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Report to the Chairman and Ranking Minority Member, Subcommittee on Medicaid and Health Care for Low-Income Families, Committee on Finance, U.S. Senate

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MEDICAID MANAGED CARE

Serving the Disabled Challenges State Programs

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The Honorable John H. Chafee
Chairman
The Honorable Bob Graham
Ranking Minority Member
Subcommittee on Medicaid and Health Care
for Low-Income Families
Committee on Finance
United States Senate

This report, prepared at your request, describes state efforts to include disabled Medicaid beneficiaries in prepaid managed care programs.

We are sending copies to the Secretary of Health and Human Services; the Administrator, Health Care Financing Administration; and state Medicaid directors. We will also make copies of this report available to others on request.

Please contact me at (202) 512-7114 if you or your staff have any questions. Major contributors to the report are listed in appendix I.

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Executive Summary

Purpose

Prepaid managed care plans, which deliver medical services for a fixed (or "capitated") per-person fee, are an increasingly common part of Medicaid, the nation's largest health care program for the poor. With their emphasis on primary care, restricted access to specialists, and control of services, prepaid plans are seen as a way to help control spiraling Medicaid costs, which totaled $159 billion in fiscal year 1995. Thus far, states have extended prepaid care largely to low-income families—about 30 million individuals—but to few of the additional 6 million Medicaid beneficiaries who are mentally or physically disabled. Managed care's emphasis on primary care and control of service use differs from the care needs of disabled beneficiaries—many of whom need extensive services and access to highly specialized providers, which in some cases are essential to prevent death or further disability. However, because over one-third of all Medicaid payments go for their care, greater attention is being focused on whether disabled individuals can be integrated successfully into managed care.

These efforts affect three key stakeholder groups: disabled beneficiaries, who include a small number of very vulnerable individuals who may be less able than others to effectively advocate on their own behalf for access to needed services; the prepaid care plans, which are concerned about the amount of financial risk involved in treating people with extensive medical needs; and the states and federal government, which run Medicaid. The Chairman and Ranking Minority Member of the Subcommittee on Medicaid and Health Care for Low-Income Families, Senate Committee on Finance, asked GAO to examine (1) the extent to which states are implementing Medicaid prepaid managed care programs for disabled beneficiaries and (2) the steps that have been taken to safeguard the interests of all three stakeholder groups. GAO's review of safeguards focused on two areas—efforts to ensure quality of care and strategies for setting rates and sharing financial risk.

Background

Medicaid is funded jointly by the states and the federal government and operated mainly by the states. It provided health care coverage for 40 million people in fiscal year 1995, about one in seven of whom was disabled. Some categories of mildly disabled individuals have health care costs that closely mirror those of the general population, but others, such as those with cystic fibrosis or end-stage acquired immunodeficiency syndrome (AIDS), have costs that are much higher.

Medicaid has traditionally been a fee-for-service program, meaning that doctors, hospitals, and other providers are paid based on the number and type of services they provide. States have relatively wide latitude in structuring Medicaid programs, including making prepaid care available to those who wish to enroll. But states must obtain federal approval to require prepaid plan enrollment or to restrict individuals to specific plans. This approval is designed to help ensure that everyone who is eligible has access to care.

Results in Brief

Serving disabled beneficiaries through Medicaid managed care poses complex, new challenges to the states. To date, few states have significant experience with prepaid care for disabled Medicaid beneficiaries, many of whom have chronic conditions that require ongoing and costly specialty care. Of the six states that require some or all of their disabled population to enroll in prepaid care, only one program is more than 3 years old. Eleven others have voluntary programs enrolling a small percentage of disabled beneficiaries. However, because of continued concern about cost containment, 13 more states have submitted proposals to enroll disabled beneficiaries in prepaid care, with 12 of them intending to make enrollment mandatory.

One of the challenges for states is developing both the service networks and the necessary assurances that the health care needs of disabled beneficiaries are being met appropriately. However, about half of the states tend to rely on mechanisms such as the freedom of disabled individuals to disenroll from or switch prepaid plans or on their access to the states' and plans' complaint and grievance systems to help ensure quality of care. While analyses of patterns of disenrollment or complaints can provide meaningful information, in the aggregate they may not be sufficient to detect systemic deficiencies in care for disabled beneficiaries. In contrast, states that either mandate enrollment or provide small, voluntary programs focused exclusively on disabled beneficiaries tend to be furthest along in developing assurances that appropriate, quality care is available to them. Examples of such actions include requiring health plans to designate advocates to help coordinate the services disabled beneficiaries receive and to provide access to specialists specifically trained in care for disabled individuals.

