MANAGING EPILEPSY CARE

A guide to optional epilepsy purchasing specifications to ensure managed care contracts provide access to appropriate services

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MANAGING EPILEPSY CARE

A guide to optional epilepsy purchasing specifications to ensure managed care contracts provide access to appropriate services

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Introduction

Epilepsy is a chronic medical condition affecting approximately 2.3 million people in the United States. Appropriate health care for people with epilepsy depends on rapid diagnosis and varying levels of care to prevent or minimize seizures. Left untreated or undertreated, epilepsy can cause profound and lasting harm to individuals. A critical goal of advocates for people with epilepsy is to ensure that all people with epilepsy become seizure free. To realize this goal, policy makers and advocates must work to ensure that the health care system is educated and oriented to provide a high level of care to people with epilepsy.

As public and private health care programs have sought new strategies to control high rates of growth, many programs have turned to managed care programs. These programs use a variety of methods to ensure greater accountability in the health care system and eliminate waste. Common features of managed care include the use of primary care providers who serve as gatekeepers for specialty care, closed networks of providers, and prior approval requirements before certain services are provided. As with other types of disability, managed care can significantly improve the quality of care received by people with epilepsy. In the absence of proper checks and inputs into managed care systems, however, this type of health care delivery — in all of its many forms — could also underserve people with epilepsy or create barriers to individuals receiving the care and services they need.

As a proactive response to many of the challenges in serving people in managed care, the Center for Health Services Research and Policy at George Washington University has worked with federal and state policy makers, researchers, consumer advocates, and consumers in order to develop optional purchasing specifications for managed care services. These specifications provide a broad menu of draft provisions for the managed care contracts that health care purchasers establish with managed care organizations (MCOs) to provide or arrange for health care services for individuals. These specifications cover a broad range of topics. Recently, the Center released new optional purchasing specifications for services related to epilepsy. While applicable to a broad range of public and private health care purchasers, these specifications were drafted specifically for Medicaid programs. Medicaid is the federal-state program that provides health insurance coverage to specific categories of low-income people, including children, the elderly and people with disabilities. In 2001, Medicaid provided health care to 42.7 million people in the United States, more than half of who received care through managed care programs.

This guide is provided to assist people with epilepsy, advocates for people with epilepsy, federal and state policy makers, and managed care program administrators to effectively use the Optional Purchasing Specifications for Services Related to Epilepsy. The guide has three main purposes:
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- To increase the understanding of the health care needs of people with epilepsy.
- To describe the basic structure of Medicaid and managed care programs, in order to explain how consumers can add their expertise to the development of Medicaid managed care contracts.
- To explain the meaning of and rationale for specific provisions of the Epilepsy Purchasing Specifications.

The guide is intended to provide an additional resource for educating MCOs and health care providers about the health care needs of people with epilepsy and to ensure that MCO contracts specify an appropriate range of services and supports to provide high quality health care to people with epilepsy.
Chapter One: The Health Care Needs of People with Epilepsy

This chapter provides a general introduction to epilepsy; describes the impact that epilepsy can have on individuals and society; and identifies some of the major health care needs of people with epilepsy.

Background on Epilepsy

Epilepsy, sometimes called a seizure disorder, is a chronic medical condition produced by temporary changes in the electrical function of the brain, causing recurrent seizures which affect awareness, movement, or sensation.\(^1\) Based on a number of international surveys, it is believed that approximately 1 in 200 adults experience epilepsy.\(^2\) When the nervous system is functioning properly, nerve fibers transmit electrical signals from throughout the body to the brain. In the brain, these signals are processed in order to allow one’s body to make sense of the signals. In response, the brain emits electrical signals that control the functioning of our body. For example, if a person is poked in the finger with a pin, nerve endings in the finger would generate an electrical signal that is passed to the brain. The brain makes sense of this signal resulting in a sensation of pain and sends its own electrical impulse to muscles to cause the body to react—and move away from the pin. Epilepsy is a disorder that temporarily disrupts the ability of nerve cells (also called neurons) in the brain to communicate in an orderly chain-like fashion.\(^3\) Epilepsy has been described as producing an “electrical storm” where the neurons send electrical signals even when they haven’t been stimulated or they send multiple signals that the brain is unable to process.

There are several factors that can cause epilepsy, for example:\(^4\)

- **Genetics**
  Some people inherit an abnormality in the way that neurons function that makes them unstable.

- **Brain Trauma**
  If an individual experiences trauma to the head, the damage to the brain could lead to epilepsy.

- **Abnormalities of Brain Development**
  Some people have structural abnormalities of the brain in which parts of the brain are malformed or have been organized incorrectly (neuronal migration disorders). Often these abnormalities may be subtle and might only be detected by special MRI examinations. Many of these conditions are now recognized as having a genetic cause.

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1. The Epilepsy Foundation, see [www.efa.org](http://www.efa.org).
2. The Epicentre, see [http://137.172.248.46/welcome.htm](http://137.172.248.46/welcome.htm).
3. Ibid.
4. Ibid.
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• **Other Injury to the brain**
  If the brain is harmed from lack of oxygen (for example, at birth during a complicated delivery) or lack of blood supply (for example, during a stroke) this could lead to epilepsy.

• **Consequences of infection**
  Serious infections of the nervous system such as meningitis or encephalitis sometimes result in epilepsy

• **Brain tumor**
  While rare, a brain tumor (an abnormal growth of cells) can also lead to epilepsy.

Seizures can last anywhere from a few seconds to several minutes. In rare cases, seizures can last for several hours. There are different categories of seizures. Partial seizures refer to seizures where the abnormal electrical discharge originates from one specific area of the brain. Generalized seizures are those that affect the whole brain. Most generalized seizures actually begin as partial seizures that secondarily spread to affect the whole brain. Within each of these categories, there are several different types of seizures. A form of generalized seizure called a “tonic-clonic” seizure, and previously known as a “grand mal” seizure often produces the type of dramatic episode that many people think of when they think of epilepsy. The individual loses consciousness completely, the limbs become stiff and rigid, and breathing stops, causing the lips to go blue. The eyes can be rolled upward and the jaws clenched. This is the “tonic” phase of the seizure, and this is followed by the “clonic” phase wherein the body is shaken by a series of violent, rhythmic jerkings of the limbs. For a day or more after this type of seizure, an individual may experience severe headaches and soreness of the muscles. Partial seizures do not cause whole body shaking but may be just as disruptive to living a normal life as generalized seizures. People with partial seizures usually have alteration of awareness and little or no recall of what happens during the seizure. People in a partial seizure may have a blank look on their face; they may behave in a manner unusual to them. Many people salivate heavily, fidget with their hands or nearby objects, or pace about during partial seizures. People with partial seizures often report that they experience strange feelings at the beginning of their seizures called auras. Typical feelings during an aura are a sensation of a rising feeling in the abdomen, a strange taste or smell, a sense of deja vu, or unusual dizziness or ringing in the ears.

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5 Ibid.
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The Impact of Epilepsy on Individuals and Society

This section is adapted from Epilepsy: A Report to the Nation, Epilepsy Foundation, 1999.6

In 1995 (the most recent year when complete data is available), 300,000 children under age 14, 1.4 million adults age 64 and under, and 550,000 people over 65 had epilepsy in the United States. Approximately 181,000 new cases of epilepsy occur each year in this country; ten percent of the U.S. population will experience at least one seizure in their lifetimes. Epilepsy costs the country approximately $12.5 billion annually in direct and indirect costs.

After being diagnosed with epilepsy and treated with medication, roughly 60% of individuals achieve remission of seizures in the first year; 15% achieve remission at a later date; but 25% of individuals are unable to fully control their seizures. For this group, many of whom are children, epilepsy is a formidable barrier to normal life — affecting education, employment, and personal fulfillment. Marriage and fertility rates are reduced in both sexes and women face special issues throughout their lives. People with epilepsy are at risk of brain damage and increased mortality when seizures resist control. In some cases, drug dosages may be increased in an attempt to control convulsions, but the trade-off is often unpleasant side-effects of the medication. Frequently, people with epilepsy are forced to choose between living with disabling seizures or disabling side-effects. While children are deeply affected by epilepsy, it can pose unique challenges for adults. For example, in some states, just a single seizure could cause an individual to lose their driving privileges. Stigma and fear of people with seizures also affects both children and adults.

Epilepsy is an additional burden for many people with other neurological disorders such as cerebral palsy, mental retardation, autism, Alzheimer’s Disease, stroke, multiple sclerosis, and a whole variety of genetic syndromes. Typically, seizures accompanying other neurological conditions are also more difficult to treat.

Ineffective treatment, delayed treatment, lack of access to high-quality specialty care, and the severity of any underlying neurological conditions may contribute to the development of seizures that are hard to control. Some evidence suggests that the sooner epilepsy is diagnosed and effective treatment is started, the better an individual’s chances of staying seizure free over the long term. Early recognition of epilepsy may also lead to lower health care expenditures. For the roughly 100,000 people in the U.S. who have either a single seizure or go into remission quickly, direct long-term medical costs are minimal. Medical expenses are limited to the initial diagnostic workup. In contrast, the medical care expenses for people with uncontrolled seizures are high and continuing.7

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When examining the cost of caring for people with epilepsy, anti-seizure medications represent the single largest expense, accounting for 30% of direct medical care costs. Inpatient hospital care accounts for 21.8% of direct costs and physician services account for 12.2% of direct costs.

The Health Care Needs of People with Epilepsy

There are two key goals of advocates working to improve the level of care received by people with epilepsy: early, accurate diagnosis and the establishment of a treatment regimen that leads to no further seizures and no side-effects. To meet this goal, it is imperative that individuals have access to a level of care that makes available, as necessary, a broad array of diagnostic tools and ensures access to a wide variety of medical and non-medical services.

The diagnosis of epilepsy can involve a variety of diagnostic procedures and laboratory tests. Procedures critical to the diagnosis of epilepsy include:8

- **Laboratory services**
  In some cases, the diagnosis of epilepsy involves eliminating the possibility of other health conditions that might mimic or provoke seizures. For this reason, many commonly performed laboratory tests that assess the functioning of major organ systems such as the liver, the kidneys, the endocrine system, or the blood and circulatory system can play a critical role in diagnosing epilepsy.

- **Electroencephalogram (EEG) testing**
  The electroencephalogram, or EEG test, involves measuring the brain’s electrical rhythms. To perform this test, electrodes are placed on the scalp. For a routine test, measurements are taken for about 30 minutes. Follow-up testing in specific cases can involve taking measurements for up to several days at a time.

- **Magnetic resonance imaging (MRI)**
  Magnetic resonance imaging is a newer technology that allows a technician to create precise images of the brain in slices. The individual usually lies on a bed and the part of the body to be imaged (in this case the head) is moved into a magnetic field. MRI technology allows for multiple scans to be taken of various slices of the brain. This allows trained physicians to examine the scans for any abnormalities. This type of testing can be useful to both identify other types of problems and, in some cases, to identify the part of the brain that is experiencing a seizure.

