those most ill. States must provide adequate funding for Medicaid managed care contracts to ensure that enrollees receive needed services.

Advocacy Points to Ensure Adequate Funding

The following advocacy points should be advanced to help ensure the proper funding for the Medicaid managed care system:

- ❖ The pharmacy benefit should **not** be added to the capitation rate; instead it should be paid for separately by the state Medicaid

agency. Pharmacy is the fastest growing portion of health care costs, and principles of underwriting the financial risk of psychopharmaceuticals are poorly understood.

- ❖ There should be an unduplicated count of persons served—not a count of the number of *services* paid for—by the public mental health system so that actual per-person service utilization is documented and known. Otherwise, the calculation of capitation rates is not based on actual data and will not be adequate to cover the cost of necessary care and treatment.
- ❖ A partial capitation system, which requires the state to pay for enrollee care and treatment over and above a specified level, is ideal because it provides a safety net if the capitation rate in the MCO contract is too low.
- ❖ States should not add the uninsured population (those who do not qualify for Medicaid and do not otherwise have health care insurance) into capitated managed care contracts until utilization patterns are known. States that have prematurely added the uninsured population into these contracts (Montana and Tennessee) have created a financial mess.
- ❖ States should not cut their budgets in anticipation of savings when implementing Medicaid managed care. The managed care program should be implemented first. Then, if there are savings, states should reinvest the funds. States should return any actual savings realized from converting the Medicaid program to a managed care system to improve services for individuals with serious mental illnesses, instead of losing them to the state's general fund (capture and reinvest).
- ❖ States should compare capitation rates, with particular emphasis on the capitation rates successfully used in other states. Even though there is considerable variation in cost and composition of professional services, comparisons will assist in determining suitable capitation rates and adequate funding for care. Also, Medicaid provider reimbursement rates (the dollar amount that health care providers are paid for providing services to enrollees) must be adequate to ensure that qualified providers are willing to participate in the plan and to attract and keep the best providers available. Medicaid reimbursement rates have historically been low compared with Medicare reimbursement rates.
- ❖ When the utilization history is not known, states should not gamble on what the capitation rate should be. Instead states should use risk corridors. Risk corridors involve a state setting limits on MCO losses and profits. In essence, the state protects an MCO from falling below a set loss amount and ensures that MCO profits do not exceed a set limit. Risk corridors should be applied whether the MCO is a for-profit or not-for-profit organization.

- ❖ Medicaid managed care plans and states should be required to account for every dollar spent on Medicaid, including the amount spent on administrative services and the amount spent on clinical care. Advocates should push for states to adopt Massachusetts's practice of devoting 100 percent of the capitation rate to clinical care; not including pharmacy in the behavioral health benefit capitation rate; operating a separately funded, adequately funded, and separately negotiated administrative budget; and tying profits to the achievement of performance goals. Massachusetts also uses risk corridors that cap potential profits and losses.

Scope of Services in the Medicaid Managed Care Contract

Medicaid managed care contracts should include criteria covering the full continuum of care, including a consideration of housing, social and family support, income support, transportation, and education and/or workplace needs. MCOs participating in Medicaid should be required to offer treatment in the least restrictive setting necessary to provide effective treatment and meet consumers' medical needs.

At the same time, advocates should be aware of an MCO's focus on "least restrictive setting." MCOs tend to favor the least costly alternative of care, which often is the least restrictive setting, and may refuse to provide care required in a more costly setting.

The Olmstead Decision

In June 1999, the United States Supreme Court issued an important decision in *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999), which affects the scope of services required in Medicaid managed care contracts. In *Olmstead*, the Court ruled that it is a form of discrimination under the Americans with Disabilities Act (ADA) when states fail to provide services in the most integrated setting appropriate to the needs of the individual. For example, under *Olmstead*, it would be considered a violation of the ADA to require individuals to remain in institutions if a community placement is the most integrated setting appropriate to their needs. Advocates may argue that the *Olmstead* decision requires states, including state-sponsored MCOs, to provide services necessary to prevent hospitalization or incarceration.

- ❖ MCOs should be required to consider appropriate community care and effective treatment through PACT and other intensive services available on a 24-hour, seven-day-a-week basis.
- ❖ A state may decide that it does not wish to carve out all of the services that it is required to provide under Medicaid to a managed care system. For example, states may decide not to contract out the early and periodic screening, diagnosis, and treatment

- (EPSDT) services required for children. Instead, EPSDT would remain the direct responsibility of the state Medicaid agency.
- ❖ Other effective treatment programs should include integrated treatment programs for consumers with co-occurring mental illnesses and addictive disorders, including 12-step programs and programs administered by faith-based organizations.
 - ❖ Comprehensive crisis services, including some staff who are themselves consumers of mental health services, must be available for consumers with serious mental illnesses, including 24-hour, 365-day-per-year telephone response service staffed by qualified mental health providers, and, if necessary, offer immediate face-to-face assessment and on-call consultation with psychiatrists. The crisis services must include a mobile response team, staffed by qualified mental health professionals and peer counselors, to respond to consumers in need of immediate care.
 - ❖ Medicaid managed care contracts should include provisions addressing consumer perspectives on long-term care, inpatient care, and involuntary treatment.

Without proper coordination, consumers with co-occurring disorders are left to navigate the system, putting them at real risk of harm when they are in crisis or in need of emergency services.

Integrated Treatment Programs

National studies commissioned by the federal government estimate that 10 to 12 million Americans have co-occurring mental and addictive disorders.

Research confirms that providing integrated treatment for co-occurring disorders is much more effective than attempting to treat these illnesses separately. Integrated treatment means delivering mental illness and addictive disorder services and interventions simultaneously at the same treatment site, ideally with cross-trained staff.

Treatment modalities that are not integrated include sequential treatment (treat one disorder first, then the other) and parallel treatment (two different treatment providers at separate locations use separate treatment plans to treat each condition separately but at the same time). Sequential or parallel

parallel treatment frequently results in clinical failure. Clinical failure often leads to homelessness or involvement with the criminal justice system.

It is critical that clinical guidelines, policies, and procedures of managed care organizations be designed to provide the best treatment available for persons with co-occurring mental illnesses and addictive disorders. This goal can be extremely difficult to attain in states that exclude substance abuse services from their Medicaid managed behav-

ioral health programs so that mental health care services and substance abuse services are not managed by the same system.

Without proper coordination, consumers with co-occurring disorders are left to navigate the system, putting them at real risk of harm when they are in crisis or in need of emergency services.

Consumer, Family, and Stakeholder Involvement in Care and Treatment

Consumers and family members must be involved in developing and implementing treatment plans and ensuring that a wide array of services are available to persons with serious mental illnesses.

Managed care systems should develop policies and procedures that offer consumers with serious mental illnesses the support network necessary for them to work toward recovery.

Empowering consumers by using effective community support programs and programs focused on rehabilitation and recovery, including programs for assertive community treatment (PACTs), results in consumers living healthier and more productive lives and leads to lower overall health care costs for the public and private managed care delivery systems. Simply put, consumers with serious mental illnesses who can access appropriate community services and be involved in treatment planning have an increased chance of recovery and a reduced dependence on high-cost services.

An effective system will combine traditional clinically based services with psychiatric rehabilitation, ACT programs, clubhouses, and consumer-run and consumer-focused programs. Also, an effective managed care system must have intensive and active facility discharge planning that is directly linked to the community to which the consumer is returning.

Stakeholder Involvement

Consumers and family members should be involved in all phases of the development of the RFP for the Medicaid managed care contract, the awarding of the contract, and the evaluation and implementation of the contract and should participate on advisory boards during the term of the contract.

Medicaid managed care plans should be encouraged to accept input from mental health providers during all phases of the contract and should update clinical criteria annually because of improvements in medical practice and/or input received from the clinical community.

Managed care plans should offer advocacy groups the opportunity to provide feedback on their policies and procedures on enrollee care.

Monitoring Performance

Family members and consumers should advocate for the following in monitoring the performance of managed care organizations:

- ❖ Consumer satisfaction teams (CSTs) are a critical component of any health care delivery system serving consumers with serious mental illnesses. CSTs involve the creation of an independent third-party monitoring team composed of consumers and family members to assess the satisfaction or dissatisfaction of enrollees with the MCO. States that have CSTs hired by the state to conduct site visits, interview consumers, and evaluate services include Alabama, Georgia, Massachusetts, Ohio, and Pennsylvania.
- ❖ The MCO must make a commitment to routinely meet with the consumer-family interview teams and to immediately work to correct identified problems.
- ❖ Any CST program should include the collection and aggregation of MCO and provider-specific data in the area of dissatisfaction, the documentation of health plan and provider responses to such dissatisfaction, and the public release of such information to help consumers make informed choices about their current or future enrollment in the managed care plan.
- ❖ If states are unwilling to provide CSTs, advocates should seek the commitment of MCOs to routinely meet with consumers and family members and to work to correct identified problems.
- ❖ Facility monitoring teams are also a critical component of every health care system. Facility monitoring teams are designed to improve the quality of care and reduce incidents of abuse and neglect in facilities that serve consumers with severe mental illnesses. The responsibilities of facility monitoring teams are similar to those of the CSTs. Facility monitoring teams operate in Delaware, Massachusetts, New Hampshire, Oklahoma, and Pennsylvania.

Ombudsperson Programs

These programs are designed to create an office, usually in state government, that assists consumers with questions and concerns related to their health plan. States are not required under federal law to include an ombudsperson program for Medicaid enrollees. However, several states have enacted laws covering private sector MCOs that provide ombudsperson programs, most often through the Department of Insurance or other executive agency responsible for regulating health and managed care plans. Advocates should press for the creation of these programs in the public and private sectors to help consumers navigate the managed care system and to enforce their right to health care treatment. Ombudsperson programs should recognize the importance of peer involvement and actively involve consumers in all aspects of the programs.

Coordination between State Agencies and Medicaid Managed Care Plans

Any public managed care program for persons with severe mental illnesses must have precise boundaries established between the Medicaid managed care entity and the public mental health systems—or no boundaries at all (i.e., consolidation). At a minimum, all consumers, families, and providers must know which agency is responsible for which services under which conditions.

If boundaries and responsibilities are not clear or if agencies remain fragmented structurally or functionally, consumers end up waiting for treatment, which results in serious harm to persons with serious mental illnesses.

As a fundamental rule, coordination must exist between the state Medicaid managed care plan and the state mental health agency, state psychiatric hospitals, the correctional system, and the court system.

Also, as a general matter, treatment plans should be required to invite consumer participation and coordinate care among mental health professionals and all other professionals involved in a consumer's care, as well as family members when appropriate.

Coordination of Care for Children

The coordination-of-benefits issue can be particularly pronounced for children with serious emotional disturbances when multiple state agencies, including mental health agencies, schools, child welfare agencies and the juvenile justice system, may be responsible for providing services.

It is critical that children and their families have one and only one integrated assessment and treatment plan and be able to access all necessary services from wherever they present in the system. The state Medicaid agency should be responsible for ensuring that the system operates in that fashion and should draft Medicaid plans accordingly.

Children and Adolescents

The Medicaid managed care contract should include distinct criteria for the treatment of children and adolescents, and clinicians should be required to have appropriate training and experience in treating this population.

A recent study conducted by the U.S. Department of Health and Human Services Office of the Inspector General entitled *Mandatory Managed Care Children's Access to Medicaid Mental Health Services* (see Resources section for full citation) found the following:

- ❖ Access to care for children with serious emotional disturbances is limited, and reductions of inpatient care for children are greater than for adults.

- ❖ Children's outpatient services lag behind those for adults, and Medicaid managed care contracts include limited provisions for children.

Advocates need to press hard for expanded and well-defined services for children in Medicaid managed care contracts. These services should include both the availability of inpatient and residential care, when necessary, and comprehensive community-based services.

Disenrollment of Members

Some state Medicaid managed care plans may permit the plan to disenroll individuals who do not accept or follow the treatment plan. This situation is especially problematic for persons with serious mental illnesses because the perceived noncompliant behavior may actually be a symptom of the mental illness.

Consumers and family members should advocate against inclusion of disenrollment provisions in Medicaid managed care contracts. However, if it appears that such a provision is inevitable, the following protections should be advocated for:

- ❖ Due process protections must be afforded to Medicaid enrollees. Due process protections consist of written notice of the alleged noncompliant behavior and the opportunity for an enrollee to be heard. If the enrollee is too severely disabled to exercise due process rights, efforts must be made to inform the enrollee's family or others (with the approval of the enrollee or consumer) who can advocate on his or her behalf.
- ❖ There should be a requirement that MCOs must show a pervasive pattern of noncompliant behavior before any action is taken so that they are not permitted to disenroll individuals because of a single occurrence.
- ❖ There should be a requirement that MCOs must show that attempts made to address the problems (e.g., changing health care providers and/or the treatment plan) were unsuccessful and that may have led to the noncompliant behavior.
- ❖ Case managers should work with providers and the consumer to develop a written treatment agreement for the consumer to sign. Consumer involvement and agreement with the treatment plan may result in a higher incidence of consumer adherence to the plan.
- ❖ Every effort should be made to link consumers with alternative services and/or a change in health care providers or treatment plan before a consumer is disenrolled.