A second challenge for states is developing and administering a managed care system for disabled beneficiaries that is financially sound. However, few states have ventured beyond current rate-setting approaches that base capitation rates on average costs for large segments of statewide Medicaid populations, such as families with children or disabled individuals. However, within the disabled population some groups, such as quadriplegics or AIDS patients, have substantially higher medical costs (sometimes more than $50,000 in a given year), while others, such as mildly disabled individuals, may have few or no additional costs beyond those of the general population. The ability to identify individuals with high-cost disabilities could lead managed care plans to try to avoid enrolling them or to encourage them to disenroll by limiting services inappropriately. The development of more appropriate rate-setting approaches that link rates more closely to individuals' likely costs is still in the experimental stage. States are further along in adopting methods to share the risk of losses experienced by plans that enroll a relatively large number of high-cost individuals. For example, reinsurance programs are the most common form of sharing such losses. A few states are adopting an approach called a "risk corridor," which limits the amount of profit that health care plans can earn as well as the amount of loss they could face, thereby reducing the incentive to inappropriately limit services or to avoid enrolling high-cost individuals.

Principal Findings

Few States Have Significant Experience

Arizona, Delaware, Oregon, Tennessee, Utah, and Virginia are the only states requiring some or all of their disabled beneficiaries to participate in prepaid care programs. These states enroll disabled beneficiaries in prepaid managed care plans that also cover other types of Medicaid recipients. Arizona's program, established in 1982 and currently enrolling more than 70,000 disabled, is the only mandatory program more than 3 years old. In contrast, Massachusetts, Ohio, Wisconsin, and the District of Columbia have small-scale voluntary programs solely for disabled individuals, none of which serves more than 3,000 beneficiaries. Seven other states (California, Colorado, Florida, Maryland, Michigan, New Jersey, and Pennsylvania), as well as Massachusetts, allow disabled beneficiaries to enroll voluntarily in plans open to other Medicaid beneficiaries. In these states, less than 20 percent of the disabled population have chosen to enroll.

One problem identified thus far in states with federal approval to restrict beneficiaries' freedom to change providers has been coordinating enrollment for the estimated one-third of disabled individuals who are "dually eligible" for health care under Medicaid and Medicare. Medicare law guarantees these individuals more freedom in switching providers than they have under Medicaid managed care programs, which require prepaid plan enrollment. The few states wrestling directly with this issue have taken varying approaches, ranging from adjusting their programs to conform with Medicare requirements to seeking waivers of Medicare law that would allow requirements closer to Medicaid's.

Significant Efforts Needed to Ensure Quality

States that rely on monitoring the services prepaid care plans provide to the average enrollee may find that these efforts do not provide enough specificity for assessing care received by disabled enrollees. For example, problems in care provided to a very vulnerable disabled category, such as quadriplegics, might escape general view because few if any cases of quadriplegia would generally appear in random samples across the entire population served by a health care plan. Most states recognize a need to specifically monitor managed care for disabled enrollees and plan to do so as they expand their programs.

Important aspects of states' quality assurance activities can fall into two main categories: (1) building safeguards into the programs through adequate planning and consensus-building and (2) tailoring various aspects of the program (such as enrollment and monitoring) to meet the specific needs of disabled beneficiaries. To date, most of the efforts have been made by several states with mandatory participation by disabled individuals or by states with programs targeted exclusively to disabled beneficiaries on a voluntary basis. The following are examples:

- Oregon's Medicaid staff met weekly with health plans, advocates for disabled individuals, and others for more than a year before the program was implemented.
- Wisconsin requires the health plan serving participants in its targeted prepaid care program, which serves only disabled beneficiaries, to have a Medicaid advocate on staff who is knowledgeable about disabilities. Wisconsin also mandates that case managers conduct needs assessments within 55 days of enrollment in the plan.
- Massachusetts allows specialists to act as primary care providers and uses a health needs assessment that assists enrollment staff in working with beneficiaries to select a plan.