- **Neuropsychological testing**
  Neuropsychology is the study of brain-behavior relationships. In clinical work with patients, neuropsychological testing can assist in making a diagnosis when patients’ primary problems include thinking, emotion and behavior. A

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8 The Epicentre, see [http://137.172.248.46/welcome.htm](http://137.172.248.46/welcome.htm).
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neuropsychological evaluation can also help family members and physicians understand the impact of a known disorder on a patient’s everyday function.9

The treatment of epilepsy relies primarily on prescription medications. Since the 1930’s, prescription medications have been available to control epilepsy. Recently, however, newer medications have been developed that are effective while causing fewer side-effects than older medications.10

When medications alone do not suppress seizures, there are other alternatives. One of these is vagus nerve stimulation therapy. Although this therapy rarely results in total cessation of seizures, it often results in a significant reduction in the number of seizures. Another option is surgical treatment. This may involve removing a part of the brain where the seizures begin or cutting nerve fibers that connect areas of the brain.

The health care needs of people with epilepsy, however, extend beyond providing pharmaceuticals, therapeutic devices, or surgical treatment. Neuropsychological assessments may be important, laboratory tests may be necessary, and individuals with epilepsy will need assistance in managing their condition. To successfully manage epilepsy, individuals will need a treatment plan, a plan for coordinating epilepsy services with related health care and support services, as well as assistance in remaining adherent to a prescribed treatment regimen. Because epilepsy can have a broader impact on a person’s life than simply their health status, appropriate health care also involves non-medical services and supports. This can include providing education to individuals so that they can better understand their condition and learn to minimize the effect it has on their lives. It can also involve providing case management services, special education services to children, and providing therapy services, such as vocational, physical, occupational, or speech therapy.

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9 The Brain Tumor Society, see http://www.tbts.org/neuropsychologist.htm.
10 The Epicentre, see http://137.172.248.46/welcome.htm.
Chapter Two: Basic Features of Medicaid, Managed Care, and Managed Care Contracting

This chapter provides a general introduction to the Medicaid program; describes basic features of managed care programs; discusses the role that contracts play in establishing the services to be provided to managed care recipients; and discusses ways for the public to influence Medicaid contracts—in order to ensure that they adequately address the health care service and support needs of people with epilepsy.

Introduction to Medicaid

In 2001, 42.7 million people in the United States received health care coverage through Medicaid at a cost of $216 billion. Medicaid programs are operated as federal-state partnerships to provide health care coverage to specific categories of low-income individuals. States must meet minimum federal requirements in exchange for federal payments that match a specific percentage of state Medicaid spending. At a minimum, the federal government finances 50% of a state’s Medicaid expenses, rising to 80%, depending on the state. The Centers for Medicare and Medicaid Services (CMS) is the agency within the Department of Health and Human Services that administers the Medicaid program at the federal level.

There are three main groups of low-income people who are eligible for Medicaid:

- **Parents and children** In 2001, Medicaid provided health care coverage to 21.7 million non-disabled children and 9.3 million non-disabled adults.
- **People with disabilities,** In 2001 Medicaid provided health care coverage to 7.1 million children and adults with disabilities including people who are blind.
- **The elderly** In 2001, Medicaid provided health care coverage to 4.3 million elderly individuals (persons over age 65).

Persons who fall into one of these three groups become eligible for Medicaid if they meet the specific requirements for one of many eligibility categories. People with epilepsy can be found in each of these categories. People who become eligible for Medicaid because they have epilepsy, however, qualify for Medicaid because they meet the Social Security Administration’s disability standard. Adults are required to be unable to work by reason of a medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. Children under age 18 are considered disabled if they have a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause

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death or that has lasted or can be expected to last for a continuous period of not less than 12 months.\textsuperscript{14}

States are required by the federal Medicaid Act to provide coverage to certain categories of people, called “mandatory” populations. These categories create a minimum eligibility standard across all states. For example, all states must cover pregnant women and children under age 6 with family incomes under 133\% of poverty ($19,458 for a family of three in 2001) and older children (age 6 to 17) with family incomes under 100\% of poverty ($14,630 for a family of three in 2001). As of September 2002, states are also required to cover all children under age 19 up to 100\% of poverty. States must also cover parents and 18 year olds whose income and resources are below state Aid to Families with Dependent Children (AFDC) standards as of July 16, 1996. States must also extend transitional Medicaid assistance (TMA) to low-income working families. TMA allows families to continue receiving health care coverage for a temporary period when a parent who had been receiving cash assistance benefits becomes employed. In most cases, states are also required to cover the elderly and people with disabilities who receive benefits through the Supplemental Security Income (SSI) program. In addition, states are required to assist certain low-income Medicare beneficiaries by paying their Medicare Part B premiums and, in some cases, cost-sharing.\textsuperscript{15}

For most beneficiaries (except for the medically needy, an optional eligibility category that provides a last-chance for eligibility for people with too much income to qualify for Medicaid until incurred medical expenses are considered), state Medicaid programs must cover, at a minimum, the following services:\textsuperscript{16}

- hospital care (inpatient and outpatient)
- nursing home care
- physician services
- laboratory and x-ray services
- early and periodic screening, diagnostic, and treatment (EPSDT) services for children
- family planning services
- Federally qualified health center (FQHC) and rural health clinic (RHC) services
- nurse midwife and nurse practitioner services

States may also cover additional services, including:

- prescription drugs (All states cover prescription drugs through Medicaid. Because it is an optional service, however, there is significant variation across states in the scope of coverage and what limitations, if any, are placed on coverage.)

\textsuperscript{15} Medicaid “Mandatory” and “Optional” Eligibility and Benefits, Kaiser Commission on Medicaid and the Uninsured, July 2001.
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- institutional care for individuals with mental retardation (ICF-MR services)
- home and community-based services
- personal care services
- oral health and vision services for adults

States have broad flexibility to go beyond federal minimum eligibility and benefits standards. Consequently, there is significant variation across states with regard to who is eligible for Medicaid and which services are covered.

Additionally, states can seek federal permission to be exempted from certain provisions of the Medicaid law by seeking a “waiver”. While waivers can take many shapes and forms, there are generally two types of waivers: program waivers and research and demonstration waivers. Program waivers are divided into two main subgroups: freedom-of-choice waivers (called 1915(b) waivers, referring to the section of the Social Security Act that gives the federal government the authority to approve this type of waiver) and home- and community-based services waivers (called 1915(c) waivers). Program waivers tend to be narrow in scope, often affecting very specific groups of Medicaid beneficiaries. In contrast, research and demonstration waivers are generally broader and allow states to pursue large-scale, new initiatives in financing and delivering care to Medicaid beneficiaries on a statewide basis. These waivers are also called 1115 waivers (again for the section of the Social Security Act that authorizes the waivers). Both program waivers and research and demonstration waivers have been used by states to require Medicaid beneficiaries to enroll in managed care programs.

Basic Features of Managed Care

Managed care is a way of providing health care that seeks to integrate the medical care delivery system (including doctors, nurses, hospitals, laboratories, and other providers of health care services) with the insurance system that finances health care. Managed care seeks to limit increases in health care costs by making consumers and providers sensitive to, and jointly responsible for, health care costs. In many ways, managed care refers to a series of rules about how individuals go about seeking care. For example, a key feature of managed care is the use of primary care providers (PCPs). A PCP is a person’s main doctor. In order to see a specialist, an individual must first see their PCP who will decide if this higher level of care is needed. If the PCP determines that an individual needs to see a specialist, they will provide a referral. The MCO will not pay for specialty care unless the individual first receives a referral. MCOs also do not allow individuals to see every provider in the area. Instead, they establish a limited list of providers who agree, in advance, to accept the payment rates that the MCO offers. Generally, people can only see providers in the network, unless a specific type of provider is not available in the

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17 Medicaid: A Primer, Kaiser Commission on Medicaid and the Uninsured, September 1999.
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MCO’s network. Other key features of managed care include prior approval requirements for certain services. For example, if a provider wants to hospitalize an individual, the MCO must give their permission in advance (except for emergencies). When providing prescription drugs, MCOs sometimes use formularies. A formulary is a list of approved drugs. If a provider prescribes a drug in the formulary, the pharmacy will fill it as instructed. If the doctor prescribes a drug that is not in the formulary, however, the pharmacy will deny the request. In this case, the provider can seek to get a higher-level approval for the drug to be dispensed. Alternatively, the MCO may try to give the patient a different (and frequently less expensive) medication.

Before the development of managed care, the only way that health insurance operated was through a system called fee-for-service. In fee-for-service systems, a health insurer establishes a list of covered benefits, and they pay a fee (or a fixed percentage of the cost up to a maximum fee) for every covered service that the insured individual receives. While recipients frequently like this system because it gives them freedom to choose their providers and places few restrictions on receiving services ordered by a provider, it is also considered highly inefficient. This system could allow an individual to get the best care imaginable, but it could also allow individuals or their providers to seek unnecessary services. Since providers in the fee-for-service system have responsibilities to their patients only when they come in for care, it could leave individuals underserved if they do not seek out the appropriate level of care.

The promise of managed care is that it will be more efficient and provide more appropriate care. By establishing management structures designed to evaluate the need for services before they are provided and, when appropriate, substituting lower cost services, managed care is intended to eliminate waste. For example, if you can only go to see a provider in a managed care organization’s network, then the MCO can negotiate discounted payment rates with the providers it accepts into its network. At the same time, managed care promises to “manage” care. This could mean that it will stress prevention and health promotion activities, or it could mean that it will develop standard protocols for how it expects all of its providers to treat people with epilepsy and other conditions.

Critics of managed care, including many people with disabilities, have claimed that managed care has not always fulfilled all of the promises it has made. Indeed, many people with chronic health conditions have charged that managed care has only saved money by placing barriers before those seeking necessary services. Others have complained that managed care has increased the hassles of getting care, so that people give up trying to navigate the system unless they are seriously ill. Some people with epilepsy and other types of disability have complained that MCO networks exclude the small number of providers in a community known for their expertise in providing epilepsy care.

As with private health insurance, Medicaid managed care programs vary greatly in quality. In some places, Medicaid beneficiaries in managed care programs have claimed
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that managed care is horrible. Certain Medicaid managed care programs, however, have pioneered new models for delivering high quality health care to people with disabilities.

It is imperative that people with epilepsy and their advocates learn to work within the managed care system. Existing protections found in the Medicaid law may be insufficient to protect patients’ health care interests because their enforcement relies only on the federal government’s oversight of state Medicaid programs. While this relationship remains important, it does not address the very critical relationship between a state Medicaid program and the MCOs with whom it contracts to provide health care services. Indeed, it is through working with state Medicaid programs to influence the contracting process and to monitor the implementation of managed care contracts that people with epilepsy and their advocates can have an enormous impact on ensuring high quality health care.