Other Important Advocacy Issues

Collective and Group Advocacy

Consumer and family advocates can often accomplish more through group advocacy than they can alone.

This was illustrated several years ago in Rhode Island when advocates came together to file a complaint with the state's Health Department against a private, for-profit MBHO with a pattern of inappropriately limiting or denying care for consumers with serious brain disorders. A thorough investigation by the Health Department resulted in the imposition of severe sanctions against the company and, eventually, in positive changes in the company's practices.

Consumer and family advocates should familiarize themselves with state and local agencies entrusted with responsibility for investigating consumer complaints about health care services and with the procedures for filing complaints. They should also participate in consumer and family advocacy organizations and protection and advocacy groups.

Disclosure of Information

Consumers and family members should advocate for meaningful participation in the development and review of materials distributed to plan participants. Consumer input will ensure that MCO materials are understandable and beneficial to enrollees and their families. Managed care plan materials should be culturally sensitive and understandable to those who are not fluent in English.

Managed care organizations should provide consumer advisory boards, representatives, or ombudspersons to assist consumers, especially those whose illnesses prevent them from understanding the materials presented, in understanding their options for care under the plans.

Consumers and family members should advocate for MCOs to be required to disclose, at a minimum, the following information:

- ❖ Health care provider identity, locations, qualifications, and availability, including a list of participating pharmacies;
- ❖ List of treatment settings covered (e.g., inpatient, outpatient community, and residential);
- ❖ Enrollee rights and responsibilities (e.g., the right to timely notice, the right to change treatment providers, and the MCO's responsibility to attempt to work with treatment providers to develop a treatment plan and/or to work to alter the plan to make it more appropriate for the consumer);
- ❖ Scope of covered mental health and addictive disorder services;

- ❖ Procedures for obtaining out-of-network care and obtaining referrals from gatekeepers to specialists;
- ❖ Definition of “medical necessity” and clinical guidelines used by the MCO and adhered to by the MCO’s treating providers;
- ❖ Description of the MCO’s confidentiality policy, including the right of consumers and family members, with consumer approval and consent, to access (and, when necessary, copy) treatment information;
- ❖ Copy of the MCO’s drug formulary;
- ❖ Procedure for substituting generic or other prescription medications and for enrollees to obtain nonformulary medications;
- ❖ The circumstances under which the plan will cover care provided in emergencies, including care sought in an emergency room (emergency care requirements) and requirements related to receiving authorization for treatment before the treatment is provided (prior authorization requirements);
- ❖ After-hours care (should be 24 hours a day, seven days a week);
- ❖ Internal and external grievance and appeal procedures, including notice and timeline requirements and the availability of MCO assistance to understand the process;
- ❖ Detailed explanation of all out-of-pocket expenses, including copayments, deductibles for services, and prescriptions; and
- ❖ Right to administrative assistance with paperwork and claims questions, including the assignment of an account manager.

Access and Adequacy of Provider Networks

Consumers and advocates should advocate for the following protections related to access to and adequacy of providers and/or should review their existing Medicaid managed care contracts to determine whether the following protections exist:

- ❖ Patient/provider ratio should be adequate so that consumers are not forced to wait unreasonably long for an appointment.
- ❖ Geographic location of providers (particularly in rural areas) should be in close proximity to population served.
- ❖ The provider network should have an adequate number of mental health and addictive disorder specialists, and Medicaid contracts should ideally include an “any willing provider” provision.
- ❖ Services should be culturally sensitive and reflect the culture and ethnicity of the persons being served.

MCO contracts should address the needs of diverse populations, including cultural and linguistic competency in the delivery of health

care services and the provision of treatment modalities that are culturally acceptable to consumers.

Mental health providers must be available 24 hours a day, seven days a week, especially for emergency and crisis interventions.

In some states, Medicaid managed care contracts do not yet cover rural areas. Instead, the state Medicaid agency covers health care costs on a fee-for-service basis, and the biggest challenge is finding qualified mental health professionals to serve the rural population. The problem of a lack of mental health providers is exacerbated by the low provider reimbursement rate for Medicaid services.

Financial Incentives

State Medicaid agencies and HCFA should prohibit MCOs from including any financial provisions in provider contracts that encourage providers to limit or deny appropriate and necessary care.

Moreover, managed care organizations should be required to disclose all financial incentives in provider contracts so that consumers and family members are aware of the arrangements and can determine the likelihood that the MCO provider incentives may interfere with the provider's judgment in recommending or not recommending care and treatment.

MCO performance must be documented, publicly available, explicit and detailed, benchmarked, standardized, and independently validated by an accrediting organization.

Performance

It is critical that MCOs participating in Medicaid be held accountable for their performance and outcomes. MCO performance must be documented, publicly available, explicit and detailed, benchmarked, standardized, and independently validated by an accrediting organization.

The National Committee on Quality Assurance (NCQA) currently accredits MCOs and MBHOs. NCQA states that it developed accreditation standards to assess and differentiate MCOs. The accreditation standards measure elements of MCO and

MBHO operations, such as quality management and improvement; accessibility, availability, referral, and triage; utilization management; and clinical evaluation and treatment records. There has been considerable debate about whether NCQA has set the performance bar high enough for the managed care industry; however, at this time NCQA is the primary accrediting organization for the managed care industry.

The Colorado Medicaid program, Colorado Health Networks, has done an outstanding job of documenting its program's performance by developing self-help groups and drop-in centers and by publicly documenting average time for first appointments, penetration rates

(showing the number of beneficiaries receiving treatment in the program), hospital readmission rates, average hospital length of stay, length of waiting list, mental health and physical health follow-up services after inpatient discharge, and involvement of family and guardians in discharge planning.

Consumers have made clear that they want plan-by-plan comparisons of MCOs using performance data. Consumers and advocates should request surveys and data collection based on diagnosis because of the unique requirements of individuals with serious mental illnesses as opposed to individuals who do not suffer from such illnesses or who are less sick.

Outcome Measures

Ideally, state Medicaid managed care systems should contract with independent third-party evaluators at the beginning of a managed care contract and continue to use the independent evaluators to evaluate managed care plan performance throughout the term of the Medicaid contract.

Outcome measures should include scientifically sound and person-centered measures of the following:

- ❖ clinical status
- ❖ general health status
- ❖ functioning
- ❖ housing status
- ❖ employment status
- ❖ education status
- ❖ treatment participation status
- ❖ addictive disorders
- ❖ treatment side effects
- ❖ suicide rates
- ❖ involvement with the criminal justice system
- ❖ subjective measures of consumer satisfaction of consumers and family members

Outcome measurement should be based on information from consumers, family members, and health care providers. The methods used to measure outcomes should ensure that people with serious brain disorders are targeted. Data from outcome measurement should be used to improve managed care and provider performance.¹⁷

¹⁷ *Stand and Deliver: Action Call to a Failing Industry*, The NAMI Managed Care Report Card (September 1997): 15–16.

Performance and Quality

All state Medicaid managed care contracts require MCOs to maintain an internal quality assurance (QA) program. QA programs typically focus on elements of care including mental health care outcomes, the appropriate use of clinical guidelines, and quality indicators and analysis of clinical care.

Many state Medicaid managed care contracts require managed care plans to report data on outcome measures and other aspects of quality care. Family members and consumer advocates may request that the state provide a copy of the data reported by the Medicaid managed care plans if their state has such a requirement.

Advocates should request that independent mental health providers be involved in the development of MCO policies and procedures on quality and all other aspects of care and be involved in annual review of QA programs.

As described above, NCQA accredits both MCOs and MBHOs. NCQA is not a regulatory body and may not require MCOs to obtain accreditation. However, states may require MCOs to be accredited by NCQA to be eligible for a Medicaid contract.

Unfortunately, “NCQA is significantly deficient in monitoring how health plans meet the needs of persons with the most severe and persistent mental illness.”¹⁸ Despite NCQA’s weaknesses, all managed care plans should be required to report Health Plan Employer Data and Information Set (HEDIS), and all MBHOs should be required to receive NCQA MBHO accreditation. In the absence of adequate regulatory protections and accountable public systems of care, NCQA provides minimum public accountability for managed care systems.¹⁹

NCQA has developed accreditation standards that establish a minimum level of quality control over MCOs and providers. Consumers may obtain MCO accreditation status from NCQA. Unfortunately, NCQA’s governing board is dominated by private sector purchasers (employers) and commercial health plans, which most likely accounts for its modest standards and performance measures targeted to serious mental illness.²⁰ However, NCQA has made recent efforts to increase

¹⁸ Clarke Ross, *NCQA Guidelines Weak for Most Seriously Ill*, Behavioral Healthcare Tomorrow (Special Report: Quality & Accountability) (June 1999): 37.

¹⁹ HEDIS is a set of standardized performance measures developed by NCQA to ensure that purchasers of managed care services (such as state Medicaid offices) and consumers have information to compare the performance of MCOs. For more information on HEDIS, visit NCQA’s Web site at www.ncqa.org.

²⁰ Clarke Ross, “Managed Care: Is Your Health Plan Publicly Accountable or Merely a Free Ride?” *NAMI Advocate*, February/March 1999.

representation of consumers, family members, and providers on its committees and panels.²¹

Direct Access to Specialists

Managed care organizations often require enrollees to obtain a referral to a specialist from a primary care provider, which presents an unnecessary obstacle for persons with serious mental illnesses, particularly when urgent or emergency care is required.

Consumers and family members should advocate for self-referrals, which allow an MCO enrollee to gain direct access to a mental health specialist without prior authorization from a primary care provider or the health plan.

Continuity of Care

Family members and consumers should advocate for inclusion of a continuity of care provision in Medicaid managed care contracts. Such a provision requires MCOs to permit current and new enrollees to continue a course of care and treatment with a provider terminated (without cause) from the MCO provider network or to continue care with an out-of-network provider (for new enrollees) at no additional cost for a specified period, usually 90 days.

Continuity of care is uniquely important for Medicaid managed care contracts because the managed care vendor awarded the Medicaid contract may not have in its network the same providers who had previously served Medicaid consumers. These circumstances may present unique challenges for consumers with serious mental illnesses who may have established a long-term and trusted relationship with their health care provider. Continuity of care provisions also allow consumers to find appropriate new providers.

Point-of-Service Plan

Managed care plans, in both the private and public sector, attempt to contain health care delivery costs by establishing a network of providers that enrollees must see for care and treatment. MCOs negotiate with these providers for a reduced fee for their services.

MCOs may have a short list of in-network providers who specialize in severe mental illnesses. Because MCOs have reduced-fee arrangements with in-network providers, they do not want plan participants to see out-of-network providers. Consequently, MCOs place financial restrictions on consumers' right to see out-of-network providers.

This type of restriction presents difficulties for consumers with severe mental illnesses, who may wish to continue a long-standing

²¹ Id.

treatment relationship with a trusted provider or may prefer a provider who is not part of the network. For these reasons, it is important that states require MCOs to provide consumers with a broad choice of providers through a point-of-service plan, which allows enrollees to go out of network for services.

Several states have enacted legislation that requires private sector MCOs to provide a point-of-service plan to enrollees. However, the laws may permit MCOs to charge a higher premium or increased out-of-pocket costs for the POS plan.

Despite its desirability for the reasons stated above, the point-of-service plan presents a dilemma for Medicaid recipients and low-income individuals with serious mental illnesses who cannot afford to pay higher costs for out-of-network providers. Their economic status may prevent them from seeking treatment from out-of-network providers and thereby reaping the benefits of a point-of-service plan.

Standing Referrals

Managed care tends to require enrollees to obtain referrals to specialists from either their primary care physician or the plan itself. MCOs may also require enrollees' primary care providers to coordinate the enrollees' care, including a requirement that the specialist provider obtain prior approval for services from the primary care physician before making secondary referrals.

This type of restriction in a managed care contract presents an unnecessary burden to people with serious mental illnesses who may require regular care from a specialist. Consumers and family members should therefore advocate for a standing referral provision in managed care contracts that would prohibit managed care plans from requiring consumers to obtain a referral from either a primary care physician or the health plan for the coverage of services provided by a mental health specialist. In essence, consumers should advocate for specialty providers to be the gatekeepers of services.