Information about the services provided to disabled patients is essential for effective monitoring. Since services are no longer paid for on a fee-for-service basis, however, the reimbursement process no longer produces this information. Developing comprehensive, consistent data on services provided under prepaid care takes time and effort. To date, only Arizona has substantial experience in doing so. The effort, which can be expensive and time-consuming, can permit states to identify areas in which service utilization rates are overly low or high. It can also allow states to track movement of high-cost individuals among health plans, a step that could help spot service delivery problems.

Experimentation Is Under Way in Rate-Setting and Risk-Sharing

Prepaid care capitation rates are normally based on average costs for broad categories of beneficiaries, such as all disabled people in a state. However, some categories of disabled individuals have very high costs, while others have relatively low costs. Paying the same rate for groups with different health care needs increases the risk that plans will seek to enroll only the healthier, less expensive individuals. If plans feel financial pressure from treating high-cost cases, they may also seek to limit inappropriately the services these individuals receive. Three states (Massachusetts, Missouri, and Ohio) are experimenting with ways to set rates for disabled enrollees that more accurately reflect their varying needs for care. For example, Ohio is exploring an approach that varies the prepaid rate based on prior medical costs, with medical plans receiving more money for people with demonstrated higher needs.

Most states that include disabled beneficiaries in prepaid care, and especially those with mandated enrollment, provide some form of “safety net” for plans that experience losses related to treating high-cost cases. The most common form is called “reinsurance”—essentially an insurance policy that plans can buy. Reinsurance is directed only at losses. Five states (District of Columbia, Massachusetts, Ohio, Utah, and Wisconsin) have implemented another type of arrangement, called a “risk corridor,” that not only shares losses between the plan and the state but also restricts how much of its capitation payments the plan can retain after paying for enrollees’ health care needs. In Massachusetts, for example, plans serving those who are severely disabled must return to the state any profit that exceeds 10 percent of the capitation payments they received. Under a risk corridor, a plan’s incentive to limit services inappropriately and thereby increase the amount it may retain is reduced because such amounts are limited to a maximum.

Recommendations

GAO is not making recommendations in this report.

Agency Comments

GAO provided a draft of this report to the Administrator, Health Care Financing Administration (HCFA), and to Medicaid officials from the 17 states in its study. In addition, GAO requested comments from several independent experts in the fields of Medicaid and prepaid care for people with disabilities. HCFA had no comments, while comments from states and researchers were primarily technical or clarifying and were incorporated as appropriate. Officials from one state commented that the draft seemed to question the suitability of prepaid managed care for people with disabilities. GAO believes, rather, that careful attention to program design and implementation is needed when including this vulnerable population in prepaid care, given their complex health care needs and the limited experience to date with serving them in prepaid settings.

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Abbreviations

AFDC	Aid to Families With Dependent Children
AIDS	acquired immunodeficiency syndrome
CMA	Community Medical Alliance
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HMO	health maintenance organization
ICF/MR	intermediate care facility for the mentally retarded
IMD	institution for mental diseases
NF	nursing facility
SSI	Supplemental Security Income

Background

Medicaid, a joint federal-state health financing program for the poor, provided health care coverage for more than 40 million people in fiscal year 1995. Medicaid expenditures—about $159 billion in fiscal year 1995[1]—have more than tripled in the past 10 years. Under current projections, they will double again within 8 years.

To help constrain rising costs, a number of states are making increased use of prepaid managed care in their Medicaid programs. Under this approach, a medical plan such as a health maintenance organization (HMO) agrees to make a specified set of medical benefits available in exchange for a prepaid amount of money per person. This approach is considered less expensive than the traditional fee-for-service approach because it eliminates the incentive to provide unnecessary or overly expensive services in order to maximize revenues.

Thus far, most states have focused their Medicaid managed care efforts on programs for low-income families, which accounted for about 73 percent of Medicaid beneficiaries in fiscal year 1994. However, states are now directing more attention to using managed care for another group of Medicaid beneficiaries—those who are disabled. These individuals constitute about 15 percent of all Medicaid beneficiaries, but because many of them have a heavy need for specialized medical services, they account for over one-third of all Medicaid expenditures.

For a number of reasons, such as their ongoing dependence on specialized care and the wide diversity of types and severity of conditions, bringing disabled people into managed care presents challenges that differ from covering many other segments of the population. Dealing with these challenges involves ensuring that adequate mechanisms are in place to safeguard the interests of all three major stakeholder groups: the disabled beneficiaries, who are concerned about adequate access to quality care; the managed care plans, which are concerned about not assuming inappropriate or excessive financial risk; and the states and federal government, which are concerned about protecting the interests of both beneficiaries and taxpayers. For the most part, this is new territory: Most states have little or no experience in adjusting their managed care programs to meet these specialized needs.