The Importance of Contracts with Managed Care Organizations


In state Medicaid managed care programs, states establish legally enforceable agreements — contracts — with MCOs that commit themselves to providing a defined set of benefits. Therefore, monitoring the relationship between a state Medicaid agency and its contractors (commercial and not-for-profit MCOs and other types of service providers) can be a direct way to impact the quality of care received by beneficiaries. Working to ensure that people with epilepsy receive high quality care may require more than strong contracts. Much of the work involved in convincing policy makers to strengthen contracts also can pay a dividend by educating policy makers about the needs of people with epilepsy.

At the federal level, the Medicaid law requires state Medicaid agencies to form a medical care advisory committee to advise the agency and participate in Medicaid policy development and program administration. This committee must include Medicaid beneficiaries and other consumers, as well as health professionals. Your state Medicaid agency must consult with this advisory committee before they implement major policy or program changes. Getting people with epilepsy and people knowledgeable about epilepsy on state medical care advisory committees can be an effective way of getting the issues and concerns of the epilepsy community addressed by state-level policy makers. Because federal law requires medical care advisory committees, consumer advocates can insist that states consult with such committees when developing Medicaid policies. If they are not, then advocates can report this non-compliance to CMS.

At the state level, there are also laws that can be used by consumer advocates to ensure that the state Medicaid program considers their views before making policy decisions.
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Further, in carrying out state functions, such as developing and implementing a Medicaid managed care contracting system, states follow various procedures for developing contract specifications and soliciting bids from health plans. By monitoring these procedures, consumer advocates can take advantage of opportunities for providing input. While specific laws and contract procedures vary from state to state, in most states they can provide consumer advocates with the opening they need to help states develop well-written contracts.

In some states, laws called Administrative Procedures Acts (APAs) may require public comments or public hearings before Medicaid managed care programs are established or before major changes are made to the programs. These laws set deadlines for public comment and/or public hearings on proposed rules, such as those involved in the shift to managed care. All fifty states and the District of Columbia have APAs. Nevada and Missouri, however, exempt Medicaid from complying with the requirements of their APAs.

Most states also have enacted procurement laws that stipulate how state agencies must conduct their purchasing activities that cover contracting with MCOs. Unless a Medicaid agency is specifically exempted, procurement laws can be an important tool in ensuring that the Medicaid agency conducts a fair bidding process and makes reasonable decisions about the organizations with which it will contract. Generally, there will be a requirement that notice of a proposed contract is made public. This notice will indicate where and when bids will be received and reviewed. The notice of a proposed contract may also identify the objective criteria by which bids will be reviewed; including the particular weighting that will be given to various evaluation criteria.

Action Steps for Strengthening Managed Care Contracts

Medicaid consumers, consumer advocates, and policy makers who wish to ensure that managed care contracts provide for high quality epilepsy care, should consider taking the following six steps:

1. **Form Relationships with Key Players**
   In a state Medicaid agency and in other parts of state government, there will be many people with the power to help or hurt your advocacy efforts. It is important to develop as many relationships with key personnel as you can. There may be a designated disability policy coordinator; this individual should serve as a natural ally, but will probably not be empowered to influence all of the decisions you care about. Therefore, you should also try to identify and get to know the persons responsible for writing and negotiating the managed care contracts, the persons responsible for communicating with the public about changes in Medicaid, and the persons responsible for monitoring and evaluating the performance of health plans.

2. **Review Waiver Applications or Terms and Conditions of Approved Waivers**
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Each state may elect to undertake a different process in developing its Medicaid managed care contracts. First, it will be necessary to determine if a state is developing or has received a waiver from the federal government to require Medicaid beneficiaries to enroll in managed care or to be exempt from other provisions of the Medicaid law. If the state is developing a waiver proposal or it has submitted a waiver application that has not been formally approved, it is important for consumer advocates to become involved in this process. If a waiver has been approved, it will be necessary to review the terms and conditions to ensure that the contracts comply with all waiver requirements.

3. **Obtain, Review and Comment on Contracts Materials**

A state will conduct a process for fairly evaluating competing bids and defining desired contract specifications. This can take place after a state obtains a federal waiver, or it can take place whenever the state decides to develop a managed care program. As an initial step, a state will issue a Request for Proposals (RFP), a Request for Information (RFI), or a Request for Applications (RFA). These different mechanisms allow the state to seek input on how to develop its managed care program, and how MCOs propose structuring a Medicaid managed care delivery system. By reviewing these requests, advocates can gain an understanding of their state’s intent with regard to contracting.

4. **Monitor Contract Renewals**

Once a contract has been signed, consumer advocates can continue to have an impact. Every contract sets out requirements on the part of the MCO and the state Medicaid agency. Consumer advocates should monitor whether the terms of the contract are being fulfilled. For example, if a contract calls for an MCO to provide access to epilepsy centers and you are aware of people who need this level of care and have been denied it, you should document such instances and report them to the state Medicaid agency.

Further, contracts do not last indefinitely and usually expire after a specified period of time, generally from one to five years. Consumer advocates have an important role to play in evaluating the performance of managed care organizations as their contracts come up for renewal. Did your experience with a particular MCO demonstrate that there are deficiencies in the contract? Did your experience demonstrate that the MCO is not fully complying with the terms of the contract? In such instances, the extent to which consumer advocates can document incidents experienced by other individuals will affect the credibility of the claims they make. It is also important to remember that an advocate’s job is not simply to identify problems. If you believe that people with epilepsy have had positive experiences with a specific MCO, or if policy decisions taken by a state Medicaid program are helping to resolve a problem, it is also necessary to document positive improvements.

5. **Raise concerns with CMS as necessary**

Federal law requires CMS to approve any Medicaid managed care contract that exceeds $1 million prior to states receiving their federal matching payments—and nearly all contracts are greater in value than this. If you do not believe that your state Medicaid agency is taking your concerns seriously, you should write to the CMS Regional Office (and send a copy to the HHS Inspector General) to express your concerns. At a minimum,
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this should compel the state to justify its actions to CMS. Also, when contracts expire, states routinely seek extensions or they renew. Most of these extensions or renewals will result in contract changes in terms and conditions. You should treat these extensions or renewals as new contracts. This means that you should review them closely—and urge CMS to do the same.

6. **The media can help consumer advocates achieve accountability**

The media can be important partners in efforts to improve the quality of health care. The media can help consumer advocates highlight the importance of quality epilepsy care in a managed care system. Frequently, news reporting can significantly further the efforts of consumer advocates when news stories link abstract policy issues, such as Medicaid contract provisions, with their impact on actual people. Additionally, media coverage of issues can play a role in focusing the attention of policy makers on specific issues.
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Chapter Three: Guide to Optional Purchasing Specifications for Services Related to Epilepsy

This chapter provides sample epilepsy purchasing specifications developed by the Center for Health Services Research and Policy at George Washington University.

Shaded text boxes provide complete and unedited text from the *Optional Purchasing Specifications for Services Related to Epilepsy*. Footnotes provide citations for the optional purchasing specifications. Endnotes, throughout the guide, provide citations related to the primary text. Throughout the specifications, references are made to the purchaser and the contractor. Generally, the purchaser is the state Medicaid agency and the contractor is the managed care organization (MCO).

This document sets forth illustrative language for the purchase of epilepsy-related services from managed care organizations (MCOs) by state agencies administering Medicaid, other state agencies, and other managed care purchasers. It has been prepared by the George Washington University Center for Health Services Research and Policy in conjunction with officials from the Centers for Disease Control and Prevention (CDC) who provided expertise, direction, and financial support for its development.

These optional purchasing specifications were drafted with guidance from experts in the medical specialties of epileptology, neurology, and primary care, health care services/delivery specialists, and patient advocates. Policy makers, managed care officials, and state Medicaid agency representatives reviewed them. They are recommended for consideration because they reflect good practice in the opinion of experts. The specifications do not reflect a formal legal policy or part of a formal practice guideline.

These optional purchasing specifications set forth a broad menu of draft provisions relating to medical management of epilepsy. This language may be incorporated into purchasing agreements in any of several types of formats, including contracts, requests for proposals (RFPs), requests for information (RFIs), and general service agreements.

The contents of this document are optional for state policymakers. This document should be viewed as a tool to assist managed care purchasers to identify key epilepsy-related issues as they negotiate and draft their purchasing agreements with MCOs.

This document is not designed to stand alone. Instead, it is designed to be incorporated, in whole or in part, into more comprehensive purchasing agreements. Thus, this document only contains illustrative language relating to the definition and delivery of epilepsy-related services. It does not contain language relating to issues such as payment, resolution of disputes between the state or other purchasers and the MCO, remedies, termination, and other elements that would be essential to any purchasing agreement.

This document is organized into two Parts. The first Part contains illustrative language defining an epilepsy services benefit. The second Part contains illustrative language articulating general MCO duties relating to the delivery of the epilepsy services benefit set forth in the first Part. Taken together, these two Parts reflect a consistent set of policies that are organized to facilitate negotiation and drafting of purchasing agreements. However, the individual elements are designed to be portable so that they can be used independently of the rest of the language. Italic insertions in certain provisions identify provisions where a drafter may wish to insert relevant state laws. Explanatory *Commentaries* are provided as footnotes to aid in understanding and interpretation.

Unless otherwise noted, all specifications in this document related to medical management services and their delivery are based in whole or in part on the best judgment and opinions of persons knowledgeable in the treatment of epilepsy, general health care practice, health care delivery, and health services organization and management. Of particular note is the specification that enrollees should be reevaluated if they do not experience an outcome free of seizures and side effects within a period of three months. This provision underlines the fact that epilepsy is a chronic disorder that needs to be managed on a continuing basis. As
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indicated above, these optional specifications do not reflect a formal legal policy or part of a formal practice guideline but are recommended for consideration because they reflect good practice in the opinion of experts.

These specifications, which are part of the Purchasing Specifications Series, may be downloaded from www.gwhealthpolicy.org or may be obtained in diskette form from:

Center for Health Services and Policy
Department of Health Policy
School of Public Health and Health Services
The George Washington University Medical Center
2021 K Street N.W. #800
Washington, D.C. 20006

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These sample specifications do not comprise a complete contract between a Medicaid agency and a managed care organization. The Center has also produced other sample
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specifications that cover other parts of a contract; specific Medicaid populations, such as children with special health care needs; sample specifications cover specific services, such as pharmaceuticals and pharmaceutical services; sample specifications cover other conditions, such as sexually transmitted diseases; and sample specifications address specific programmatic issues, such as access to services and cultural competence.

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Part 1. Epilepsy-Related Service Benefits

Part 1 addresses the range of services and benefits that the state Medicaid program intends to purchase from a health plan.