Summary: Advocacy in the Public Sector

Obtain and review the following Medicaid-related documents:

- ❖ RFIs provided by the state to MCOs
- ❖ RFPs provided by the state to MCOs
- ❖ Medicaid contracts available from states and counties
- ❖ Document with MCO's operational definition of medical necessity
- ❖ MCO's utilization review guidelines
- ❖ MCO's practice guidelines
- ❖ MCO's provider reimbursement scheme

- ❖ MCO's and/or state's internal and/or independent external review and clinical review process

Provide input to the state on the Medicaid managed care contract by participating in the following:

- ❖ State Medicaid agencies must establish medical care advisory committees. These committees must include consumers, and state Medicaid agencies must consult with the committees on policy decisions.
- ❖ State Medicaid law may provide an opportunity for public input. Advocates should familiarize themselves with state Medicaid law. Also, state and federal procurement laws require states to be even-handed in awarding Medicaid managed care contracts and may provide an opportunity for public involvement in the awarding of Medicaid managed care contracts.

Advocate for a health care delivery system that best serves people with severe mental illnesses by addressing the following factors:

Critical Advocacy Issues

- ❖ Medical necessity is a critical issue that dictates whether people with severe mental illnesses receive gravely needed and appropriate services. All too often, MCOs use medical necessity criteria to limit or deny services.
- ❖ Regarding grievance procedures (internal and external appeals), federal Medicaid law requires state Medicaid managed care contracts to provide an internal appeal. Unfortunately, the law does not require an independent external appeal, which is needed because the internal process is conducted by the MCO, often resulting in a rubber stamping of the initial decision to deny or limit services.
- ❖ Some state Medicaid agencies and their managed care agents are considering or taking steps to restrict access to newer and often far more effective antipsychotic and antidepressant medications. This practice must be stopped.
- ❖ Advocates must push for adequate funding for the Medicaid program to ensure enrollee access to the full array of medically appropriate and effective services.
- ❖ Medicaid managed care contracts must include the full continuum of care required by people with severe mental illnesses, in the appropriate settings.
- ❖ Medicaid managed care contracts must include provisions that allow for the delivery of services for mental illnesses and addictive disorders simultaneously, at the same treatment site, and by cross-trained staff.

- ❖ There must be consumer and stakeholder involvement in care and treatment.
- ❖ State agencies and Medicaid managed care plans must coordinate the services provided to people with severe mental illnesses.
- ❖ Medicaid managed care contracts must address the unique service needs of children and adolescents.
- ❖ Safeguards must be in place to prevent Medicaid managed care plans from disenrolling people with severe mental illnesses on the basis of the symptoms of their illnesses or their willingness to accept a treatment plan.

Other Important Advocacy Issues

- ❖ Consumers, family members, and stakeholders must work together in collective and group advocacy to address managed care practices that are harmful to people with severe mental illnesses.
- ❖ Managed care organizations must fully disclose plan information to consumers and advocates. Also, MCOs should provide consumers and advocates with meaningful involvement in the preparation and dissemination of plan information.
- ❖ Managed care organizations should provide consumers with appropriate access to treatment and services and should maintain an adequate provider network.
- ❖ Financial incentives that encourage health care providers to limit or deny necessary and appropriate care should be banned.
- ❖ MCOs should be held accountable for their performance through outcome measures, accreditation, and meaningful quality assurance programs.
- ❖ Consumers with severe mental illnesses should have direct access to specialists without having to obtain a referral from a primary care provider.
- ❖ Medicaid managed care contracts should include a continuity of care provision that allows consumers to continue for a reasonable period of time with a treating provider if the provider is terminated (without cause), when consumers enroll in the plan and the provider is not in the managed care network, and when the state changes managed care contractors.
- ❖ Medicaid managed care contracts should include a POS option that allows consumers to see providers outside the MCO network.
- ❖ Medicaid managed care contracts should allow enrollees with severe mental illnesses to maintain a standing referral to their treating mental health provider without requiring a referral from their primary care physician.

Legal Rights in Private Sector Managed Care

Consumer Grievance Rights in MCOs Operating in the Private Sector

Consumers should become familiar with the managed care system's internal grievance and external appeals procedures.

States require managed care organizations operating in the private sector to have an internal grievance process. Thirty-six states and the District of Columbia require health plans to participate in independent external review, usually available to consumers when they have exhausted the plan's internal grievance process.

Also, in the private health care system, NCQA has established standards for accreditation of managed care organizations and managed behavioral health care organizations. NCQA is not a regulatory body and may not require MCOs to seek and obtain accreditation. However, the health care market dynamics are such that health plans must receive NCQA accreditation in order to remain competitive with those that have been accredited. *The NCQA MCO and MBHO standards stipulate that MCOs should have a formal grievance procedure and that consumers should have the right to an independent clinical review of denial of care decisions.*

Consumers and family members should consider the following issues when filing a grievance and/or appeal:

- ❖ What are the timelines for conducting the review and issuing decisions? These vary widely, with some states allowing managed care organizations to impose very short timelines within which consumers may file a grievance or appeal. The timelines typically run from the time that the notice of denial of care is issued. Several state independent external review laws require managed care plans to have an emergency appeal process that concludes within a given period, ideally in less than 72 hours.
- ❖ Is your issue one that may be reviewed and/or appealed? There is usually little doubt if it is a denial of care decision. However, some states restrict issues that may be reviewed to those involving medical necessity.
- ❖ Who is responsible for conducting the review and issuing a decision? Are clinicians involved, and are they qualified to render care decisions for someone with a severe mental illness? Ideally, clinicians should be independent of the MCO. Decisions should be based on the medical record of the person appealing, provider's

recommendations, consulting reports from health care professionals, the health plan's terms of coverage, the plan's clinical review guidelines, and other pertinent information provided by consumers and their families.

- ❖ Are there monetary considerations associated with the independent external review (i.e., a filing fee associated with pursuing an independent external appeal)? Several states permit MCOs to charge a nominal filing fee (\$25 to \$50). Ideally, filing fees should be waived for individuals who cannot afford to pay them.
- ❖ Is there a requirement that the amount in controversy meet a minimum threshold (sometimes \$500)?
- ❖ Who is responsible for paying for the review? In most cases it will either be the MCO or an agency in the state government. Consumers should not encounter any monetary considerations associated with an internal grievance.
- ❖ What is the procedure for hearing complaints? Does the MCO use an in-person appeal process or does it review the appeal on paper? Whenever possible, you should present your complaint in person.
- ❖ What documentation, if any, are you responsible for providing?
- ❖ What procedure will the MCO use in issuing its decision? You should always ask for the MCO's decision in writing with a detailed explanation of the reasons for the decision.

Grievance and appeals mechanisms may also be available through other state agencies, such as the Department of Health, Department of Insurance, or Department of Consumer Affairs.

Other Action Short of Litigation

If you believe that you have been wronged by a managed care plan in violation of state law, you may wish to contact the state agency with monitoring and oversight responsibility for managed care plans, most often the Department of Insurance or the Department of Health. Not all states take action against managed care organizations for oppressive practices that unfairly deny covered services. Recently, however, states have appeared more willing to take action in light of evidence that some managed care practices have and will continue to harm health care consumers.

Most states issue licenses to MCOs to conduct business within the state. Such a license is often conditioned on the MCOs' complying with the state's consumer protection laws. States have shown a willingness to impose fines and/or penalties on managed care plans that fail to comply with the state laws and regulations designed to protect consumers.

Commencing a Legal Action

While filing a lawsuit is always an action of last resort, requiring investment of time and resources on the part of consumers, it may be the only option when other methods for obtaining redress have failed. Despite the fact that many states have enacted consumer protection laws, a federal law—the Employee Retirement Income Security Act (ERISA)—may preempt enforcement of those laws against large self-insured employers and may also preempt commencement of a lawsuit based on a state law claim.

ERISA

Background

In 1974, the federal government enacted ERISA to establish the regulation of employee benefit plans as an exclusively federal concern and to ensure that health plans would be subject to a uniform body of federal benefits laws to minimize the burden to health plans of complying with conflicting state and federal laws and regulations.

Preemption

ERISA is a federal law that preempts state laws and regulations that “relate to any employee benefit plan.” The type of claims that are preempted by ERISA are those that seek relief for the denial of plan benefits.²² Employers that self-insure (use their own funds to cover employee health claims) are often exempt from complying with state negligence, contract, and consumer protection laws through the ERISA preemption. Instead of being subject to state law claims and regulation, these employers and insurance plans are regulated under ERISA (which applies only to managed care systems through private, self-insured plans, and does not apply to Medicaid or other public sector managed care systems).

²² The U.S. Supreme Court recently decided an important ERISA case that is not a preemption case but that indirectly addressed ERISA preemption in a significant way. In *Pegram v. Herdrich*, 120 S.Ct. 2143 (June 12, 2000), the Court discussed the difference between pure eligibility/coverage decisions made by health plans (which fall squarely within the ERISA preemption) and treatment/medical necessity decisions. The Court suggested that medical necessity determinations do not amount to MCO representatives acting as a fiduciary, in which case those determinations would not be subject to state law preemption. The analysis by the Supreme Court signals the end of ERISA preemption for state law claims focused on managed care medical necessity determinations. (George Parker Young, “ERISA Preemption of HMO Lawsuits: New Case Law,” *BNA’s Health Plan & Provider Report*, 6 (32): 979–991.)

The reality and frustration of ERISA is that consumers' state law claims are preempted by the broad sweep of ERISA, consumers are denied meaningful legal redress, and MCOs are protected from liability for their misdeeds. While the U.S. Supreme Court and some federal circuit courts have narrowed the ERISA preemption, ERISA remains an obstacle to consumers pursuing state law claims against managed care organizations. The fate of the ERISA preemption may lie in the legislative process.

The reality and frustration of ERISA is that consumers' state law claims are preempted by the broad sweep of ERISA, consumers are denied meaningful legal redress, and MCOs are protected from liability for their misdeeds.

There is a great need for the U.S. Congress to amend ERISA to account for the changing realities of the managed care delivery system. Recently, a number of bills have been introduced in the U.S. Congress that would limit the exemption of ERISA plans from state laws that regulate insurance and other causes of action. However, these bills are opposed by the insurance and business lobbies.

Federal Law ERISA Actions

ERISA provides limited federal law rights and remedies for consumers who believe that they have been denied benefits due them.

A federal ERISA lawsuit may be brought against managed care organization representatives on the grounds that they have breached their fiduciary duty to act solely in the interest of managed care plan participants and beneficiaries.²³ In essence, MCO representatives are the fiduciaries entrusted with the duty of administering the health plan and must act in the best interests of beneficiaries.

It is possible to sue an employer and/or health plan administrator under ERISA for failure to provide a full and fair review of a decision to deny a health care coverage claim. ERISA plan participants are also entitled to sue ERISA plans to recover the cost of the denied benefit under the terms of the plan, to enforce rights under the terms of the plan, or to clarify rights to future benefits under the terms of the plan.

The ERISA laws and regulations give the courts discretion to award attorney fees and costs to either party in an action brought to enforce the ERISA laws.

The ERISA regulations require ERISA plans to notify plan participants of coverage decisions within a reasonable period. Furthermore, ERISA plans must provide every claimant who is denied a claim for benefits written notice of the decision, including (i) the specific reason or reasons for the denial; (ii) specific reference to pertinent plan provisions on which the denial is based; (iii) a description of any additional material or information necessary for the claimant to perfect the claim

²³ 29 U.S.C. Section 1109(a)(1).

and an explanation of why such material or information is necessary; and (iv) appropriate information concerning the steps that may be taken if the participant wishes to submit the claim for review.

ERISA plans also are required to establish and maintain a procedure that allows claimants an opportunity to appeal a denied claim.

New ERISA Regulations

On November 21, 2000, the U.S. Department of Labor released regulations that simplify and improve the claims and appeals processes for people in employer-based self-insured health plans (including managed care plans). The new rules, which are effective January 2002, are the first change to the ERISA claims and appeals process since its enactment in 1974. They give private sector employees the right to have their claims resolved more quickly and provide more time to appeal a decision to deny health care insurance coverage. The changes are meant to address enrollee concerns that they have sometimes been forced to wait months for approval of medical procedures and are frustrated by the appeals process.

The new rules require health plans to make treatment coverage decisions within 72 hours for initial or preservice urgent care claims. Nonurgent preservice claims must be resolved within 15 days and postservice claims within 30 days. Health plans, including managed care plans, are permitted one 15-day extension for pre- and postservice claims.