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[1] Amounts include both health services and administration for federal fiscal year 1995, which ended Sept. 30, 1995.

Disabled People Are One of Several Groups Eligible for Medicaid

The range of services provided under Medicaid varies from state to state. Established in 1965 as title XIX of the Social Security Act (42 U.S.C. 1396-1396s), Medicaid programs are required under federal law to provide eligible beneficiaries with certain primary, acute, and long-term care benefits. Examples include physician services, hospital care, laboratory services, preventive care for children, and nursing facility care. At their option, states[2] may also elect to provide coverage for an array of other services, such as prescription drugs, medical equipment, eyeglasses, dental care, and ancillary services such as physical and speech therapy. Medicaid is administered at the state level, with the Health Care Financing Administration (HCFA) within the Department of Health and Human Services (HHS) providing oversight and coordination at the federal level.

Those eligible for Medicaid come primarily from two cash assistance programs: Aid to Families With Dependent Children (AFDC) and Supplemental Security Income (SSI). AFDC is the primary route by which children and their families become eligible, while elderly, blind, and disabled individuals become eligible primarily through SSI. Coverage expansions since 1984 have also increased the number of beneficiaries not linked to cash assistance payments. These include people who are eligible for Medicare, low-income children and pregnant women who are not receiving AFDC, and several mandatory and optional coverage groups among disabled and elderly individuals.

About 6 million disabled individuals were covered by Medicaid in fiscal year 1994. To qualify for SSI—and therefore for Medicaid in most states[3]—beneficiaries must meet certain program criteria for disability and for maximum allowable financial resources. Eligibility criteria center on an individual's ability to function in daily life and the existence of a disabling diagnosis or condition.[4] In 1996, the maximum allowable income was $470 per month for an individual and $705 for a couple.[5] States have

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[2] Besides the 50 states, 6 other entities have programs: the District of Columbia, American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the Virgin Islands. For this report, we refer to all 56 as "states."

[3] Eleven states elect to retain the more restrictive Medicaid eligibility criteria that were in place for blind, disabled, and elderly beneficiaries before SSI was established in 1972. These states may use more restrictive definitions of disability or more restrictive financial eligibility criteria than SSI.

[4] Specifically, a disabled person is one who is unable to engage in any substantial gainful activity because of a medically determined physical or mental impairment that is expected to result in death or that has lasted (or can be expected to last) at least 12 months. Eligibility for children is based on developmental delays and functional impairment.

[5] Maximum financial assets exclusive of a home, automobile, burial space(s), and personal effects were $2,000 for an individual and $3,000 for a couple.

the option of extending eligibility to people who receive state payments that supplement SSI benefits;[6] to some people whose incomes are above SSI levels but who are sufficiently disabled to need institutional care; and, with federal approval, to some people who are at risk of needing institutional care. For 1996, the federally specified maximum income level for an "SSI-related" individual was $1,410 per month.

More than half of all disabled people receiving SSI as of December 1994 were eligible on the basis of a mental disability. Such disabilities included mental retardation, autism, schizophrenia, paranoia, and, under certain circumstances, substance abuse.[7] For those who were eligible on the basis of physical disabilities, the main categories were diseases of the nervous system, sense organs,[8] musculoskeletal and connective tissues, or circulatory system. Specific conditions in these categories included blindness, muscular dystrophy, cerebral palsy, Parkinson's syndrome, brain tumors, rheumatoid arthritis, osteoporosis, and chronic heart disease.

Children constitute about 22 percent of disabled SSI recipients. Among them, mental retardation is the leading cause for eligibility. Since a 1990 U.S. Supreme Court decision,[9] SSI disability criteria for those 18 and younger have been based on developmental delays and limitations in ability to engage in age-appropriate activities.

Disabled People Account for Over One-Third of Medicaid Expenditures

Many disabled Medicaid beneficiaries have a level of medical need that is atypical of the general population. A disabled person's degree of disability can range from mild to very severe. At the more severe levels, individuals may be technology-dependent, requiring medical devices to compensate for loss of a vital body function. Many of them also require ongoing nursing care to avert death or further disability.