### Part 1. Epilepsy-Related Service Benefits

#### §101. In General

In developing a contract, state Medicaid officials will be focused on defining expectations for MCOs that apply to all beneficiaries. The purpose of this first section is to ensure that MCOs are required to follow practices for enrollees with epilepsy that are consistent with good medical practice.

#### §101. In General

(a) **Contractor Duties** — Contractor shall, for each enrollee, cover and furnish, or arrange for the furnishing of, epilepsy-related services enumerated in §103 in accordance with:

1. guidelines and references enumerated in §107; and
2. coverage determination standards and procedures enumerated in §108.

#### §102. Scope of Benefit

The purpose of this section is to comprehensively describe all of the types of services that are covered by the contract—those that the MCO will be expected to provide when medically necessary. This section lists general types of services to be provided, and references other sections where the true scope of these services is described in detail. This section is critical for establishing the up-front expectation that a service is a covered benefit.

Interested parties are encouraged to examine this section of the contract to make certain that it covers all aspects of epilepsy care. The goal is to avoid uncertainty about whether a service is covered by stating up front that it is covered. The golden rule of contract law is that if it is not explicitly mentioned, then it is not a covered service.

Important elements of a comprehensive package of benefits (which are described in greater detail in subsequent sections) include:

- **Medical management services.** These benefits encompass most of the types of services that people think of when they think of medical care, including services needed to diagnose and treat epilepsy.

- **Non-medical support services.** It has been well documented that the impact of epilepsy can reverberate beyond the seizures and associated clinical symptoms.
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High quality health also encompasses a range of services and supports to mitigate any harmful non-medical consequences of epilepsy. It is important that this section establishes that these non-medical services are covered benefits.

- **Diagnostic procedures and laboratory services.** These services encompass the range of laboratory and other procedures and services that are used to determine whether a person has epilepsy, the type of epilepsy, and to assess other clinical factors that may influence decisions about the treatment or remediation of seizures.

- **Pharmaceuticals and therapeutic devices and supplies.** Pharmaceuticals and therapeutic devices play a central role in the treatment of epilepsy. This section establishes that these services are part of the package of covered services.

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<th>§102. Scope of Benefit</th>
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<tr>
<td>(a) <strong>Epilepsy-related services</strong> — Epilepsy-related services are:</td>
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<td>(1) services relating to medical management of epilepsy enumerated in §103;</td>
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<td>(2) services relating to the non-medical support services enumerated in §104;</td>
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<td>(3) services relating to diagnostic procedures and laboratory services enumerated in §105; and</td>
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<td>(4) services relating to pharmaceuticals and therapeutic devices and supplies enumerated in §106.</td>
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<th>§103. Medical Management Services</th>
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<tr>
<td>This is one of the most important sections of the contract. The purpose of this section is to list all of the types of services that the MCO will be expected to provide related to the medical management (i.e. primary and specialty medical care) of people with epilepsy and to define how and when these services are to be provided. Please note that the contract may include a separate comprehensive list of medical management services for all enrollees. This section lists all those services that the MCO is expected to provide specifically to manage epilepsy.</td>
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This section consists of two parts. The first is primarily a list of general categories of services. While the listing provided in the optional purchasing specifications is fairly comprehensive, consumer advocates are encouraged to determine if their Medicaid program offers additional optional services that have not been included in this listing. The second part describes how covered medical services are to be provided.

Critical aspects of the purchasing specifications include provisions that describe when an individual should be provided a higher level of specialty care; require every individual with epilepsy to receive a detailed treatment plan, and if necessary, one that is co-managed or directed by a specialist; and provide for a time period within which re-
evaluation and revisions to the treatment plan should be made. The specifications also require the treating physician to document the reason for any deviations from established guidelines, and they explicitly require MCOs to cover all EPSDT services. EPSDT stands for early and periodic screening, diagnosis, and treatment. These are specific federal Medicaid requirements that require a state Medicaid program to regularly screen children under age 21. For children diagnosed with health conditions, EPSDT requires a state to provide all medically necessary Medicaid services, including services that the state may not cover for adults.

**RECOMMENDED STANDARD — Three Months: No Seizures, No Side-Effects**

The specifications establish a standard that calls for reevaluation and, as necessary, revisions to the treatment plan for any individual who is still experiencing seizures or side-effects within three months of the implementation of the treatment plan. This process of reevaluation and revision should continue until no seizures or treatment-related side effects are experienced for a three-month period or the patient is referred to a more specialized level of care.

§103. Medical Management Services

(a) Medical Management Services — Services for the medical management (diagnosis and treatment) of enrollees at risk for epilepsy or epilepsy-related medical complications are the following items and services delivered in accordance with subsection (b):

1. neuropsychological assessments when indicated;
2. laboratory tests enumerated in §105(a);
3. pharmaceuticals and therapeutic devices and supplies enumerated in §106(a); and
4. in the case of an enrollee in whom epilepsy is diagnosed, epilepsy management services shall include:
   - (A) an individualized assessment of the enrollee for purposes of developing a plan of assistance;
   - (B) a plan of assistance based on the assessment;
   - (C) coordination of epilepsy-related services that are prescribed for the enrollee and covered under this Part; and
   - (D) assistance to the enrollee in gaining access to prescribed services and in adherence to self-management recommendations.

(b) **Delivery of Medical Management Services** — In delivering the medical management services covered under this Section, Contractor shall ensure that:

1. an initial or preliminary diagnosis of epilepsy made by a family physician, pediatrician, emergency department physician, internist, urgent care center, or other health care provider is made in accordance with applicable guidelines and references outlined in §107 and is confirmed by a neurologist\(^2\), and in the case of any exceptions to this provision, such exceptions must be documented with a justification for such exception; and

2. the confirming diagnosis includes:
   - (A) seizure type; and
   - (B) epilepsy syndrome when possible;

3. in the event a general neurologist can neither confirm nor exclude a diagnosis of epilepsy, the neurologist may refer the enrollee to a neurologist specializing in epilepsy or to a level three or level four epilepsy center;

4. for every enrollee with a diagnosis of epilepsy, the physician confirming the diagnosis develops a detailed treatment plan that is implemented at the most primary level of care that is appropriate, including co-management or principal care by a specialist where appropriate;

5. for every enrollee with a diagnosis of epilepsy, the physician confirming the diagnosis may refer the patient for medical or surgical treatment when the patient has not responded to treatment in a timely manner (e.g., is still experiencing seizures within three months after implementation of the treatment)\(^3\);

6. the treatment plan includes appropriate non-medical support services described in §104;

7. the treating physician addresses necessary revisions to the treatment plan:
   - (A) in the case of an enrollee with a diagnosis of epilepsy who has reported a seizure or treatment-related side effects within three months after implementation of the treatment plan, the treating physician will reevaluate and, as necessary, revise the treatment plan, and continue to do so, until the enrollee does not experience any seizures or treatment-related side effects for a three-month period or the patient is referred to a more specialized level of epilepsy care;
   - (B) in the case of an enrollee with a diagnosis of epilepsy who has not experienced a seizure or epilepsy-related side effects in the preceding three months, the treating physician periodically will review the treatment plan to determine if any changes are necessary (at a minimum, the treating physician should review the treatment plan once a year);

8. in the event a treating physician deviates from an established treatment guideline in the treatment of an enrollee with a diagnosis of epilepsy, the medical reason for such a deviation is documented; and

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\(^2\) **Commentary:** Exceptions to the need for a neurologist’s confirmation of a diagnosis of epilepsy may be justified when the primary care pediatrician, family practitioner, or internist has extensive training and experience diagnosing and treating epilepsy and when the condition is uncomplicated and responds fully to initial treatment.

\(^3\) **Commentary:** Three months is suggested as a practical interval within which a patient’s treatment for epilepsy can be implemented, evaluated, and – where necessary – modified. However, the determination of a timely response to treatment should take into account individual circumstances such as the time required to effect changes in medication regimens and the frequency of subsequent seizures (if any). A high frequency of subsequent seizures may indicate that patient referral is more urgent.
§104. Non-Medical Support Services

In order to prevent epilepsy from leading to isolation, and negatively impacting an individual’s access to education, employment, and other vital interactions within their family and community, non-medical support services are necessary. They are often as important as medical treatment in caring for a person with epilepsy. The purpose of this section is to ensure that non-medical support services are included as covered health care services by the MCO.

Important non-medical services include the development of a psychosocial support plan, the provision of case management services (when necessary), and ensuring that individuals have access to necessary special education, physical, occupational, and vocational therapy services.

§104. Non-Medical Support Services

(a) Non-Medical Support Services — In delivering the non-medical support services that are covered under §102(a)(2), Contractor shall ensure that:

(1) the treating physician, in coordination with a case manager, develops a psychosocial support services plan for enrollees with a diagnosis of epilepsy;

(2) a case manager is provided for enrollees with complicated epilepsy, e.g., enrollees with treatment-resistant epilepsy or enrollees with epilepsy who have physical or mental disabilities that adversely affect their educational or vocational performance, their social participation, or their activities of daily living;

(A) For purposes of this section, a case manager is someone other than the enrollee’s Medicaid social worker or Medicaid case manager, and someone other than a managed care plan’s utilization case manager;

(3) enrollees with a diagnosis of epilepsy receive medical case management services outlined in §103(a)(4) and the psychosocial support services plan described in paragraph (a)(1) outlined in this section; and

(4) enrollees with a diagnosis of epilepsy receive education about the condition and available support services;

(5) enrollees with a diagnosis of epilepsy receive any necessary vocational counseling;

(6) enrollees with a diagnosis of epilepsy receive any necessary occupational, physical, and speech therapy with clearly stated goals; and

(7) special education needs are met for children of school-age with a diagnosis of epilepsy.

4 See § 1905(r) of the Social Security Act, 42 U.S.C. § 1396d(r). For additional information on purchasing EPSDT services from MCOs, see Part 1 of Medicaid Pediatric Purchasing Specifications (Sept. 1999), available at www.gwhealthpolicy.org.

5 Commentary. The role of the case manager is to expand access to care and services for enrollees with a diagnosis of epilepsy. Therefore, the case manager in this section is specifically distinguished from a managed care plan’s utilization case manager or a Medicaid social worker. The need for a case manager may be stronger for children at lower levels of care.

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§105. Diagnostic Procedures and Laboratory Services

The purpose of this section is to ensure that not only are all of the laboratory services used to diagnose and treat epilepsy covered, but also to define which services should be provided when attempting to diagnose epilepsy, as well as which services may be necessary for people who are diagnosed with epilepsy.

This part of the contract should be reviewed to ensure that all diagnostic procedures or laboratory services that are recommended for the diagnosis or treatment of epilepsy are included. If specific tests are used only rarely or in specific circumstances, it can also be important to specify under which circumstances these procedures or services are to be provided.