The new regulations require nonurgent and preservice appeals to be resolved within 30 days and postservice appeals within 60 days. Urgent care appeals must be resolved within three days. The regulations also extend the previous 60-day window for health care consumers to appeal a denied claim to 180 days. The regulations address several other aspects of claims processing and appeals that are designed to protect and benefit consumers.²⁴

Consumers may commence a legal action against managed care plans that are not exempted from state laws by ERISA using the following legal theories:

Negligence Lawsuits

If you believe that you or someone you care about has been harmed owing to lack of treatment or inappropriate treatment by a managed care organization, you may be able to file a negligence lawsuit against that MCO. Traditionally, negligence lawsuits have been available only to remedy inappropriate care by physicians. However, state legislatures and courts increasingly recognize the rights of consumers to file

²⁴ The regulations were published in the *Federal Register*, 65 (225): 70245–70271 (November 21, 2000) and are available online at www.access.gpo.gov/su_docs/aces/aces140.html (search in Vol. 65, with the page numbers provided).

negligence lawsuits directly against managed care organizations when denials of care can be directly attributed to the MCO.

In addition, a handful of states have enacted legislation that opens the door to negligence/medical malpractice claims against MCOs. Texas enacted legislation in 1997 establishing the right of individuals to sue their health plans, including managed care organizations, for negligence.²⁵ Missouri took a slightly different approach by enacting a law that repeals a state statute that stated that managed care plans do not practice medicine, thereby opening the door to medical malpractice actions against MCOs. Many other states have introduced similar legislation that would allow consumers to sue their MCOs for medical malpractice.

In response to consumer demands for managed care reform, legislation has been introduced in the U.S. Congress that would allow consumers to sue managed care organizations for negligence. Despite the flurry of legislative activity, state legislatures and Congress appear reluctant to enact such legislation. The insurance and business lobbies have adamantly opposed such legislation, frequently citing the threat of runaway costs and fear that employers will refuse to provide health care insurance to their employees.

Lawyers who specialize in negligence and medical malpractice cases may be willing to accept cases on a contingency fee basis. This means that the lawyers are willing to represent individuals who are unable to pay hourly legal fees in return for receiving a percentage of the money awarded by the court as compensation for their services. However, since lawyers who accept contingency fee cases risk earning nothing if they lose these cases, they carefully evaluate all cases that come before them and generally accept only those cases they believe have strong chances of succeeding.

Confidentiality of Medical Information

There are a myriad of state and federal laws and regulations related to protecting the confidentiality of medical information.

The Health Privacy Project of the Institute for Health Care Research and Policy recently released a report on state laws pertaining

²⁵ Health insurers challenged Texas's health plan liability law by arguing that the state could not regulate ERISA plans under the liability law because of ERISA's general preemption clause, which preempts state insurance laws insofar as they relate to any employee benefit plan. On appeal, the court held that narrowly interpreted, the liability provisions are not preempted. *Corporate Health Insurance, Inc. v. The Texas Department of Insurance*, (5th Cir., June 20, 2000) (Case No. 98-20940). (George Parker Young, "ERISA Preemption of HMO Lawsuits: New Case Law.") The liability provisions are not preempted to the extent that they hold physicians accountable for medical decisions that may ultimately cause harm to plan participants; however, malpractice/liability lawsuits are preempted for coverage decisions made in the course of administering the plan.

to the confidentiality of medical information entitled *The State of Health Privacy: An Uneven Terrain/A Comprehensive Survey of State Health Privacy Statutes* (July 1999). The report can be accessed on the Health Privacy Project Web site, www.healthprivacy.org.

The report reveals the following concerning the legal remedies and penalties available to individuals:

Most state health privacy statutes contain some form of remedies and penalties that are triggered by violations of the law. Commonly found are private right of action provisions granting people the ability to bring lawsuits when the statute has been violated, without first having to meet any additional standard of proof, i.e. that the violation was willful or intentional. It is enough that the law was violated. A full range of damages, remedies, and attorney's fees and costs are usually available, however, the monetary damages are often set quite low. In some cases, these statutory remedies may be construed as exclusive, thereby barring people from raising other [legal] claims....²⁶

State mental health privacy information laws are among the most detailed and complex. Currently, state laws written to protect individuals' privacy information in mental health records may include the following provisions:²⁷

- ❖ allow individuals the right to refuse to disclose and to prevent a mental health provider from disclosing confidential information acquired in the professional relationship;
- ❖ prohibit the use of identifying data in research studies;
- ❖ limit an individual's access to records by prohibiting the disclosure of psychotherapy notes;
- ❖ allow mental health professionals to provide a summary of the mental health record instead of the record itself;
- ❖ allow mental health providers the discretion to supply records to another authorized provider rather than the patient;
- ❖ allow family members, guardians, and caretakers access to mental health information; and
- ❖ allow law enforcement officers and other third parties to disclose mental health information when the provider determines that the person receiving treatment poses a danger to the community.

²⁶ Health Privacy Project, Institute for Health Care Research and Policy, Georgetown University, *The State of Health Privacy: An Uneven Terrain/A Comprehensive Survey of State Health Privacy Statutes*. Report accessed online at www.healthprivacy.org, August 21, 2000.

²⁷ *Id.*

New Federal Regulations Governing the Confidentiality of Medical Information

On December 20, 2000, President Clinton issued comprehensive rules governing the privacy of medical information.²⁸ The rules are intended to create a uniform national standard to replace the confusing patchwork of state laws and regulations addressing the confidentiality of medical information.

The Health Insurance Portability and Accountability Act, a federal law enacted in 1996, required that, if Congress failed to pass health privacy legislation by August 1999, then the U.S. Department of Health and Human Services (HHS) would be required to issue health privacy regulations. Congress failed to pass health privacy legislation by the deadline, so responsibility shifted to HHS.

The final rule applies broadly to paper records, electronic records, and oral communications between health care providers and health plans, including managed care plans. The following is a summary of several key provisions:

The rules are intended to create a uniform national standard to replace the confusing patchwork of state laws and regulations addressing the confidentiality of medical information.

❖ *Informed consent:* Health care providers must obtain informed consent from consumers before disclosing protected health information for purposes of treatment, payment, or health care operations. However, providers may condition the provision of treatment on consumers providing consent (except for psychotherapy notes; see discussion below).

- ❖ *Consumer access to records:* Individuals have the right to see and copy their health information. A limited exception applies when providers can show that such access would endanger the life or safety of an individual.
- ❖ *Family members/next of kin:* Medical information may be shared with next of kin without written consent unless the consumer expressly objects to the disclosure. Consumers must be given notice and the opportunity to refuse to disclose before the information is disclosed.
- ❖ *Psychotherapy notes:* The regulations provide added protections for medical information in psychotherapy notes. Consumer written authorization is required for disclosure, and health plans may not condition enrollment or benefit coverage on the consumer authorizing use or disclosure of psychotherapy notes.

²⁸ A copy of the federal health privacy regulations issued on December 20, 2000, is available at www.aspe.hhs.gov/admnsimp. Key provisions of the proposed regulations are also summarized at www.healthprivacy.org.

- ❖ *Notice:* Health plans and providers must provide written notice of consumers' medical privacy rights. Consumers must be advised of their right to inspect and copy their medical records and the need for authorization before any medical information may be disclosed.
- ❖ *State laws:* The federal regulations do not preempt or override stricter state laws that address the confidentiality of medical information. The federal regulations provide minimal requirements, and states are free to enact stricter laws to protect the privacy rights of consumers.

Vicarious Liability

In simple terms, the legal theory behind vicarious liability is to hold a person or entity legally responsible for an act or omission if that person/entity had some authority or control over the activity or omission at issue. This situation often arises in employment arrangements when an employer is sued for the actions of an employee over whom the employer had some authority or control.

In the context of managed care, consumers may have a legal cause of action against MCOs under a vicarious liability theory for the negligence or other misdeeds of their network providers.

Breach of Contract Lawsuits

A managed care organization that fails to perform its responsibilities under a contract may be sued for breach of contract. If a court determines that the managed care organization has breached its contract, it may force the MCO to carry out its responsibilities under the contract or it may require the MCO to pay damages to remedy harm that has occurred. Courts tend to limit these remedies to those who are considered "parties" to the contract.

In managed care, the parties to the contract are typically MCOs and states (for Medicaid coverage) or MCOs and employers (for private coverage). Therefore, while consumers are most directly affected by inappropriate managed care practices, they are seldom able to file breach of contract lawsuits.

However, some courts may recognize consumers as "third-party beneficiaries" in managed care contracts. If so, consumers may be able to file breach of contract lawsuits against managed care organizations. To determine if this option is available, consult an attorney concerning the status of the law in your local jurisdiction.

Americans with Disabilities Act

The ADA is a federal law and therefore is not subject to the ERISA preemption. The ADA prohibits discrimination against persons with disabilities, including mental disabilities, in a wide range of public and private activities.

For the most part, courts have been conservative in their interpretations of the ADA, particularly in cases involving persons with serious

mental illnesses. Consequently, little case law has emerged that is helpful in the managed care context. However, this may change as the case law continues to evolve. Therefore, you should initiate contacts with legal advocates specializing in disability rights in your state to monitor the development of the ADA as a tool for advocating for the rights of consumers in managed care systems.

In 1999, the U.S. Supreme Court issued an important ADA decision in *Olmstead v. L.C.*, which affects state Medicaid programs and other programs operated by state public health agencies. In *Olmstead*, the Court decided that the ADA's prohibition against discrimination *may* require states to place persons with mental disabilities in community settings rather than in institutions. The operative word is "may," and in its decision, the Court described conditions for the requirement of community placement. The case makes clear that states have the responsibility, under their Medicaid programs, to periodically review the services of their residents in Medicaid-funded institutional settings. This responsibility includes the requirement that states respond to institutionalized individuals who request a review of their institutionalization to determine if a community setting is appropriate.

HCFA issued a letter on January 14, 2000, to state Medicaid directors recommending that states involve consumers and family members in the design, development, and implementation of their working plans for meeting the dictates of the *Olmstead* case. Therefore, consumers and family members should contact their state Medicaid office and inquire about the development of an *Olmstead* community placement plan and request involvement in developing and implementing the plan.

HCFA has developed a Web site dedicated to the *Olmstead* decision, www.hcfa.gov/medicaid/olmstead/olmshome.htm.

Title II of the ADA prohibits discrimination on the basis of disability in the services, programs, or activities of all state and local governments. Therefore, state Medicaid agencies and their managed care contractors are prohibited from discriminating in the administration and operation of the Medicaid program.

An ADA case is currently scheduled to be heard by the U.S. Supreme Court, challenging the constitutionality of the ADA as it applies to state government. If the Court decides that the ADA is unconstitutional as it relates to state programs, then the preceding discussion as it relates to state Medicaid programs may no longer be relevant.

Class Actions

Traditionally, class action lawsuits have been effectively used to institute broad changes in systems of care having a negative impact on the lives of persons with serious brain disorders. However, class actions are expensive, can be extremely complex to administer, and frequently last for years. Statutory restrictions and funding cutbacks further

limit the ability of public interest legal services organizations to initiate class action lawsuits. Nevertheless, filing a class action lawsuit may be an option to address widespread systemic abuses or neglect by managed care organizations.

If you believe that a managed care organization engages in a widespread pattern of discrimination against large numbers of people with severe mental illnesses, you should contact either a legal services organization or protection and advocacy organization in your state to consider a possible class action.

Attorney Referrals

If you are interested in proceeding with a legal action and want to obtain a referral to an attorney, please contact the NAMI legal department. NAMI maintains a list of attorneys interested in providing legal services in several different areas of the law. (To learn more about the NAMI Lawyer Referral Panel, visit the NAMI Web site at www.nami.org.)

Potential Administrative Burdens in the Managed Care System

Consumers who have used a high volume of services in the managed care system, particularly over a short period, have undoubtedly been deluged with claims paperwork. This is especially true for consumers who receive inpatient and/or residential care and treatment, which frequently involves contact with many mental health providers.

This deluge of paperwork can be daunting even at the best of times. It becomes extremely difficult to keep up with when consumers and family members are focusing their time and energy on recovery and providing support.

The managed care system is not likely to be sympathetic to the realities of caring for oneself or a family member with a severe mental illness. Consumers and family members often find that they have a mountain of paperwork that needs to be addressed and they cannot make heads or tails of the pile. There are multiple claims from multiple providers and sometimes duplicate bills for the same dates that do not contain the same information.

The best defense against this problem is a good offense. The following suggestions may help to address the problem:

- ❖ *Keep a log:* The log should list the dates of service and all health care providers seen on those dates. In this way, when you receive the MCO's explanation of benefits (EOB) form, you can match the information against your log. Update the log as the care is provided, because it may be difficult to go back and recall or recreate the information.
- ❖ *Request an audit:* If your log or health care records do not agree with the MCO's EOB, call the MCO's customer service department

and request assistance. Unfortunately, customer service representatives are not always helpful and may not provide adequate assistance or may not have the patience to work with you to resolve multiple claims. If there are many EOBs that do not agree with your records, you may wish to request that the managed care plan conduct an audit and prepare a document for you that lists your claims history so that you can review all of the information yourself.