Because of their atypical medical needs, disabled individuals have medical costs that are generally higher than those of the typical Medicaid beneficiary. In fiscal year 1994, disabled individuals were about 15 percent

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[6] In some cases, states are required to provide supplemental payments. In February 1994, less than 0.1 percent of SSI recipients qualified for these required payments.

[7] Drug or alcohol addiction by itself does not qualify an individual for SSI benefits. Rather, individuals must be disabled (as defined by SSI law) with addiction as a factor contributing to the disability.

[8] Because blindness is included among disabilities of the sense organs, throughout this report we will refer to blind and disabled beneficiaries collectively as disabled.

[9] Sullivan v. Zebley, 493 U.S. 521 (1990).

of the Medicaid population and accounted for 39 percent of Medicaid expenditures, including long-term care. Table 1.1 shows an Urban Institute analysis of how expenditures for different services in 1993 were distributed on a per-person basis. Average total expenditures for disabled ($7,956) and elderly individuals ($9,293) were each more than three times the spending for other children and adults.

Table 1.1: Average Medicaid Per-Person Expenditures by Beneficiary Group, 1993

	Primary and acute care						
Beneficiary group	**Inpatient**	**Physician, lab, X ray**	**Outpatient**	**Other[a]**	**Total**	**Long-term care[b]**	**All services**
Disabled	$2,072	$443	$773	$1,183	$4,471	$3,485	$7,956
Elderly	541	139	155	793	2,385[c,d]	6,907	9,293[c]
Other adults	805	381	304	313	2,041[c,d]	27	2,067[c]
Other children	452	159	165	203	1,116[c,d]	74	1,191[c]

Note: Some data on this table are estimates made by the Urban Institute to correct problems in data reported to HCFA by states.

[a] Includes prescription drugs, case management, family planning, dental, children's preventive services, vision, and other practitioner care (such as therapy).

[b] Long-term care includes institutional care, inpatient mental health care, and home health services.

[c] Totals do not add because of rounding.

[d] Totals do not sum from the listed services because they include payments to Medicare and prepaid health plans that cannot be assigned to specific services.

Source: Urban Institute calculations based on HCFA data.

Managed Care Is Growing Throughout the Medicaid Program

In general terms, managed care refers to a range of health care models that use primary care practitioners to control and coordinate the delivery of services. The best-known options are prepaid (or "capitated") models that involve payment of a set monthly amount per enrollee (the capitation fee) to provide or arrange for a specified set of services.[10] Faced with rising Medicaid expenditures—the fastest-growing portion of most state budgets—many states have begun to incorporate managed care into their service delivery approach. Managed care is seen as a way to help control these costs because it discourages providers from providing unnecessary

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[10] Other managed-care options include primary care case management models, which are similar to traditional fee-for-service arrangements except that providers generally receive a per capita case management fee to coordinate the care for enrolled patients in addition to reimbursement for each service they deliver.

services and directs beneficiaries to obtain care in the most cost-effective settings (for example, obtaining primary care at a clinic rather than a hospital emergency room).

Managed care is also seen as a way to better ensure that Medicaid beneficiaries have access to quality care. In theory, managed care improves access and quality by linking individual beneficiaries with a single provider responsible for coordinating their health care needs. Our earlier review of these efforts found that the capitated managed care programs were succeeding, at least to some degree, in providing the kinds of benefits for which they had been designed. We found access to care was slightly better than in traditional fee-for-services programs and quality was about equal between the two.[11]

In June 1995, almost 15 percent of all those who received Medicaid services were enrolled in prepaid managed care plans.[12] Their numbers, while still small in relationship to the total number of beneficiaries, are growing swiftly. For example, from June 1993 to June 1995 enrollment in capitated plans more than doubled, from 2.1 million to 5.3 million.

To date, most states have largely targeted their managed care programs—particularly those that require enrollment in prepaid plans—to children and adults who qualify for Medicaid through AFDC or other programs, not toward elderly and disabled individuals. However, states are increasingly including—or planning to include—disabled and aged populations as well.

Federal Requirements Govern State Use of Managed Care in Medicaid

A key feature of state Medicaid programs historically has been beneficiaries' freedom to choose from among participating providers. While this freedom helped protect quality because beneficiaries who felt the care they received was inadequate or inferior could simply change providers, it did not guarantee that providers would be available to treat them. Managed care approaches attempt to guarantee access to a provider but often in exchange for some limitation on beneficiaries' freedom of choice. The extent to which state Medicaid managed care programs restrict beneficiaries' choice of providers determines, in part, whether

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[11] Medicaid: States Turn to Managed Care to Improve Access and Control Costs (GAO/HRD-93-46, Mar. 17, 1993).