In particular, the optional specifications indicate that when diagnosing epilepsy, the following services should all be performed: any necessary general medical tests of the blood, kidney, liver, metabolism, or immune system; electroencephalography (EEG); magnetic resonance imaging (MRI); and a full neuropsychological battery of tests.

For persons positively diagnosed with epilepsy, the specifications also indicate that, as needed, additional tests should be provided, for example: testing of the available levels of epilepsy medication in the blood; prolonged video EEG monitoring; and repeat MRI testing.

§105. Diagnostic Procedures and Laboratory Services

(a) Laboratory Services — Laboratory services that are covered under §103(a)(2) are the following tests delivered in accordance with subsection (b) of this Section:

Epilepsy requires a two-part diagnostic procedure that focuses on two questions: Does the patient have seizures? If so, is there an identifiable cause?

Laboratory tests are to be used to address both of these questions and to monitor treatment.

(1) In the case of an enrollee for whom an assessment indicates the possible diagnosis of epilepsy, the following shall be performed:

(A) All hematologic, hepatic, renal, metabolic, endocrine, and other tests of help in general medicine;

(B) Routine electroencephalography (EEG) performed with a minimum of 16 channels, asleep and awake with photic stimulation and hyperventilation;

(C) Magnetic resonance imaging (MRI) of high resolution with appropriate sequences prescribed by the treating physician to detect subtle brain lesions; and

(D) Full, prolonged neuropsychological battery to assess intelligence, focal brain damage, and memory.
(2) If the enrollee has the diagnosis of epilepsy, additional tests may be needed:

(A) Antiepilepsy medication blood levels including unbound levels;

(B) Routine hemograms, liver function tests and renal tests for monitoring of possible toxicity. Serum electrolytes and bone density determinations are required in selected cases;

(C) Repeat MRI with high-resolution fields and special angles to assess mesial temporal sclerosis and migration disorders;

(D) Prolonged video EEG monitoring (often for several days) with or without sphenoidal electrodes;

(E) Positron emission tomography (PET), interictal and ictal single photon emission computed tomography (SPECT), functional MRI, magnetoencephalography (MEG) and other neuro-imaging tests may be needed if surgery is being considered; and

(F) Intracarotid sodium amytal test (Wada test) in preparation for surgery.

(b) Delivery of Laboratory Tests — In delivering the laboratory tests covered under this Part, Contractor shall ensure that the tests are provided in accordance with the guidelines and references enumerated in §107.

§106. Pharmaceuticals and Therapeutic Devices and Supplies

The purpose of this section is to describe which pharmaceuticals the MCO must cover. The optional specifications indicate that the MCO must cover all FDA drugs approved for the treatment of epilepsy. The specifications also seek to ensure that pharmacy benefits are provided in a manner consistent with current standards for the care of people with epilepsy.

Some MCOs may have a list of approved drugs, called a formulary. If a provider wishes to prescribe a medication that is not in the formulary, they may have to substitute a different medication (of the same drug class) that is in the formulary. Frequently, the least expensive drugs in a class of drugs are in the formulary, and the most expensive drugs are excluded. In many cases, this type of substitution is acceptable and appropriate. However, for some people with epilepsy, changing from one drug to another—even in the same medication class—could result in loss of seizure control or an increase in side effects. Similarly, because of differences in drug absorption, changing brands of the same drug (or changing from a brand to a generic version of the drug) can effect seizure control and side effects. Thus, the specifications establish that the treating physician determines when substitution is inappropriate, and when the treating physician indicates that substitution is contraindicated (i.e. potentially harmful), then the MCO or its subcontractors are prohibited from making substitutions.
§106. Pharmaceuticals and Therapeutic Devices and Supplies

(a) Pharmaceuticals and Therapeutic Devices and Supplies — Pharmaceuticals and therapeutic devices and supplies that are covered under §103(a)(3) are the following, delivered in accordance with subsection (b):

(1) Pharmaceuticals: Contractor shall cover all drugs currently approved by the U.S. Food and Drug Administration for the treatment of epilepsy; and

(2) Therapeutic devices: Contractor shall cover implantation of vagus nerve stimulators.

(b) Delivery of Pharmaceuticals and Therapeutic Devices and Supplies — In delivering the therapeutic devices and supplies covered under subsection (a), Contractor shall ensure that the devices and supplies are provided in accordance with the guidelines and references enumerated in §107.

(c) Prohibited Substitutions — In the case that the treating physician considers such substitutions contraindicated, neither Contractor nor its network providers or subcontractors may use any procedure, including a formulary, as a substitute for indicated pharmaceuticals or therapeutic devices or supplies.

§107. Guidelines and References

The purpose of this section is to ensure that the MCO is aware of and required to comply with numerous clinical practice guidelines related to the treatment of people with epilepsy. These guidelines represent the recommendations of a broad range of experts and stakeholders for providing optimal quality epilepsy care.

These guidelines do not make firm determinations about a course of treatment, and all are subject to the best medical judgment of the treating provider and personal decisions of the patient. Nonetheless, these guidelines have been developed to weigh a large volume of scientific evidence and make recommendations that have received the consideration and best judgment of leading physicians, consumers, consumer advocates, and others.

§107. Guidelines and References

(a) Guidelines


(3) American Academy of Neurology (www.aan.com):


7 For additional information on purchasing pharmaceuticals, see Purchasing Specifications for Pharmaceutical and Pharmaceutical Services (Dec. 2001), available at www.gwhealthpolicy.org.
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(B) Management Issues for Women with Epilepsy (Oct. 1998)  
(http://www.aan.com/public/practiceguidelines/wwe.pdf)

(C) EEG/Video Monitoring for Epilepsy (Aug. 1999)  
(http://www.aan.com/public/practiceguidelines/00000059.pdf)

(D) Vagus Nerve Stimulation for Epilepsy (July 1997)  
(http://www.aan.com/public/practiceguidelines/00000076.pdf)

(E) Reassessment: Vagus Nerve Stimulation for Epilepsy (Sept. 1999)  
(http://www.aan.com/public/practiceguidelines/VNS.pdf)


(b) References

(1) Federal Early Periodic Screening Diagnosis and Treatment (EPSDT) requirements for children with a diagnosis of epilepsy, § 1905© of the Social Security Act, 42 U.S.C. §1396d©.


§108. Coverage Determinations

The purpose of this section is to describe how MCOs are expected to determine whether a service or benefit is covered—and which they are obligated to provide. This section also serves to prohibit MCOs from substituting one covered service for another if this change is contraindicated by previously referenced practice guidelines. While the strength of a contract stems from the sum of its parts, this section is one of the more important parts of the contract. Making sure that MCOs make coverage decisions in a consistent and appropriate manner, based on the medical condition of the enrollee, should be one of the highest priorities of consumer advocates and others working to ensure that people with epilepsy receive high quality care.

Frequently, consumer concerns with managed care stem from their experiences when services have been denied. The reasons for denials of a service are many. In some cases, an individual may desire a service that is not medically necessary. In other cases, a provider may not adequately demonstrate to the MCO that a particular service is necessary. In other cases, however, inappropriate denials may result if the process for making coverage determinations is not clearly defined in the contract.

Further complicating this issue, many providers participate in multiple provider networks, wherein each may have different standards and processes for making coverage determinations. This can lead to providers prescribing services that are not covered and
then having the MCO fail to authorize payment for the service. It can also lead to providers “dumbing down” their practices and only prescribing services that are generally accepted by the many MCOs with which they participate. In general, a service is covered if it is described in other parts of the contract as being a covered benefit by the health plan and it has been determined to be medically necessary.

§108. Coverage Determinations

(a) Evidence Used in Making Coverage Determination — In making coverage determinations (as defined in §109(a)) with respect to an enrollee at risk or with a diagnosis of epilepsy, Contractor shall base such determinations on the following evidence:

(1) appropriate clinical guidelines and references enumerated in §107;

(2) the enrollee’s health status including pregnancy, psychosocial factors and other factors that could adversely affect or complicate successful medical management of epilepsy in the enrollee;

(3) clinical evidence of the condition for which approval of services is requested; and

(4) the opinion of the treating physician and the provider confirming a diagnosis of epilepsy.

(b) Prohibited Substitutions — If substitutions are contraindicated under appropriate guidelines and references enumerated in §107, neither Contractor nor Contractor’s provider network or subcontractors may use any procedure, including a formulary, to substitute pharmaceuticals, therapeutic devices or supplies, or lab tests unless directed to do so by the treating physician.

§109. Definitions

The definitions section of a contract may seem like a mundane technicality, but it is not. Since the goal of consumer advocacy is to create a legally enforceable document, it is important for there to be a high level of specificity about what is meant by various provisions. The optional purchasing specifications contain definitions for terms that are used throughout the contract. Use these terms as guidance for making sure there is clarity between both the state Medicaid program and the MCO regarding all of these contract elements.

§109. Definitions

(a) Coverage Determination — a determination by Contractor (or by the provider or other entity to whom Contractor has delegated such determination as to whether, in the case of an enrollee, an item or service enumerated under §102 is necessary to:

(1) prevent, correct or ameliorate a condition, disability, illness or injury; or

(2) maintain functioning.

(b) Epilepsy — a central nervous system disorder that is characterized by unprovoked, recurrent seizures that disrupt communication among brain cells.

(c) Successor Provider — a provider who assumes responsibility for furnishing medical services to a former enrollee of Contractor’s plan.
Part 2. Epilepsy-Related Service Delivery and Health Care Quality

Part 2 addresses the expectations of the state Medicaid agency with regard to the systems that the health plan must put in place to ensure that enrollees receive all of the medically necessary services to which they are entitled, as described in Part 1.

§201. Enrollee Access to Health Care Providers

The purpose of this section is to ensure individuals with epilepsy receive the covered services described in part one in a timely manner and by appropriate health care professionals. Whereas part one of the optional specifications covered which services should be provided, this provision describes timeliness standards for receiving access to providers. It also indicates that individuals should have access both to generalist and specialist providers.

§201. Enrollee Access to Health Care Providers

(a) Timelines for Certain Epilepsy-related Services — In administering services covered under Part 1, Contractor shall comply with the following timelines:

(1) provider visits for enrollees with epilepsy shall be scheduled to occur in accordance with timelines recommended in appropriate guidelines and references enumerated in §107; and

(2) enrollees should have ready access to consultation and continuing care by generalist and specialist providers.

§202. Enrollment and Disenrollment

The purpose of this section is to describe how the MCO is expected to manage the care of people with epilepsy when they are being enrolled or disenrolled from an MCO. In particular, the optional purchasing specifications in this section address two issues: how the MCO plan should ensure continuity of care when enrolling people with epilepsy before they are evaluated by the MCO’s network providers, and the MCO’s responsibilities when terminating care at the time of disenrollment.