- ❖ *Request assignment of an account manager:* If customer service representatives do not provide adequate assistance or do not have the patience to work with you to resolve multiple claims, you may wish to request that the managed care organization assign an account manager to assist you in understanding the multiple pending claims. You should attempt to have your concerns addressed by a person at the highest managerial level within the customer service area, since that person will have the most authority to assign individual attention to resolving your concerns. With private sector health insurance provided through an employer, the best place to start is with the employer's human resources department. Your employer is paying the MCO to provide good-quality service, and your employer has purchasing leverage to demand assistance for its employees.

You may know more about the legal and regulatory requirements than your health plan.

Do not assume that your managed care organization understands and complies with state and federal laws. State and federal consumer protection laws regulating managed care organizations have evolved rapidly, and not all managed care organizations have kept pace with the laws in revising their policies and procedures. You may know more about the legal and regulatory requirements than your health plan.

Summary: Legal and Other Rights in the Private Sector

Consumers may take action against managed care organizations operating in the private sector in one or more of the following ways:

1. Participate in the grievance process. All managed care organizations operating in the private sector must provide an internal grievance process that allows consumers to appeal an adverse decision to deny or limit care and/or coverage. Also, many states require MCOs to participate in an independent external review. The independent external review process is always preferable to

the internal grievance process because it involves having an adverse decision reconsidered by an impartial third party.

2. Report MCO violations of state law and/or practices that may harm managed care consumers to the state agency that regulates the health insurance industry.
3. Commence a legal action against the managed care organization.

Potential barrier: ERISA preemption.

Potential causes of action for a lawsuit (which may or may not be preempted by the ERISA law):

- ❖ negligence and medical malpractice;
- ❖ breach of confidentiality of medical information;
- ❖ vicarious liability—holding MCOs accountable for the acts of network providers;
- ❖ breach of contract; and
- ❖ MCO violation of the Americans with Disabilities Act.

Consumers may also discover that there are administrative burdens associated with care provided in the managed care system. If consumers and/or family members are inundated with paperwork as a result of a high volume of services, they should consider taking the following steps to minimize the administrative burden:

- ❖ Keep a log of the dates of service and names of treating providers.
- ❖ Request that the MCO's customer service department conduct an audit of the services provided and provide all pertinent information in an organized manner.
- ❖ Request that the MCO assign an account manager to work directly with the consumer and/or family member to organize and make sense of the paperwork.

Advocacy in Private Sector Managed Care

Managed care in the private sector operates like managed care in the public sector, with the following two major differences:

- ❖ The public sector tends to attract the most seriously ill population because it pays for the widest array of services, and people who exhaust their private health care benefits are left with no choice but to seek services in the public sector.
- ❖ Unlike the private system with many payers (e.g., employers and full-service insurance organizations), the public system has a single payer, the state.

Despite those differences, many of the advocacy points and legal protections that pertain to consumers with serious mental illnesses are the same in both systems.

Just as there is variation from state to state in consumer protections for Medicaid recipients, there is considerable variation in consumer protection laws that apply to MCOs operating in the private sector.

The advocacy points below should be advanced with state legislators and state agencies responsible for regulating managed care organizations. The time is right because states are responding to consumer demands for managed care reform by introducing consumer protection legislation. Many states have recently enacted comprehensive consumer rights legislation.

Many of the issues below that pertain to managed care in the private sector require advocacy positions similar to those for MCOs participating in Medicaid. For that reason, only the topics that have significant differences are included below, and those that have similar advocacy positions are listed at the end of this section.

Grievance Procedures (Internal and External Appeals)

In the private sector, all 50 states and the District of Columbia have laws requiring managed care organizations to establish internal consumer grievance and appeals processes for decisions denying services and/or coverage of services.²⁹

²⁹ Health Policy Tracking Service, *Consumer Grievance Procedures: Internal and Independent Appeals*, Issue Brief (June 5, 2000).

In addition to the internal grievance requirements, 36 states and the District of Columbia require private health insurance plans, including managed care plans, to provide an independent external appeal to enrollees.³⁰ Some state laws require managed care enrollees to appeal their decision to the state Department of Insurance; others require enrollees to appeal adverse decisions to private organizations, commonly referred to as independent review organizations (IROs). To find out about your state's law and how it operates, contact the state agency that maintains regulatory authority over managed care plans, usually the Department of Insurance or Department of Health.

A handful of state laws place conditions on the opportunity for managed care consumers to use the independent review process, including Ohio (the cost of the service must exceed \$500), Oklahoma (the cost of the service must exceed \$1,000), Tennessee (proposed service would require the managed care plan to incur \$500 or more of expenditures to cover the service), and Virginia (the independent review requirement applies to adverse decisions for services costing more than \$300).

A common and continuing concern about the independent appeal process is that it fails to achieve its purpose of ensuring that consumers receive the care they are entitled to because the appeals process is unduly difficult and burdensome to use. The failure to provide a user-friendly system to appeal adverse treatment decisions presents an unnecessary challenge to most health care consumers. It presents an unreasonable obstacle to consumers with severe mental illnesses, who are most likely attempting to access care at a time when services are critically needed and symptoms prevent them from navigating complicated procedures.

³⁰ Id. The states that require health plans to establish or participate in an independent external appeal process to provide enrollees who have exhausted internal appeal processes with an independent appeal process, either through regulation laws, are Alaska, Arizona, California, Colorado, Connecticut, Delaware, the District of Columbia, Florida, Georgia, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Missouri, Montana, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Utah, Vermont, Virginia, Washington, and Wisconsin. Texas had enacted a law requiring health plans to participate in an independent external appeal process. However, the U.S. Court of Appeals for the Fifth Circuit held that law's provisions pertaining to the independent external appeal are preempted by ERISA. *Corporate Health Ins. Inc. v. Texas Department of Insurance*, (5th Cir., June 20, 2000) (Case No. 98-20940) (petition for rehearing en banc. denied, July 20, 2000). The state of Texas may request the U.S. Supreme Court to review and reverse the judgment of the U.S. Court of Appeals for the Fifth Circuit. The impact of the *Corporate Health Ins.* case is significant because 36 states and the District of Columbia have independent review laws similar to the Texas law.

Advocates should focus on requiring MCOs to make the external independent review process easy to navigate. This must include eliminating the need for consumers to pay even a nominal fee for appeals. There also should be a prohibition against strict timelines for appeals that may prove unrealistic for consumers with severe mental illnesses who are in crisis.

Many of the advocacy points included in the Medicaid section above also apply to the private sector.

In both Medicaid and private managed care systems, laws that require MCOs to provide an independent external review procedure should include a provision that establishes an agency within the state government that must assist consumers with filing complaints and understanding the internal and external grievance processes.

Drug Formulary/Drug Coverage

In private sector managed care systems, states have been very active in legislating on the issue of drug formularies and drug coverage.

At the end of 1999, 34 states had laws requiring MCOs to disclose either the drugs in their formulary, the procedures for obtaining drugs excluded from the formulary, or both.³¹

Therefore, you should ask whether your managed care plan uses a formulary and request a copy of the formulary list and the procedures to obtain coverage for medications that are not listed on the formulary. If the MCO refuses to disclose its drug formulary, contact the state Department of Insurance or other executive branch agency with oversight for health insurance plans.

³¹ According to an Issue Brief prepared by the Health Policy Tracking Service of the National Conference of State Legislatures (July 3, 2000), the 34 states with laws that require MCOs to either disclose the drugs in their formularies, the procedures for obtaining the drugs not included in the formulary, or both are Arizona (disclosure only), Arkansas (disclosure and procedures), California (disclosure and procedures), Colorado (disclosure), Connecticut (disclosure and procedures), Florida (disclosure), Georgia (disclosure and procedures), Idaho (disclosure), Illinois (disclosure), Indiana (disclosure and procedures), Iowa (disclosure), Kansas (disclosure), Kentucky (disclosure), Louisiana (disclosure and procedures), Maine (disclosure and procedures), Maryland (procedures), Michigan (disclosure and procedures), Missouri (disclosure and procedures), New Hampshire (disclosure and procedures), New Jersey (disclosure), New York (disclosure), North Carolina (disclosure and procedures), North Dakota (disclosure), Ohio (procedures), Oklahoma (procedures), Oregon (disclosure and procedures), Rhode Island (disclosure), South Dakota (disclosure and procedures), Texas (disclosure and procedures), Utah (disclosure), Vermont (disclosure and procedures), Virginia (disclosure and procedures), Washington (disclosure and procedures), and Wyoming (disclosure).

See also the advocacy points included above in the section on advocacy in public sector managed care.

Mental Health Parity

Thirty-two states and the federal government have enacted mental health parity laws.³² The state laws vary in scope, with the most comprehensive mandating health care coverage for mental illness on par with the coverage for other physical illnesses. This requires MCOs to provide equal terms and conditions for mental health benefits and benefits for all other illnesses. Some state parity laws require equal benefit coverage for mental health care and addictive disorders. Most are silent on requirements for co-occurring disorders.

The Federal Mental Health Parity Act is more limited in scope. It requires insurers to include the same annual and lifetime limits for mental health care coverage as exist for the coverage of all other illnesses. The federal law excludes addictive disorders from the parity requirement.

Although most of the state parity laws do not provide for a separate legal cause of action against MCOs that fail to comply with the parity laws, if you believe that MCOs are not operating in compliance with parity laws, you should notify the state agency that has authority to regulate the managed care system. Contact HCFA (for plans that are not self-funded and are therefore subject to state regulations) or the U.S. Department of Labor (for ERISA/self-funded plans) to report a managed care plan's failure to comply with the Federal Mental Health Parity Act.

³² The following 32 states have enacted mental health parity laws: Alabama (2000), Arkansas (1997), California (1999), Colorado (1997), Connecticut (1997, broadened in 1999), Delaware (1998), Georgia (1998), Hawaii (1999), Indiana (state employees only in 1997, broadened beyond state employees in 1999), Kentucky (2000), Louisiana (1999), Maine (1995), Maryland (1994), Massachusetts (2000), Minnesota (1995), Missouri (1997, broadened in 1999), Montana (1999), Nebraska (1999), Nevada (1999), New Hampshire (1994), New Jersey (1999), New Mexico (2000), North Carolina (state employees only 1991, broadened for state employees only in 1997), Oklahoma (1999), Pennsylvania (1998), Rhode Island (1994), South Carolina (state employees only in 2000), South Dakota (1998), Tennessee (1998), Texas (state employees only in 1991, broadened beyond state employees in 1997), Vermont (1997), and Virginia (1999). In addition to the states listed above, 15 states also enacted state "parity" laws that match the federal Mental Health Parity Act.

Emergency Care

In private sector managed care systems, many states have considered or passed legislation that prohibits managed care organizations from requiring prior authorization for emergency services and requires managed care organizations to pay for emergency care using a “prudent layperson” standard. The “prudent layperson” standard is as follows:

A medical condition manifesting itself by acute symptoms of sufficient severity such that a prudent layperson, who possesses an average knowledge of health and medicine, could reasonably expect the absence of immediate medical attention to result in placing the health of an individual in serious jeopardy, serious impairment to bodily functions or serious dysfunction of a bodily organ.³³

The standard really boils down to requiring coverage for care when an individual’s symptoms reasonably indicate an emergency medical condition. Some of the state laws make clear that managed care plans must reimburse for emergency care services regardless of whether the care was received from in-network or out-of-network providers.

Many of the state laws prohibit managed care plans from denying coverage for emergency care when a prudent layperson, as defined above, would have believed that emergency care was necessary. However, several of the laws require consumers and/or their representatives to promptly notify managed care plans of the emergency care services after the consumer is stabilized.

Similar advocacy strategies apply to the following topics in the private sector, as discussed above in the section entitled Advocacy in Public Sector Managed Care:

Medical Necessity	Access and Adequacy of Provider Networks
Integrated Treatment Programs	Financial Incentives
Consumer, Family, and Stakeholder Involvement in Care and Treatment	Performance
Children and Adolescents	Direct Access to Specialists
Collective or Group Advocacy	Continuity of Care
Disclosure of Information	Point of Service Plan
	Standing Referrals

³³ Health Policy Tracking Service, *Emergency Care*, Issue Brief (April 3, 2000).

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Graham, Mary, and the National Mental Health Association. *Best (& Worst) Practices in Private Sector Managed Mental Healthcare Part III: Benefit Materials*. 2000. For more information on obtaining a copy of this publication, visit the NMHA Web site at www.nmha.org or contact Publications at 703-838-7534.

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Internet Resources

The following Web sites include information about managed care in the private and/or public sectors. Many also include links to other sites that may provide information on issues related to managed care.

Government

Center for Mental Health Services (CMHS): www.mentalhealth.org. CMHS is a component of SAMHSA and is responsible for leading the federal government's efforts to treat mental illnesses. The site includes a link to CMHS's Knowledge Exchange Network, which was developed for consumers, family members, and others to provide information on mental health.

Health Care Financing Administration (HCFA): www.hcfa.gov. HCFA is the federal agency that administers Medicaid.

Substance Abuse and Mental Health Services Administration (SAMHSA): www.samhsa.gov. SAMHSA is charged with improving the quality and availability of mental health services, substance abuse prevention, and addiction treatment.

Health Law

Bazon Center for Mental Health Law: www.bazon.org.

National Health Law Program: www.healthlaw.org.

Other Sites

American Managed Behavioral Health Care Association (AMBHA): www.ambha.org. AMBHA represents organizations in the managed behavioral health care industry.

Families USA: www.familiesusa.org.

Health Privacy Project, Institute for Health Care Research and Policy, Georgetown University: www.healthprivacy.org. Resource for information on the privacy of medical information.

Kaiser Family Foundation: www.kff.org.

National Association of State Mental Health Program Directors (NASMHPD): www.nasmhpd.org.

National Committee on Quality Assurance (NCQA): www.ncqa.org.

National Mental Health Association: www.nmha.org.

Treatment Advocacy Center: www.psychlaws.org.

Appendix A: State Protection and Advocacy Offices

CAP	Client Assistance Program
PADD	Protection and Advocacy for Developmental Disabilities
PAIMI	Protection and Advocacy for Individuals with Mental Illness
PAIR	Protection and Advocacy for Individual Rights

ALABAMA

CAP
State of Alabama Client Assistance Program
2125 East South Boulevard
Montgomery, AL 361116-2454
Phone: 334-281-2276 (Voice/TDD)
Email: sacap@hotmail.com
URL: sacap.homestead.com/sacap

PADD/PAIMI/PAIR
Alabama Disabilities Advocacy Program
The University of Alabama
Box 870395
Tuscaloosa, AL 35487-0395
Phone: 205-348-4928 (Voice);
205-348-9484 (TDD);
800-826-1675
Fax: 205-348-3909
Email: adap@law.ua.edu
URL: www.adap.net

ALASKA

CAP
ASIST
2900 Boniface Parkway, #100
Anchorage, AK 99504-3195
Phone: 907-333-2211
Fax: 907-333-1186
Email: akcap@alaska.com

PADD/PAIMI/PAIR
Disability Law Center of Alaska
3330 Arctic Boulevard, Suite 103
Anchorage, AK 99503
Phone: 907-565-1002 (Voice/TDD);
800-478-1234
Fax: 907-565-1000
Email: cklinger@dlcak.org
URL: www.dlcak.org

AMERICAN SAMOA

CAP/PADD/PAIMI/PAIR
Client Assistance Program and Protection & Advocacy
P. O. Box 3937
Pago Pago, AS 96799
Phone: 011-684-633-2441
Fax: 011-684-633-7286
Email: opad@samoatelco.com

ARIZONA

CAP/PADD/PAIMI/PAIR
Arizona Center for Disability Law
100 North Stone Avenue, Suite 305
Tucson, AZ 85701
Phone: 520-327-9547 (Voice/TDD)
Fax: 520-884-0992
Email: lcohen@acdcl.com
URL: www.acdcl.com

ARKANSAS

CAP/PADD/PAIMI/PAIR
Disability Rights Center, Inc.
Evergreen Place, Suite 201
1100 North University
Little Rock, AR 72207
Phone: 501-296-1775 (Voice/TDD);
800-482-1174
Fax: 501-296-1779
Email: panda@advocacyservices.org
URL: www.advocacyservices.org

CALIFORNIA

CAP
Client Assistance Program
2000 Evergreen Street, 2nd Floor
Sacramento, CA 95815
Phone: 916-263-7372; 800-952-5544
Fax: 916-263-7464
Email: smentkow@rehab.cahwnet.gov
URL: www.rehab.cahwnet.gov

PADD/PAIMI/PAIR
Protection & Advocacy, Inc.
100 Howe Avenue, Suite 185N
Sacramento, CA 95825
Phone: 916-488-9955 (Admin. Off.);
916-488-9950 (Legal Off.); 800-776-5746
Fax: 916-488-2635 or 916-488-9962
Email: legalmail@pai-ca.org
URL: www.pai-ca.org

COLORADO

CAP/PADD/PAIMI/PAIR
The Legal Center
455 Sherman Street, Suite 130
Denver, CO 80203
Phone: 303-722-0300 (Voice/TDD);
800-288-1376
Fax: 303-722-0720
Email: tlcmal@thelegalcenter.org
URL: www.thelegalcenter.org

CONNECTICUT

CAP/PADD/PAIMI/PAIR
Office of P&A for Persons with Disabilities
60B Weston Street
Hartford, CT 06120-1551
Phone: 860-297-4300; 860-566-2102 (TDD);
800-842-7303 (statewide)
Fax: 860-566-8714
Email: james.mcgaughey@po.state.ct.us
URL: www.state.ct.us/opapd

DELAWARE

CAP
Client Assistance Program
United Cerebral Palsy, Inc.
254 East Camden-Wyoming Avenue
Camden, DE 19934
Phone: 302-698-9336; 800-640-9336
Fax: 302-698-9338
Email: capucp@magpage.com

PADD/PAIMI/PAIR
Disabilities Law Program
913 Washington Street
Wilmington, DE 19801
Phone: 302-575-0660 (Voice/TDD)
Fax: 302-575-0840
Email: BJHartman@diamondnet.org

DISTRICT OF COLUMBIA

CAP/PADD/PAIMI/PAIR
University Legal Services
300 I Street NE, Suite 202
Washington, DC 20002
Phone: 202-547-0198
Fax: 202-547-2083
Email: jbrown@uls-dc.com
URL: www.dcpanda.org

FLORIDA

CAP/PADD/PAIMI/PAIR
Advocacy Ctr. for Persons with Disabilities
2671 Executive Center, Circle West
Webster Building, Suite 100
Tallahassee, FL 32301-5024
Phone: 850-488-9071; 800-342-0823;
800-346-4127 (TDD)
Fax: 850-488-8640
Email: g.blumenthal@advocacycenter.org
URL: www.advocacycenter.org

GEORGIA

CAP

Georgia CAP
123 North McDonough
Decatur, GA 30030
Phone: 404-373-3116
Fax: 404-373-4110
Email: GaCAPDirector@theOmbudsman.com
URL: www.theOmbudsman.com/CAP

Department of Human Resources
Division of Rehab. Service
2 Peachtree Street, NW, Room 23-307
Atlanta, GA 30303
Phone: 404-657-3003
Fax: 404-657-7855

PADD/PAIMI/PAIR
Georgia Advocacy Office, Inc.
100 Crescent Centre Parkway, Suite 520
Tucker, GA 30084
Phone: 404-885-1234 (Voice/TDD);
800-537-2329
Fax: 770-414-2948
Email: ringer@thegao.org
Email: info@thegao.org
URL: www.thegao.org

GUAM

CAP

Parent Agencies Network
2238 Route 16, Suite 1-B
J. Madarang Dental Building
Harmon, GU 96912
Phone: 011-671-637-4227
Fax: 011-671-637-4211
Email: capguam@ite.net

PADD/PAIMI/PAIR
Guam Legal Services
113 Bradley Place
Hagatha, GU 69610
Phone: 011-671-477-9811
Fax: 011-671-477-1320
Email: glsc@netpci.com

HAWAII

CAP/PADD/PAIMI/PAIR
Protection & Advocacy Agency
1580 Makaloa Street, Suite 1060
Honolulu, HI 96814
Phone: 808-949-2922 (Voice/TDD)
Fax: 808-949-2928
Email: pahi@pixi.com
URL: www.pixi.com/~pahi

IDAHO

CAP/PADD/PAIMI/PAIR
Co-Ad, Inc.
4477 Emerald, Suite B-100
Boise, ID 83706
Phone: 208-336-5353 (Voice/TDD);
800-632-5125
Fax: 208-336-5396
Email: coadinc@uswest.net
URL: www.users.moscow.com/co-ad

ILLINOIS

CAP
Illinois Client Assistance Program
100 North First Street, 1st Floor
Springfield, IL 62702
Phone: 217-782-5374
Fax: 217-524-1790
Email: dhsvred@dhs.state.il.us

PADD/PAIMI/PAIR
Equip for Equality, Inc.
11 East Adams, Suite 1200
Chicago, IL 60603
Phone: 312-341-0022 (Voice/TDD);
800-537-2632
Fax: 312-341-0295
Email: zena@equipforequality.org
URL: www.equipforequality.org

INDIANA

CAP/PADD/PAIMI/PAIR
Indiana Protection and Advocacy Services
4701 North Keystone Avenue, Suite 222
Indianapolis, IN 46204
Phone: 317-722-5555 (Voice/TDD);
800-622-4845
Fax: 317-722-5564
Email: tgallagher@ipas.state.in.us

IOWA

CAP

Client Assistance Program
Division on Persons with Disabilities
Lucas State Office Building
Des Moines, IA 50310
Phone: 515-281-3957; 800-652-4298
Fax: 515-242-6119
Email: harlietta.helland@dhr.state.ia.us

PADD/PAIMI/PAIR

Iowa P&A Service, Inc.
3015 Merle Hay Road, Suite 6
Des Moines, IA 50310
Phone: 515-278-2502; 515-278-0571 (TDD);
800-779-2502
Fax: 515-278-0539
Email: info@ipna.org

KANSAS

CAP

Client Assistance Program
2914 SW Plass Court
Topeka, KS 66611
Phone: 785-266-8193; 800-432-2326
Fax: 785-266-8574
Email: mreyer5175@aol.com

PADD/PAIMI/PAIR

Kansas Advocacy & Protection Services
3745 SW Wanamaker Road
Topeka, KS 66610
Phone: 785-273-9661
Fax: 785-273-9414
Email: jim@ksadv.org

KENTUCKY

CAP

Client Assistance Program
209 St. Clair, 5th Floor
Frankfort, KY 40601
Phone: 502-564-8035; 800-633-6283
Fax: 502-564-2951

PADD/PAIMI/PAIR

Office for Public Advocacy
Division for P&A
100 Fair Oaks Lane, 3rd Floor
Frankfort, KY 40601
Phone: 502-564-2967; 800-372-2988 (TDD)
Fax: 502-564-0848
Email: mfitzgerald@mail.pa.state.ky.us

LOUISIANA

CAP/PADD/PAIMI/PAIR

Advocacy Center for the Elderly and
Disabled
225 Baronne, Suite 2112
New Orleans, LA 70112-2112
Phone: 504-522-2337 (Voice/TDD);
800-960-7705
Fax: 504-522-5507
Email: simplo@advocacyLA.org

MAINE

CAP

CARES, Inc.
4-C Winter Street
Augusta, ME 04330
Phone: 207-622-7055; 800-773-7055
Fax: 207-621-1869
Email: capsite@aol.com

PADD/PAIMI/PAIR

Disability Rights Center
24 Stone Street
P. O. Box 2007
Augusta, ME 04338
Phone: 207-626-2774; 800-452-1948 (TDD)
Fax: 207-621-1419
Email: advocate@drcme.org
URL: www.drcme.org

MARYLAND

CAP

Client Assistance Program
Maryland Rehabilitation Center
Division of Rehabilitation Services
2301 Argonne Drive
Baltimore, MD 21208
Phone: 410-554-9358; 800-638-6243
Fax: 410-554-9362

PADD/PAIMI/PAIR

Maryland Disability Law Center
Central Maryland Office
The Walbert Building, Suite 204
1800 North Charles Street
Baltimore, MD 21201
Phone: 410-234-2791;
410-727-6387 (Voice/TDD);
800-233-7201
Fax: 410-234-2624
Email: philf@mdlcbalto.org

MASSACHUSETTS

CAP

MA Office on Disability
Client Assistance Program
One Ashburton Place, Room 1305
Boston, MA 02108
Phone: 617-727-7440
Fax: 617-727-0965
Email: Barbara.Lybarger@modi.state.ma.us
URL: www.state.ma.us/mod/MSCAPBRO

PADD/PAIR

Disability Law Center, Inc.
11 Beacon Street, Suite 925
Boston, MA 02108
Phone: 617-723-8455 (Voice/TDD)
Fax: 617-723-9125
Email: cgriffin@gbls.org
URL: www.dlc-ma.org

PAIMI

Center for Public Representation
22 Green Street
Northampton, MA 01060
Phone: 413-586-6024 (Voice/TDD)
Fax: 413-586-5711
Email: rfleischner@gbls.org

MICHIGAN

CAP/PADD/PAIMI/PAIR

Michigan P&A Service
106 West Allegan, Suite 300
Lansing, MI 48933
Phone: 517-487-1755 (Voice/TDD);
CAP only: 800-292-5896
Fax: 517-487-0827
Email: ebauer@mpas.org
URL: www.mpas.org