§202. Enrollment and Disenrollment

(a) Enrollment of an Individual Receiving Medical Management Services for Epilepsy — In the case that Contractor enrolls an individual who, at the time of enrollment, is receiving medical management services for epilepsy, Contractor shall furnish such medical management services covered under Part 1 until the enrollee has been medically evaluated and medical management services have been prescribed by the enrollee’s treating physician and, if indicated in the opinion of the treating physician, by one or more specialist or subspecialist providers enumerated in §203(a).

(b) Disenrollment of an Individual Receiving Medical Management Services for Epilepsy — In the case of an individual who ceases to be an enrollee and who, at the time of disenrollment, is receiving medical management services for epilepsy under §103, Contractor shall:

1. continue to furnish such services until the earlier of:
   1. notice to Contractor that the enrollee is under the care of a successor provider as defined in §109(c); or
   2. the end of the period for which a premium has been paid to Contractor for coverage of the individual; and

2. at the request of an enrollee:
   1. arrange for timely transfer of all medical records to the individual’s successor provider [drafter insert time frame]; and
   2. ensure that network providers furnishing epilepsy-related medical management services to the individual at the time of disenrollment make themselves available to the successor provider for review of the individual’s treatment plan.

§203. Provider Network Requirements

The purpose of this section is to specify the duties that the state Medicaid agency is placing on MCOs with regard to their provider networks. These provisions are important because access to care for people with epilepsy has the potential to be restricted unless the Medicaid agency ensures that the right types of providers, specialists, and epilepsy centers are included in the MCO’s network. The optional specifications also include anti-discrimination provisions to ensure that providers who provide care to people with epilepsy are not financially penalized because they provide epilepsy services or excluded from participating in a particular MCO because of their expertise in providing care to people with epilepsy.

Key elements of this section include provisions that:

- List the types of providers that must be included in an MCO’s network, including access to specialists and epilepsy centers;

- Require the MCO, when establishing its provider network, to adopt practices to ensure that providers demonstrating a high level of performance in providing epilepsy services are included in the network;
• Prohibit arbitrary exclusions of providers from the MCO network (or financially penalizing providers) on the basis that the provider provides epilepsy services; and

• Provide options for Medicaid programs and other purchasers for establishing payment rates for providers that are not in the MCO network. This can be especially important if an individual with epilepsy accesses specialty services or seeks services from an epilepsy center through an out-of-network referral. If the contract does not specify how payment rates are to be established, then the MCO could restrict access to such providers by setting an unacceptably low payment rate.

§203. Provider Network Requirements

(a) Network Requirements — Contractor’s provider network shall include the following classes of providers:

   (1) generalist providers whose practice includes treatment of individuals with epilepsy;

   (2) specialist providers who are board-certified or board-eligible in neurology and subspecialist providers who are board-certified or board-eligible in neurology with additional training in epileptology;

   (3) comprehensive epilepsy center\(^9\) (either through direct network participation or through a contractual or referral relationship);

   (4) referral relationship with a pediatric neurologist;

   (5) a medical case manager who has background or training as a registered nurse or social worker;

   (6) providers trained to meet the special education needs of school-age children;

   (7) epilepsy educators as part of an epilepsy education program;

   (8) laboratories that are certified under the Clinical Laboratory Improvements Act of 1988\(^10\) and provide the services listed under §105;

   (9) providers of behavioral health services who may be in one or more of the following classes of providers: clinical psychologists, board-certified or board-eligible psychiatrists, or social workers with Master’s degrees;

   (10) speech, occupational, vocational, and physical therapists; and

   (11) registered pharmacists.\(^{11}\)

\(^9\) Commentary: The National Association of Epilepsy Centers have established criteria for what constitutes a “comprehensive” epilepsy center. See www.naepilepsy.org


\(^{11}\) Commentary: In the case of a Medicaid purchaser that has elected to “carve out” pharmaceutical services from a purchasing agreement and to continue providing such services on a fee for service basis, this specification would not be applicable.
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<table>
<thead>
<tr>
<th>(b) <strong>Network Selection Practices</strong> — Contractor’s provider selection practices shall ensure the inclusion of providers that demonstrate a high level of performance in furnishing epilepsy-related services, including a referral relationship contract with an epilepsy center.</th>
</tr>
</thead>
</table>
| (c) **Criteria for Provider Network Participation and Compensation** — In calculating a network provider’s penalty or incentive payment, Contractor shall not, solely on the grounds of the amount, scope or duration of epilepsy-related services covered under §102:
|   (1) exclude the provider from participation in Contractor’s provider network; or |
|   (2) reduce or withhold compensation from, or otherwise impose financial penalties upon a provider participating in Contractor’s provider network. |
| (d) **Payment for Certain Services Furnished by Non-network Providers** — In the event that an enrollee receives treatment for epilepsy on an emergency basis from a provider who is not a network provider, such provider shall be reimbursed for such service at:
|   (1) **[Alternative A]** Medicaid rates; or |
|   (2) **[Alternative B]** network provider rates; or |
|   (3) **[Alternative C]** negotiated rates. |

§204. **Memorandum of Understanding** [reserved]

There are currently no optional specifications for developing a memorandum of understanding specifically related to epilepsy services.

The purpose of this section is to define parameters for a Memorandum of Understanding (MOU) between an MCO and another entity. An MOU is a legal document signed by two parties that describes how two parties will work collaboratively, and covers issues such as what and how information will be shared and how parties will be compensated, if at all, for various services.

The Center has developed optional specifications for memoranda of understanding between MCOs and public health agencies. These are available as part of the purchasing

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12 **Commentary:** This provision addresses a specific use of data on the enumerated services. It does not prohibit a Contractor from collecting the data or from using it for other purposes such as quality measurement and improvement.

13 **Commentary:** “Exclusion” refers to a) initial Contractor determinations with regard to including a provider in the Contractor’s network and b) Contractor determinations with regard to retaining a provider in Contractor’s network.

14 **Commentary:** For Medicaid purchasers, the Balanced Budget Act of 1997 requires Medicaid managed care contracts to provide “for coverage for emergency services [as defined in the Act] without regard to prior authorization or the emergency care provider’s contractual relationship with the organization [or primary care case manager].” §1932(b)(1)(A)(ii) of the Social Security Act, 42 U.S.C. §1396u-2(b)(1)(A)(ii).

15 **Commentary:** Several alternative reimbursement-related specifications are provided for consideration by Medicaid and non-Medicaid purchasers.
§205. Quality Measurement and Improvement

The purpose of this section is to place requirements on MCOs with regard to quality improvement activities. As discussed in section 103, a critical component of the optional specifications is the standard that individuals with epilepsy should be free of seizures and side-effects within three months. This section seeks to link an MCO’s quality measurement and improvement activities to meeting this three-month standard.

The optional specifications also require the MCO to disseminate to network providers information about available epilepsy-related services and practice guidelines and clinical protocols that the MCO uses to evaluate a provider’s performance.

Importantly, this section also requires the MCO to collect data specifically related to the provisioning of epilepsy-related services.

§206. Data Collection and Reporting

The purpose of this section is to make sure that the MCO reports to the state Medicaid agency (or other purchaser) information collected during its quality assurance activities. It also provides for the MCO to make available, on request, specific documents, including the provider’s manual, guidelines and protocols, and standards and procedures for deciding when a requested service is a covered benefit.
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§206. Data Collection and Reporting

(a) **Quality Assurance Reporting** — At least [drafter insert frequency of reporting], Contractor shall report epilepsy quality improvement indicators.

(b) **Availability to Purchaser of Certain Documents** — Upon request, Contractor shall make available to Purchaser the most recent version of each of the following documents:

   - (1) Contractor’s provider manual and any other directives, guidelines or protocols transmitted in writing or electronically by Contractor to providers participating in Contractor’s provider network relating to the provision or coverage of items and services covered under §102;

   - (c) standards and procedures for Contractor’s coverage determinations under §108; and

   - (d) sufficient data collection and monitoring to comply with applicable state laws regarding epilepsy reporting.

§207. Information for Enrollees

The purpose of this section is to ensure that the MCO informs enrollees of their policies and procedures for providing epilepsy-related services. The optional specifications require the MCO to provide this information when the individual first becomes a member of an MCO and whenever significant changes are made related to coverage for epilepsy-related services.

§207. Information for Enrollees

(a) **Information on Covered Services**[^16] — Contractor shall make available information on epilepsy-related services covered under §102 before and at the time of enrollment and when there are material changes in epilepsy-related coverage.

[^16]: Commentary: This optional specification is consistent with the requirement in Medicaid law that potential enrollees and enrollees be provided with information about services covered under the state Medicaid agency’s managed care contract. §1932(a)(5) of the Social Security Act, 42 U.S.C. §1396u-2(a)(5).
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Chapter Four: Additional Resources

This chapter is a compendium of resources. It includes:

- List of State Medicaid Contacts
- Glossary of Terms

State Medicaid Contacts

Source: National Association of State Medicaid Directors, updated March 2003, see http://medicaid.aphsa.org/members.htm.

Alabama
Mr. Michael Lewis, Commissioner
Alabama Medicaid Agency
501 Dexter Avenue
P.O. Box 5624
Montgomery, AL 36103-5624 (36104 FedEx)
Commercial (334) 242-5600
Fax Number (334) 242-5097

Arkansas
Mr. Roy Jeffus, Interim Director
Division of Medical Services
Department of Human Services
P.O. Box 1437, Slot 1100
103 E. 7th Street
Little Rock, AR 72203
Commercial (501) 682-1671
Fax Number (501) 682-1197

Alaska
Mr. Bob Labbe, Director
Division of Medical Assistance
Department of Health and Social Services
P.O. Box 110660
Juneau, AK 99811
Commercial (907) 465-3355
Fax Number (907) 465-2204

California
Mr. Stan Rosenstein, Assistant Deputy Director
Medical Care Services
Department of Health Services
714 P Street - Room 1253
Sacramento, CA 95814
Commercial (916) 654-0391
Fax Number (916) 657-1156

American Samoa
Mr. Andy Puletasi, Medicaid Program Director
Medicaid Program Director
LBJ Tropical Medical Center
Pago Pago, AS 96799
Phone (011 684) 633-4590
Fax Number (011 684) 633-1869

Colorado
Ms. Vivianne Chaumont, Director
Office of Medical Assistance
Department of Health Care Policy & Financing
1575 Sherman - 10th Floor
Denver, CO 80203-1714
Commercial (303) 866-5401
Fax Number (303) 866-2803

Arizona
Ms. Phyllis Biedess, Director
Arizona Health Care Cost Containment System (AHCCCS)
801 East Jefferson
Phoenix, AZ 85034
Commercial (602) 417-4680
Fax Number (602) 252-6536