MINNESOTA

CAP/PADD/PAIMI/PAIR

Minnesota Disability Law Center
430 First Avenue North, Suite 300
Minneapolis, MN 55401-1780
Phone: 612-332-1441; 800-292-4150
Fax: 612-334-5755
Email: icohen@midmnlegal.org

MISSISSIPPI

CAP

Client Assistance Program
Easter Seal Society
3226 North State Street
Jackson, MS 39216
Phone: 601-982-7051
Fax: 601-981-1951
Email: pposey8803@aol.com

PADD/PAIMI/PAIR

Mississippi P&A System for DD, Inc.
5305 Executive Place, Suite A
Jackson, MS 39206
Phone: 601-981-8207 (Voice/TDD)
Fax: 601-981-8313
Email: mspna@bellsouth.net

MISSOURI

CAP/PADD/PAIMI/PAIR

Missouri P&A Services
925 South Country Club Drive, Unit B-1
Jefferson City, MO 65109
Phone: 573-893-3333; 800-392-8667
Fax: 573-893-4231
Email: mopasjc@socket.net
URL: www.members.socket.net/~mopasjc/MOP&A

MONTANA

CAP/PADD/PAIMI/PAIR

Montana Advocacy Program
400 North Park, 2nd Floor
P. O. Box 1681
Helena, MT 59624
Phone: 406-449-2344 (Voice/TDD);
800-245-4743
Fax: 406-449-2418
Email: bernie@mtadv.org
URL: www.mt.net/~advocate

NATIVE AMERICAN

PADD

DNA-People's Legal Services, Inc.
P. O. Box 392
Shiprock, NM 87240
Phone: 505-368-3216
Fax: 505-368-3220
Email: napap@cyberport.com

NEBRASKA

CAP

Client Assistance Program
Division of Rehabilitation Services
Nebraska Department of Education
301 Centennial Mall South
Lincoln, NE 68509
Phone: 402-471-3656; 800-742-7594
Fax: 402-471-0117
Email: Vicki_r@nde4.nde.state.ne.us

PADD/PAIMI/PAIR

Nebraska Advocacy Services, Inc.
522 Lincoln Center Building
215 Centennial Mall South
Lincoln, NE 68508
Phone: 402-474-3183 (Voice/TDD)
Fax: 402-474-3274
Email: nas@navix.net

NEVADA

CAP

Client Assistance Program
2450 Wrondel Way, Suite E
Reno, NV 89502
Phone: 775-688-1440; 800-633-9879
Fax: 775-688-1627
Email: wbauer@govmail.state.nv.us
URL: www.members.delphi.com/nvcap

PADD/PAIMI/PAIR

Nevada Advocacy & Law Center, Inc.
6039 Eldora Avenue, Suite C
Las Vegas, NV 89102
Phone: 702-257-8150; 702-257-8160 (TDD);
888-349-3843
Fax: 702-257-8170
Email: ndalc@earthlink.net (Las Vegas office);
reno@ndalc.org (Reno office)
URL: www.ndalc.org

NEW HAMPSHIRE

CAP

Client Assistance Program
Governor's Commission on Disability
57 Regional Drive
Concord, NH 03301-9686
Phone: 603-271-2773
Fax: 603-271-2837
Email: bhagy@gov.state.nh.us
URL: www.state.nh.us/disability/
caphomepage

PADD/PAIMI/PAIR

Disabilities Rights Center
P. O. Box 3660
18 Low Avenue
Concord, NH 03302-3660
Phone: 603-228-0432 (Voice/TDD)
Fax: 603-225-2077
Email: advocacy@drcnh.org

NEW JERSEY

CAP/PADD/PAIMI/PAIR

New Jersey P&A, Inc.
210 South Broad Street, 3rd Floor
Trenton, NJ 08608
Phone: 609-292-9742; 800-922-7233
Fax: 609-777-0187
Email: advoca@njpanda.org
URL: www.njpanda.org

NEW MEXICO

CAP/PADD/PAIMI/PAIR

Protection & Advocacy, Inc.
1720 Louisiana Boulevard, NE, Suite 204
Albuquerque, NM 87110
Phone: 505-256-3100 (Voice/TDD);
800-432-4682
Fax: 505-256-3184
Email: nmpanda@nmprotection-advocacy
.com
URL: www.nmprotection-advocacy.com

NEW YORK

CAP/PADD/PAIMI/PAIR
NY Commission on Quality of Care
for the Mentally Disabled
401 State Street
Schenectady, NY 12305-2397
Phone: 518-381-7098; 800-624-4143 (TDD)
Fax: 518-381-7095
Email: marcelc@cqc.state.ny.us
URL: www.cqc.state.ny.us

NORTH CAROLINA

CAP
Client Assistance Program
North Carolina Division of Vocational
Rehabilitation Services
P. O. Box 26053
Raleigh, NC 27611
Phone: 919-733-6300; 800-215-7227
Fax: 919-715-2456
Email: Kathy.Brack@ncmail.net

PADD/PAIMI/PAIR
Governor's Advocacy Council for Persons
with Disabilities
2113 Cameron Street, Suite 218
Raleigh, NC 27605
Phone: 919-733-9250 (Voice/TDD);
800-821-6922
Fax: 919-733-9173
Email: allen.perry@ncmail.net
URL: www.doa.state.nc.us/doa/gacpd/gacpd

NORTH DAKOTA

CAP
Client Assistance Program
600 South Second Street, Suite 1B
Bismarck, ND 58504-4038
Phone: 701-328-8947; 800-207-6122
Fax: 701-328-8969
Email: solyod@state.nd.us

PADD/PAIMI/PAIR

The North Dakota Protection &
Advocacy Project
400 East Broadway, Suite 616
Bismarck, ND 58501
Phone: 701-328-2950; 800-472-2670/
800-642-6694 (24-hour line);
800-366-6888 (TDD)
Fax: 701-328-3934
Email: tlarsen@state.nd.us
URL: www.ndpanda.org

N. MARIANA ISLANDS

CAP/PADD/PAIMI/PAIR
Northern Marianas
Protection and Advocacy System, Inc.
P. O. Box 503529
Saipan, MP 96950-3529
Phone: 670-235-7274/3
Fax: 670-235-7275
Email: lbarcinasp&a@saipan.com

OHIO

CAP/PADD/PAIMI/PAIR
Ohio Legal Rights Service
8 East Long Street, 5th Floor
Columbus, OH 43215
Phone: 614-466-7264 (Voice/TDD);
800-282-9181
Fax: 614-644-1888
Email: CKnight@olrs.state.oh.us
URL: www.state.oh.us/olrs

OKLAHOMA

CAP
Client Assistance Program
Oklahoma Office of Handicapped Concerns
2712 Villa Prom
Oklahoma City, OK 73107
Phone: 405-521-3756; 800-522-8224
Fax: 405-522-6695
Email: CAP@ohc.state.ok.us
URL: www.state.ok.us/~ohc/cap

PADD/PAIMI/PAIR

Oklahoma Disability Law Center, Inc.
2915 Classen Boulevard, Suite 300
Oklahoma City, OK 73106
Phone: 405-525-7755; 800-880-7755
Fax: 405-525-7759
Email: odlcokc@flash.net
URL: www.oklahomadisabilitylaw.org

OREGON

CAP/PADD/PAIMI/PAIR
Oregon Advocacy Center
620 SW Fifth Avenue, 5th Floor
Portland, OR 97204-1428
Phone: 503-243-2081; 800-452-1694;
800-556-5351 (TDD)
Fax: 503-243-1738
Email: welcome@oradvocacy.org
URL: www.oradvocacy.org

PENNSYLVANIA

CAP
Center for Disability Law & Policy
1617 J.F.K. Boulevard, Suite 800
Philadelphia, PA 19103
Phone: 215-557-7112; 888-745-2357
Fax: 215-557-7602
Email: info@equalemployment.org
URL: www.netslink.com/dislaw

PADD/PAIMI/PAIR

Pennsylvania P&A, Inc.
North Cameron Street, Suite C
Harrisburg, PA 17103
Phone: 717-236-8110 (Voice/TDD);
800-692-7443
Fax: 717-236-0192
Email: ppa@ppainc.org

PUERTO RICO

CAP/PADD/PAIMI/PAIR
Office of the Ombudsman for Persons
with Disabilities
P. O. Box 41309
San Juan, PR 00940-1309
Phone: 787-725-2333; 787-721-4299;
800-981-4125 (TTY); 787-725-4014
Fax: 787-721-2455
Email: mromero@oppi.prstar.net
URL: www.oppi.prstar.net

REPUBLIC of PALAU

CAP
Client Assistance Program
Bureau of Public Health
Ministry of Health
P. O. Box 6027
Koror, PW 96940
Phone: 011-680-488-2813
Fax: 011-680-488-1211
Email: phpal@palaunet.com

RHODE ISLAND

CAP/PADD/PAIMI/PAIR
Rhode Island Disability Law Center Inc.
349 Eddy Street
Providence, RI 02903
Phone: 401-831-3150; 401-831-5335 (TDD);
800-733-5332
Fax: 401-274-5568
Email: hn7384@handsnet.org

SOUTH CAROLINA

CAP
South Carolina Client Assistance Program
Office of the Governor
P. O. Box 11369
Columbia, SC 29211
Phone: 803-734-0285; 800-868-0040
Fax: 803-734-0546
Email: lbarker@govoepp.state.sc.us
URL: www.govoepp.state.sc.us/cap

PADD/PAIMI/PAIR

Protection & Advocacy for People with
Disabilities, Inc.
3710 Landmark Drive, Suite 208
Columbia, SC 29204
Phone: 803-782-0639 (Voice/TDD);
800-922-5225
Fax: 803-790-1946
Email: scpa@sc-online.net

SOUTH DAKOTA

CAP/PADD/PAIMI/PAIR
South Dakota Advocacy Services
221 South Central Avenue
Pierre, SD 57501
Phone: 605-224-8294 (Voice/TDD);
800-658-4782
Fax: 605-224-5125
Email: sdas@sdadvocacy.com
URL: www.sdadvocacy.com

TENNESSEE

CAP/PADD/PAIMI/PAIR
Tennessee P&A, Inc.
P. O. Box 121257
Nashville, TN 37212
Phone: 615-298-1080 (Voice/TDD);
800-342-1660
Fax: 615-298-2046
Email: shirleys@tpainc.org

TEXAS

CAP/PADD/PAIMI/PAIR
Advocacy, Inc.
7800 Shoal Creek Boulevard, Suite 171-E
Austin, TX 78757
Phone: 512-454-4816 (Voice/TDD);
800-252-9108
Fax: 512-323-0902
Email: infoai@advocacyinc.org
URL: www.advocacyinc.org

UTAH

CAP/PADD/PAIMI/PAIR
Disability Law Center
455 East 400 South, Suite 410
Salt Lake City, UT 84111
Phone: 801-363-1347 (Voice/TDD);
800-662-9080
Fax: 801-363-1437
Email: dlcall@disabilitylawcenter.org
URL: www.disabilitylawcenter.org

VERMONT

CAP
Vermont Disability Law Project
Box 1367
Burlington, VT 05402
Phone: 802-863-2881; 800-747-5022
Fax: 802-863-7152
Email: lphilipps@vtlegalaid.org

PADD/PAIMI/PAIR
Vermont Protection & Advocacy
15 East State Street, Suite 101
Montpelier, VT 05602
Phone: 802-229-1355; 800-834-7890
Fax: 802-229-1359
Email: info@vtpa.org

VIRGINIA

CAP/PADD/PAIMI/PAIR
Dept. for Rights of Virginians with Disabilities
Ninth Street Office Building
202 North Ninth Street, 9th Floor
Richmond, VA 23219
Phone: 804-225-2042 (Voice/TDD);
800-552-3962
Fax: 804-225-3221
Email: fergusst@drvd.state.va.us
URL: www.cns.state.va.us/drvd

VIRGIN ISLANDS

CAP/PADD/PAIMI/PAIR
Virgin Islands Advocacy Agency
7A Whim Street, Suite 2
Frederiksted, VI 00840
Phone: 340-772-1200; 340-776-4303;
340-772-4641 (TDD)
Fax: 340-772-0609
Email: viadvocacy@worldnet.att.net

WASHINGTON

CAP
Client Assistance Program
P. O. Box 22510
Seattle, WA 98122
Phone: 206-721-5999; 800-544-2121
Fax: 206-721-4537
Email: capseattle@adccomsys.net

PADD/PAIMI/PAIR
Washington P&A System
180 West Dayton, Suite 102
Edmonds, WA 98020
Phone: 425-776-1199 (Voice);
800-562-2702 (TDD);
800-905-0209
Fax: 425-776-0601
Email: wpas@wpas-rights.org
URL: www.wpas-rights.org

WEST VIRGINIA
CAP/PADD/PAIMI/PAIR
West Virginia Advocates, Inc.
Litton Building, 4th Floor
1207 Quarrier Street
Charleston, WV 25301
Phone: 304-346-0847 (Voice/TDD);
800-950-5250
Fax: 304-346-0867
Email: wvadvocates@intelos.net
URL: www.newwave.net/~wvadvocates

WISCONSIN
CAP
Department of Agriculture
Trade & Consumer Protection
2811 Agriculture Drive
Madison, WI 53718
Phone: 608-224-5070; 800-362-1290
Fax: 608-224-5069
Email: linda.vegoe@datcp.state.wi.us

PADD/PAIMI/PAIR
Wisconsin Coalition for Advocacy
16 North Carroll Street, Suite 400
Madison, WI 53703
Phone: 608-267-0214; 608-267-0214 (TDD)
Fax: 608-267-0368
Email (Madison): wcamsn@w-c-a.org
Email (Milwaukee): wcamke@w-c-a.org

WYOMING
CAP/PADD/PAIMI/PAIR
Wyoming P&A System
320 West 25th Street, 2nd Floor
Cheyenne, WY 82001
Phone: 307-638-7668; 307-632-3496;
800-821-3091; 800-624-7648 (Voice/TDD)
Fax: 307-638-0815
Email: wypanda@vcn.com
URL: www.vcn.com/~wypanda

Appendix B: State Medicaid Offices

ALABAMA

Alabama Medicaid Agency
501 Dexter Avenue
P. O. Box 5624
Montgomery, AL 36103-5624
(36104 FedEx)
Phone: 334-242-5600
Fax: 334-242-5097

ALASKA

Division of Medical Assistance
Department of Health and Social Services
P. O. Box 110660
Juneau, AK 99811
Phone: 907-465-3355
Fax: 907-465-2204

AMERICAN SAMOA

Medicaid Program Director
LBJ Tropical Medical Center
Pago Pago, AS 96799
Phone: 011-684-633-4590
Fax: 011-684-633-1869

ARIZONA

Arizona Health Care Cost Containment
System (AHCCCS)
801 East Jefferson
Phoenix, AZ 85034
Phone: 602-417-4680
Fax: 602-252-6536

ARKANSAS

Division of Medical Services
Department of Human Services
P. O. Box 1437, Slot 1100
103 East Seventh Street
Little Rock, AR 72203
Phone: 501-682-8292
Fax: 501-682-1197

CALIFORNIA

Medical Care Services
Department of Health Services
714 P Street, Room 1253
Sacramento, CA 95814
Phone: 916-654-0391
Fax: 916-657-1156

COLORADO

Office of Medical Assistance
Department of Health Care Policy
& Financing
1575 Sherman, 10th Floor
Denver, CO 80203-1714
Phone: 303-866-5401
Fax: 303-866-2803

CONNECTICUT

Medical Care Administration
Department of Social Services
25 Sigourney Street
Hartford, CT 06106
Phone: 860-424-5116
Fax: 860-424-5114

DELAWARE

Medical Services
Department of Health and Social Services
P. O. Box 906, Lewis Building
New Castle, DE 19720
Phone: 302-577-4901
Fax: 302-577-4405

DISTRICT OF COLUMBIA

Medical Assistance Administration
Department of Health
825 North Capitol Street NE, Suite 5135
Washington, DC 20002
Phone: 202-442-9054
Fax: 202-442-4790

FLORIDA

Agency for Health Care Administration
2727 Mahan Drive, Building 3
Tallahassee, FL 32308
Phone: 850-488-3560
Fax: 850-488-2520

GEORGIA

Department of Medical Assistance
Two Peachtree Street, 40th Floor
Atlanta, GA 30303
Phone: 404-656-4496
Fax: 404-651-6880

GUAM

Bureau of Health Care Financing
Department of Public Health and
Social Services
P. O. Box 2816
Agana, GU 96910
Phone: 011-671-735-7269
Fax: 011-671-734-6860

HAWAII

Med-Quest Division Administrator
Department of Human Services
P. O. Box 339
Honolulu, HI 96809-0339
(FedEx: 601 Kamokila Boulevard, Room 518
Kapolei, HI 96707)
Phone: 808-692-8050
Fax: 808-692-8173

IDAHO

Department of Health and Welfare
Division of Medicaid
3380 Americana Terrace, Suite 230
Boise, ID 83706
Phone: 208-364-1802
Fax: 208-364-1811

ILLINOIS

Medical Programs
Illinois Department of Public Aid
201 South Grand Avenue East
Springfield, IL 62763-0001
Phone: 217-782-6717
Fax: 217-524-7979

INDIANA

Medicaid Policy & Planning
Family & Social Services Administration
402 West Washington Street, Room W382
Indianapolis, IN 46204-2739
Phone: 317-233-4455
Fax: 317-232-7382

IOWA

Division of Medical Services
Department of Human Services
Hoover State Office Building, 5th Floor
Des Moines, IA 50319-0114
Phone: 515-281-8798
Fax: 515-281-4597

KANSAS

Director of Medical Policy
Department of Social and
Rehabilitation Services
915 SW Harrison, 5th Floor
Topeka, KS 66612
Phone: 785-296-3773
Fax: 785-296-5507

KENTUCKY

Department for Medicaid Services
275 East Main Street, 6 West
Frankfort, KY 40621
Phone: 502-564-4321
Fax: 502-564-0509

LOUISIANA

Bureau of Health Services Financing
Department of Health and Hospitals
1201 Capitol Access Road
P. O. Box 91030
Baton Rouge, LA 70821-9030
Phone: 225-342-3891
Fax: 225-342-9508

MAINE

Bureau of Medical Services
Department of Human Services
Statehouse Station #11
Building 205, 3rd Floor
Augusta, ME 04333
Phone: 207-287-3832
Fax: 207-287-2675

MARYLAND

Health Care Financing
Department of Health and Mental Hygiene
201 West Preston Street
Baltimore, MD 21201
Phone: 410-767-4664
Fax: 410-333-7687

MASSACHUSETTS

Division of Medical Assistance
600 Washington Street
Boston, MA 02111
Phone: 617-210-5690
Fax: 617-210-5697

MICHIGAN

Medical Services Administration
Department of Community Health
400 South Pine Street
P. O. Box 30037
Lansing, MI 48933
Phone: 517-335-5001
Fax: 517-335-5007

MINNESOTA

Commissioner for Health Care
Department of Human Services
444 Lafayette Road
St. Paul, MN 55155-3852
Phone: 651-282-9921
Fax: 651-215-9453

MISSISSIPPI

Medicaid Director
Division of Medicaid
Office of the Governor
239 North Lamar Street
Jackson, MS 39201-1399
Phone: 601-359-6050
Fax: 601-359-6048

MISSOURI

Division of Medical Services
Department of Social Services
615 Howerton Court
P. O. Box 6500
Jefferson City, MO 65102
Phone: 573-751-6922
Fax: 573-751-6564

MONTANA

Health Policy and Services Division
Department of Public Health & Human
Services
1400 Broadway
Helena, MT 59601
Phone: 406-444-4141
Fax: 406-444-1861

NEBRASKA

Medical Services Division
Department of Health & Human Services
P. O. Box 95026
301 Centennial Mall South, 5th Floor
Lincoln, NE 68509
Phone: 402-471-9147
Fax: 402-471-9092

NEVADA

Division of Health Care Financing and Policy
1100 East Williams, Suite 116
Carson City, NV 89710
Phone: 775-687-4176, ext. 251
Fax: 775-684-8792

NEW HAMPSHIRE

Medicaid Administration Bureau
Department of Health and Human Services
6 Hazen Drive
Concord, NH 03301-6521
Phone: 603-271-4348
Fax: 603-271-4232

NEW JERSEY

Division of Medical Assistance
& Health Services
Department of Human Services
P. O. Box 712
Trenton, NJ 08625-0712
Phone: 609-588-2600
Fax: 609-588-3583

NEW MEXICO

Medical Assistance Division
Department of Human Services
P. O. Box 2348
Santa Fe, NM 87504-2348
Phone: 505-827-3106
Fax: 505-827-3185

NEW YORK

Office of Medicaid Management
Department of Health
Empire State Plaza
Corning Tower Building, Room 1466
Albany, NY 12237
Phone: 518-474-3018
Fax: 518-486-6852

NORTH CAROLINA

Division of Medical Assistance
Department of Health & Human Services
1985 Umstead Drive,
2517 Mail Service Center
Raleigh, NC 27699-2517
Phone: 919-857-4011
Fax: 919-733-6608

NORTH DAKOTA

Medical Services
Department of Human Services
600 East Boulevard Avenue
Bismarck, ND 58505-0261
Phone: 701-328-3194
Fax: 701-328-1544

NORTHERN MARIANA ISLANDS

Medicaid Administrator
Commonwealth of the Northern
Mariana Islands
P. O. Box 409CK
Saipan, MP 96950
Phone: 670-664-4884
Fax: 670-664-4885

OHIO

Office of Medicaid
Department of Human Services
30 East Broad Street, 31st Floor
Columbus, OH 43266-0423
Phone: 614-644-0140
Fax: 614-752-3986

OKLAHOMA

Oklahoma Health Care Authority
4545 North Lincoln Boulevard, Suite 124
Oklahoma City, OK 73105
Phone: 405-522-7417
Fax: 405-522-7471

OREGON

Office of Medical Assistance Programs
Department of Human Resources
500 Summer Street
Salem, OR 97310-1014
Phone: 503-945-5767

PENNSYLVANIA

Department of Public Welfare
Health and Welfare Building, Room 515
Commonwealth Avenue & Forster Street
Harrisburg, PA 17120
Phone: 717-787-1870
Fax: 717-787-4639

PUERTO RICO

Office of Economic Assistance to
the Medically Indigent
Department of Health
Call Box 70184
San Juan, PR 00936
Phone: 787-250-7429 or 787-765-1230
Fax: 787-250-0990

RHODE ISLAND

Division of Health Care Quality
Department of Human Services
600 New London Avenue
Cranston, RI 02920
Phone: 401-462-3113
Fax: 401-462-6338

SOUTH CAROLINA

Department of Health & Human Services
P. O. Box 8206
Columbia, SC 29202-8206
Phone: 803-898-2504
Fax: 803-898-4515

SOUTH DAKOTA

Medical Services
Department of Social Services
Kneip Building
700 Governors Drive
Pierre, SD 57501-2291
Phone: 605-773-3495
Fax: 605-773-5246

TENNESSEE

TennCare Director
Department of Finance & Administration
729 Church Street
Nashville, TN 37247-6501
Phone: 615-741-0213
Fax: 615-741-0882

TEXAS

Health and Human Services Commission
4900 North Lamar Street, 4th Floor
P. O. Box 13247
Austin, TX 78711 (78751 FedEx)
Phone: 512-424-6517
Fax: 512-424-6585

UTAH

Department of Health
P. O. Box 141000
Salt Lake City, UT 84114-1000
Phone: 801-538-6111
Fax: 801-538-6306

VERMONT

Office of Health Access
Department of Social Welfare
Agency of Human Services
103 South Main Street
Waterbury, VT 05676
Phone: 802-241-3985
Fax: 802-241-2974 or 2897

VIRGINIA

Department of Medical Assistance Services
600 East Broad Street, Suite 1300
Richmond, VA 23219
Phone: 804-786-8099
Fax: 804-371-4981

VIRGIN ISLANDS

Bureau of Health Insurance and
Medical Assistance
210-3A Altona, Suite 302
Frostco Center
St. Thomas, VI 00802
Phone: 340-774-4624
Fax: 340-774-4918

WASHINGTON

Medical Assistance Administration
Department of Social & Health Services
P. O. Box 45080
Olympia, WA 98504-5080
Phone: 360-902-7807
Fax: 360-902-7855

WEST VIRGINIA

Bureau for Medical Services
Department of Health & Human Resources
350 Capitol Street, Room 251
Charleston, WV 25301-3706
Phone: 304-558-1700
Fax: 304-558-1451

WISCONSIN

Division of Health Care Financing
Dept. of Health and Family Services
One West Wilson Street, Room 350
P. O. Box 309
Madison, WI 53701-0309
Phone: 608-266-8922
Fax: 608-266-1096

WYOMING

Office of Medicaid
Health Care Access & Resource Division
154 Hathaway Building
2300 Capitol Avenue
Cheyenne, WY 82002
Phone: 307-777-7848
Fax: 307-777-6964



**National Alliance
for the Mentally Ill**

Colonial Place Three
2107 Wilson Boulevard,
Suite 300
Arlington, VA
22201-3042

PHONE: 703/524-7600

FAX: 703/524-9094

www.nami.org