Connecticut
Mr. David Parrella, Director
Medical Care Administration
Department of Social Services
25 Sigourney Street
Hartford, CT 06106
Commercial (860) 424-5116
Fax Number (860) 424-5114
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Delaware
Mr. Philip P. Soule, Sr., Deputy Director
Medical Services
Department of Health and Social Services
P.O. Box 906, Lewis Building
New Castle, DE 19720
Commercial (302) 577-4901
Fax Number (302) 577-4405

Washington, D.C.
Ms. Wanda Tucker, Interim Senior Deputy Director
Medical Assistance Administration
Department of Health
825 North Capitol Street NE
Suite 5135
Washington, D.C. 20002
Commercial (202) 442-9054
Fax Number (202) 442-4790

Florida
Mr. Bob Sharpe, Deputy Secretary
Agency for Health Care Administration
2727 Mahan Drive, Building 3
Tallahassee, FL 32308
Commercial (850) 488-3560
Fax Number (850) 488-2520

Georgia
Mr. Mark Trail, Acting Director
Department of Medical Assistance
Two Peachtree Street, 40th Floor
Atlanta, GA 30303
Commercial (404) 656-4496
Fax Number (850) 283-0128

Guam
Ms. Tess Arcangel, Acting Administrator
Bureau of Health Care Financing
Department of Public Health and Social Services
P.O. Box 2816
Agana, GU 96910
Overseas Operator (671) 735-7269
Fax Number (671) 734-6860

Hawaii
Ms. Aileen Hiramatsu, Med-Quest Division Administrator
Department of Human Services
PO Box 339
Fed. Ex (601 Kamokila Blvd., Room 518
Kapolei, HI 96707)
Honolulu, HI 96809-0339
Commercial (808) 692-8050
Fax Number (808) 692-8173

Idaho
Mr. Joe Brunson, Administrator
Department of Health and Welfare
Division of Medicaid
3380 Americana Terrace, Suite 230
Boise, ID 83706
Commercial (208) 334-5747
Fax Number (208) 364-1811

Illinois
Mr. A. George Hovanec, Acting Director
Medicaid Programs
Illinois Department of Public Aid
201 S. Grand Avenue, East
Springfield, IL 62763-0001
Commercial (217) 782-7755
Fax Number (217) 524-7979

Indiana
Ms. Melanie Bella, Director
Medicaid Policy & Planning
Family & Social Services Administration
402 W. Washington Street, Room W382
Indianapolis, IN 46204-2739
Commercial (317) 233-4455
Fax Number (317) 232-7382

Iowa
Ms. Sally Cunningham, Interim Director
Division of Medical Services
Department of Human Services
Hoover State Office Building, 5th Floor
Des Moines, IA 50319-0114
Commercial (515) 281-5452 or 5454
Fax Number (515) 281-4597

Kansas
Mr. Robert Day, Medicaid Director
Director of Medical Policy
Department of Social and Rehabilitation Services
915 SW Harrison, 5th Floor
Topeka, KS 66612
Commercial (785) 296-3773
Fax Number (785) 296-5507

Kentucky
Mr. Mike Robinson, Commissioner
Department for Medicaid Services
275 East Main Street, 6 West
Frankfort, KY 40621
Commercial (502) 564-4321
Fax Number (502) 564-0509
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Louisiana
Mr. Ben A. Bearden, Director
Bureau of Health Services Financing
Department of Health and Hospitals
1201 Capitol Access Road
P.O. Box 91030
Baton Rouge, LA 70821-9030
Commercial (225) 342-3891
Fax Number (225) 342-9508

Maine
Mr. Eugene Gessow, Director
Bureau of Medical Services
Department of Human Services
Statehouse Station #11
Building 205, 3rd Floor
Augusta, ME 04333
Commercial (207) 287-3832
Fax Number (207) 287-2675

Maryland
Ms. Debbie Chang, Deputy Secretary for Health Care Financing
Department of Health and Mental Hygiene
201 West Preston Street
Baltimore, MD 21201
Commercial (410) 767-4664
Fax Number (410) 333-7687

Massachusetts
Ms. Wendy Warring, Commissioner
Division of Medical Assistance
600 Washington Street
Boston, MA 02111
Commercial (617) 210-5690
Fax Number (617) 210-5697

Michigan
Mr. Patrick Barrie, Deputy Director
Department of Community Health
320 S. Walnut
Lansing, MI 48913
Commercial (517) 335-0196
Fax Number (517) 335-3090

Minnesota
Ms. Mary Kennedy, Medicaid Director
Assistant Commissioner for Health Care
Department of Human Services
444 Lafayette Road
St.Paul, MN 55155-3852
Commercial (651) 282-9921
Fax Number (651) 215-9453

Mississippi
Ms. Rica Lewis-Payton, Medicaid Director
Division of Medicaid
Office of the Governor
239 North Lamar Street
Jackson, MS 39201-1399
Commercial (601) 359-6050
Fax Number (601) 359-6048

Missouri
Mr. Greg Vadner, Director
Division of Medical Services
Department of Social Services
615 Howerton Court
P.O. Box 6500
Jefferson City, MO 65102
Commercial (573) 751-6922
Fax Number (573) 751-6564

Montana
Mr. John Chappuis, Deputy Director
Department of Public Health & Human Services
1400 Broadway
Helena, MT 59601
Commercial (406) 444-4084
Fax Number (406) 444-1970

Nebraska
Mr. Bob Seiffert, Administrator
Medical Services Division
Department of Health & Human Services
P.O. Box 95026
301 Centennial Mall South, 5th Floor
Lincoln, NE 68509
Commercial (402) 471-9147
Fax Number (402) 471-9092

Nevada
Mr. Chuck Duarte, Administrator
Division of Health Care Financing and Policy
1100 E. Williams
Suite 116
Carson City, NV 89710
Commercial (775) 684-3676
Fax Number (775) 684-8792

New Hampshire
Ms. Lori Real, Medicaid Director
Health Policy & Medicaid
Department of Health and Human Services
Office of the Commissioner
129 Pleasant Street
Concord, NH 03301-6521
Commercial (603) 271-3676
Fax Number (603) 271-8431
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**New Jersey**
Ms. Kathryn Plant, Acting Director  
Division of Medical Assistance & Health Services  
Department of Human Services  
P.O. BOX 712  
Trenton, NJ 08625-0712  
Commercial (609) 588-2600  
Fax Number (609) 588-3583

**New Mexico**
Ms. Carolyn Ingram, Acting Director  
Medical Assistance Division  
Department of Human Services  
P.O. Box 2348  
Santa Fe, NM 87504-2348  
Commercial (505) 827-3106  
Fax Number (505) 827-3185

**New York**
Ms. Kathryn Kuhmerker, Deputy Commissioner  
Office of Medicaid Management  
Department of Health  
Empire State Plaza  
Room 1466, Corning Tower Building  
Albany, NY 12237  
Commercial (518) 474-3018  
Fax Number (518) 486-6852

**North Carolina**
Ms. Nina Yeager, Director  
Division of Medical Assistance  
Department of Health & Human Services  
1985 Umstead Drive, 2517 Mail Service Center  
Raleigh, NC 27699-2517  
Commercial (919) 857-4011  
Fax Number (919) 733-6608

**North Dakota**
Mr. David Zentner, Director  
Medical Services  
Department of Human Services  
600 E. Boulevard Avenue  
Bismarck, ND 58505-0261  
Commercial (701) 328-3194  
Fax Number (701) 328-1544

**Northern Mariana Islands**
Ms. Helen Sablan, Administrator  
Medicaid  
Commonwealth of the Northern Mariana Islands  
PO Box 409CK  
Saipan, CM 96950  
Commercial (670) 664-4884  
Fax Number (670) 664-4885

**Ohio**
Ms. Barbara Edwards, Deputy Director  
Office of Medicaid  
Department of Human Services  
30 East Broad Street - 31st Floor  
Columbus, OH 43266-0423  
Commercial (614) 644-0140  
Fax Number (614) 752-3986

**Oklahoma**
Mr. Mike Fogarty, CEO  
Oklahoma Health Care Authority  
4545 N. Lincoln Boulevard, Suite 124  
Oklahoma City, OK 73105  
Commercial (405) 522-7417  
Fax Number (405) 522-7471

**Oregon**
Ms. Lynn Read, Director  
Office of Medical Assistance Programs  
Department of Human Resources  
500 Summer Street  
Salem, OR 97310-1014  
Commercial (503) 945-5772  
Fax Number (503) 373-7689

**Pennsylvania**
Ms. Peg J. Dierkers, Ph.D. Deputy Secretary  
Department of Public Welfare  
Health and Welfare Building, RM 515  
Commonwealth Avenue & Forster Street  
Harrisburg, PA 17120  
Commercial (717) 787-1870  
Fax Number (717) 787-4639
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Puerto Rico
Mr. William Gonzalez, Medicaid Director
Office of Economic Assistance to the Medically Indigent
Department of Health
Call Box 70184
San Juan, PR 00936
Commercial (787) 250-7429 or (787) 765-1230
Fax Number (787) 250-0990

Rhode Island
Mr. John Young, C.P.M., Associate Director
Division of Health Care Quality
Department of Human Services
600 New London Avenue
Cranston, RI 02920
Commercial (401) 462-3113
Fax Number (401) 462-6338

South Carolina
Mr. Bill Prince, Medicaid Director
Department of Health & Human Services
P.O. Box 8206
Columbia, SC 29202-8206
Commercial (803) 898-2504
Fax Number (803) 898-4515

South Dakota
Mr. Damian Prunty, Administrator
Medical Services
Department of Social Services
Kneip Building
700 Governors Drive
Pierre, SD 57501-2291
Commercial (605) 773-3495
Fax Number (605) 773-5246

Tennessee
Mr. Manny Martins, TennCare Director
Department of Finance & Administration
729 Church Street
Nashville, TN 37247-6501
Commercial (615) 741-0213
Fax Number (615) 741-0882

Texas
Mr. Jason Cooke, Medicaid and SCHIP Director
Health and Human Services Commission
4900 N. Lamar Street, 4th Floor
P.O. Box 13247
Austin, TX 78711 (78751 FedEx)
Commercial (512) 424-6517
Fax Number (512) 424-6585

Utah
Mr. Rod Betit, Executive Director
Department of Health
P.O. Box 141000
Salt Lake City, UT 84114-1000
Commercial (801) 538-6111
Fax Number (801) 538-6306

Vermont
Mr. Paul Wallace-Brodeur, Director
Office of Health Access
Department of Social Welfare
Agency of Human Services
103 South Main Street
Waterbury, VT 05676
Commercial (802) 241-3985
Fax Number (802) 241-2974 or 2897

Virginia
Mr. Patrick Finnerty, Director
Department of Medical Assistance Services
600 East Broad Street - Suite 1300
Richmond, VA 23219
Commercial (804) 786-8099
Fax Number (804) 371-4981

Virgin Islands
Ms. Priscilla Berry-Quetel, Executive Director
Bureau of Health Insurance and Medical Assistance
210-3A Altona, Suite 302
Frostco Center
St. Thomas, US Virgin Islands 00802
Commercial (340) 774-4624
Fax Number (340) 774-4918

Washington
Mr. Doug Porter, Assistant Secretary
Medical Assistance Administration
Department of Social & Health Services
P.O. Box 45080
Olympia, WA 98504-5080
Commercial (360) 902-7807
Fax Number (360) 902-7855
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Ms. Kathy Leitch, Assistant Secretary
Aging and Adult Services Administration
P.O. Box 45050
Olympia, WA 98504-5050
Commercial (360) 902-7797
Fax Number (360) 902-7848

West Virginia
Ms. Nancy Atkins, Commissioner
Bureau for Medical Services
Department of Health & Human Resources
350 Capitol Street - Room 251
Charleston, WV 25301-3706
Commercial (304) 558-1700
Fax Number (304) 558-1451

Wisconsin
Ms. Peggy Handrich, Administrator
Division of Health Care Financing
Dept. Of Health and Family Services
1 West Wilson Street - Room 350
PO Box 309
Madison, WI 53701-0309
Commercial (608) 266-8922
Fax Number (608) 266-1096

Wyoming
Ms. Iris Oleske, State Medicaid Agent
Office of Medicaid
Health Care Access & Resource Division
154 Hathaway Building
2300 Capitol Avenue
Cheyenne, WY 82002
Commercial (307) 777-7848
Fax Number (307) 777-6964
Glossary of Terms

Administrative Procedures Act (APA): A type of state law enacted by every state and the District of Columbia that defines the parameters within which state agencies, including the state Medicaid agency, must operate. In general, these laws require state agencies to provide for public notice and comment on all regulations and policies that are issued by state agencies. With the exception of Missouri and Nevada, whose Medicaid programs are exempt from their APA, these laws can be used as a tool by consumer advocates to obtain access to and provide comment on requests for proposals (RFPs) and other policies before they are issued in final form by the state.

Centers for Medicare and Medicaid Services (CMS): The federal agency that administers the Medicaid program. CMS is part of the Department of Health and Human Services.

Contract: A legal agreement between two parties. In Medicaid managed care programs, it can be the legal agreement between a state Medicaid program and a managed care organization (MCO).

Contractor: Organization with whom a state Medicaid program signs a legally enforceable contract to provide specified health care services to Medicaid beneficiaries. In many cases, the managed care organization (MCO) is the contractor.

Coverage Determination: Process through which a managed care organization (MCO) makes a decision regarding whether they will provide to an enrollee a covered service. The contract between the state and the MCO will require the MCO to provide services whenever they are “medically necessary”. The coverage determination process refers to the methods used by an MCO to assess whether a service is medically necessary.

Electroencephalogram: A test that involves measuring the brain’s electrical rhythms and that is used to diagnose epilepsy.

Enrollee: A Medicaid beneficiary who has joined a specific managed care organization (MCO). Many MCOs also refer to their enrollees as members.

Epilepsy: A chronic medical condition produced by temporary changes in the electrical function of the brain, causing recurrent seizures which affect awareness, movement, or sensation. Also called a seizure disorder.

Fee-for-Service: A way of paying for health care services that has been also called, “traditional health insurance”. Fee-for-service programs pay providers an established fee (or portion of a fee) for each covered service that the provider delivers to an enrollee.

Food and Drug Administration (FDA): The agency of the federal government responsible for assuring the safety of food, medicines, and medical supplies and
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equipment. An important role of the FDA is to evaluate and approve the safety and efficacy (usefulness) of drugs before they can be legally prescribed in the United States.

**Formulary:** A list of approved medications that a managed care organization (MCO) agrees to provide to its enrollees when prescribed by a health care provider. Drugs not on the formulary are not covered, unless the provider seeks a higher level approval and justifies the individual’s need for the medication.

**Gatekeeper:** A person employed by (or paid by) a managed care organization, generally the individual’s primary care provider. This person is responsible for monitoring and coordinating an individual’s health care. This individual must pre-approve certain services before the individual can receive them, such as access to a specialist.

**Generalized Seizure:** A category of epileptic seizure that involves the entire brain.

**Guidelines:** Recommendations for health care providers on the types of diagnostic procedures and prevention and treatment services that should be provided to persons with a specific health condition. Guidelines are general recommendations that may define the current standard for how to treat a specific condition, and generally result from a consensus process that seeks broad input before making recommendations.

**Magnetic Resonance Imaging (MRI):** A scanning technique that produces a detailed picture of the brain, in some cases used to identify the location of abnormalities that might be the cause of seizures in people living with epilepsy.

**Managed Care:** A way to deliver health care services that seeks to integrate the medical care delivery system (i.e. physicians, hospitals, laboratories, etc.) with the insurance system that finances health care.

**Managed Care Organization (MCO):** A broadly defined term that refers to various types of organizations that provide health care services to groups of people using at least some of the basic principles of managed care.

**Mandatory Population:** A category of low-income persons for whom the federal Medicaid law requires each state to provide Medicaid coverage.

**Mandatory Service:** A specified list of Medicaid services that the federal Medicaid law requires each state to provide to all Medicaid beneficiaries, except for the medically needy.

**Medicaid:** A health care program created by federal law that allows each state to provide health insurance coverage to specified categories of low-income individuals. In exchange for meeting federal program standards, the federal government pays a portion of state expenditures, ranging from 50% to 80% of total state costs. In 2001, 42.7 million people received health care coverage through Medicaid.
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Medical Care Advisory Committee: Advisory committee that each state is required to convene under the federal Medicaid law. This committee must include Medicaid beneficiaries and states must seek input from this committee before making any major policy changes to the Medicaid program.

Medical Management Services: A type of health care services that involves providing direct medical care to individuals to treat a specific condition.

Medically Needy: A type of Medicaid beneficiary that becomes eligible only at state option. These individuals fall into a Medicaid eligibility category, but they exceed the income standards. Once the cost of medical expenses they incur is subtracted from their income, they fall below a state-established medically needy income limit. Unlike all other types of Medicaid beneficiaries, states do not need to provide the medically needy the full range of “mandatory” Medicaid services.

Memorandum of Understanding (MOU): A legal document signed by two parties that describes how two parties will work collaboratively, and covers issues such as what and how information will be shared and how parties will be compensated, if at all, for various services.

Network: A group of providers with whom a managed care organization (MCO) has established an agreement to cover payment for specific services. Individual enrollees of the MCO select a primary care provider from this group of providers or, when needing specialty care, they will be given a referral to one of the providers in this group.

Neuron: A cell of the nervous system.

Neuropsychological Testing: Neuropsychology is the study of brain-behavior relationships. Neuropsychological testing can assist in making a diagnosis when patients’ primary problems include thinking, emotion and behavior.

Non-Medical Management Services: A category of covered health care services that are not medical in nature. This can include a range of services including special education, case management services, and speech, vocational, occupational or physical therapy.

Partial Seizure: A class of seizure in which only part of the brain is affected.

Pharmaceuticals: Medications delivered by a pharmacy. This can include drugs that are only available by prescription, as well as over the counter medications.

Primary Care Provider (PCP): The provider an individual sees for most of their health care. This individual is responsible for coordinating an individual’s care needs and must authorize any specialty care.
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**Prior Approval:** A requirement of some managed care organizations (MCOs) for certain services that individuals or their providers must obtain advance permission from the MCO before accessing a certain service, unless there is an emergency.

**Private Health Care Program:** A health care program that is not operated by the government. Most people in the United States obtain health insurance through their employer (or the employer of a family member). This type of insurance is considered a private health insurance program.

**Procurement Law:** A type of state law that stipulate how state agencies must conduct their purchasing activities. These laws can create requirements for Medicaid programs to seek public input before purchasing health care services from managed care organizations (MCOs).

**Public Health Care Program:** A health care program that is operated by a federal or state government. In the United States, three major public health insurance programs are Medicaid, Medicare, and the State Children’s Health Insurance Program.

**Purchasing Specification:** Sample provisions for a contract that describe what services a health care program is purchasing from a managed care organization (MCO).

**Quality Assurance:** A wide variety of actions, policies, and procedures of managed care organizations (MCOs) intended to ensure that individual enrollees of an MCO receive high quality care.

**Referral:** An authorization form (that may be transmitted on paper, by telephone, or over the computer) that gives an enrollee of a managed care organization (MCO) permission to receive health care services from another provider. In most cases, these are specialty services.

**Request for Applications (RFA):** An announcement issued by a state Medicaid agency that notifies the public of its intention to enroll its Medicaid recipients into managed care and asks for managed care organizations (MCOs) to submit applications to provide a specific set of services to a specified population of Medicaid beneficiaries. It will also describe how the state will review the applications that it receives and select health plans with which it would like to contract. MCOs that are interested in applying would develop a proposal that describes their expertise and capacity in providing such services, describes how they would structure a health care delivery system to provide the services identified, and outlines a cost proposal or a fee structure to serve the identified population.

**Request for Information (RFI):** This is similar to an RFA, only it indicates that a state Medicaid agency is at a preliminary stage in deciding how they will structure their managed care program. Managed care organizations (MCOs) that respond to an RFI would develop a similar application, only there is likely to be less specificity regarding
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how an MCO would structure its health care delivery system and it would provide little or no cost information.

**Request for Proposals (RFP):** An RFP is very similar to an RFA. In an RFA, the state Medicaid program may be more specific in the requirements it would impose on health plans with which it contracts, whereas an RFP may give a health plan more latitude to structure its own proposal. In short, where a state has used an RFP process, there is likely to be more variations in how health plans structure their programs and networks than in states that have contracted with health plans through an RFA process.

**Specialist:** A type of provider that provides health care services in a specific area of medicine in which they have expertise. Specialists often charge higher fees than generalist physicians. In managed care programs, a managed care organization (MCO) may limit access to specialists by requiring individuals to see their primary care provider who must authorize specialist services by providing a referral.

**Supplemental Security Income (SSI):** An income support program for low-income people with disabilities. In most states, recipients of SSI automatically qualify for Medicaid.

**Tonic-Clonic Seizure:** A form of generalized seizure previously known as a “grand mal” seizure. It produces the type of dramatic episode or “convulsion” that many people think of when they think of epilepsy. The individual loses consciousness completely, the limbs become stiff and rigid, and breathing stops, causing the lips to go blue. The eyes can be rolled upward and the jaws clenched. This is the “tonic” phase of the seizure which is followed by the “clonic” phase wherein the body is shaken by a series of violent, rhythmic jerkings of the limbs. For a day or more after this type of seizure, an individual may experience severe headaches and soreness of the muscles.

**Waiver:** Permission from the Secretary of Health and Human Services to be exempted from certain provisions of federal law. In Medicaid, states use waivers, in some cases, to require Medicaid beneficiaries to enroll in managed care programs.