[12] The percentage enrolled would be somewhat lower if calculated on the number of people eligible to receive services rather than those who actually did. Data on the number of eligible people in fiscal year 1995 were not available.

states will need to seek approval from HCFA to waive one or more provisions of Medicaid law.

States have three options for using capitated managed care plans in their Medicaid programs—one that requires no waiver of Medicaid statute and two that do. Since the late 1960s, states have had the option—with no need for a waiver—to contract with prepaid managed care plans to deliver health care services to Medicaid beneficiaries, provided certain conditions are met. One is voluntary enrollment: Beneficiaries must ordinarily be permitted to disenroll at any time and return to the Medicaid fee-for-service program.[13] Other conditions relate to such matters as the kinds of plans that can participate: They must be federally qualified or state-certified HMOs,[14] have a mix of enrollment that is no more than 75 percent Medicaid/Medicare enrollees, and engage in a range of quality assurance activities.

The other options for using managed care exist under waiver authorities granted to the Secretary of HHS. These authorities allow the Secretary to waive certain statutory requirements—including the beneficiaries' freedom to choose from among participating providers—so that a state can develop alternative methods of service delivery or reimbursement. These waivers are of two general types—program[15] and demonstration.[16] Table 1.2 compares various characteristics of the two types of waivers. Although managed care approaches and mandated enrollment (that is, a program that requires Medicaid participants to select among managed care approaches) can be authorized under either type of waiver, waiving the federal regulations concerning the types and enrollment mix of prepaid organizations can only be done under a demonstration waiver.

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[13] An exception exists for federally qualified HMOs and certain other federally designated organizations. After a 1-month trial period has passed, states may restrict an enrollee's ability to disenroll for 5 months.

[14] A limited set of other organizations also qualify, such as certain types of federally designated community health centers.

[15] Program waivers are of several types, all of which are authorized under section 1915 of the Social Security Act.

[16] Demonstration waivers are also known as section 1115 waivers, after the portion of the Social Security Act that authorizes them.

Table 1.2: Comparison of Managed Care Flexibility Under Program and Demonstration Waivers

Program waivers	Demonstration waivers
General characteristics	
Allows for waiver of a limited set of Medicaid requirements	Allows for waiver of nearly any provision in Medicaid law
Approval is generally based on meeting certain established conditions	Approval is based on the discretion of the Secretary of HHS
Waivers can be renewed for 2- to 5-year periods	Generally not renewable[a]
Generally used to establish primary care case management programs and home and community-based service programs	More recently used to establish broad changes in Medicaid programs
Characteristics pertaining to prepaid managed care	
Prepaid plans must still meet federal requirement for 25% or more private enrollment	Prepaid plans may enroll Medicaid patients exclusively
Full range of mandatory services must be offered	Benefit package may be modified[b]
Prepaid plan enrollment “lock-in” limited to 1 month[c]	Prepaid plan enrollment “lock-in” may be extended to 12 months
No restrictions on access to family planning providers	Access to family planning providers may be restricted

[a] The Congress has authorized renewal of some demonstration waivers.

[b] To date, only Oregon has been permitted to modify the benefits package for traditional Medicaid beneficiaries. Other states have been permitted to offer a modified package only to those newly eligible for Medicaid coverage under the demonstration.

[c] Lock-in is 6 months for prepaid plans meeting certain federal requirements.

The use of prepaid managed care to provide health care for disabled beneficiaries is also affected by the statutory requirements of other programs besides Medicaid. Specifically, because many disabled Medicaid beneficiaries are simultaneously eligible for one or more other federal programs—most notably Medicare[17]—state prepaid programs must accommodate requirements of these other programs. The Medicare statute, in particular, contains a number of provisions that cannot be waived and that directly affect basic features of Medicaid prepaid care. For example, the Medicare statute requires participating health plans to have an enrollment mix with no more than 50 percent publicly insured

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[17] Medicare, authorized by title XVIII of the Social Security Act, is a federal health insurance program that covers most people aged 65 or older, all people who receive Social Security disability benefits for 24 months or more, and most people who suffer from kidney failure. Medicare consists of two parts: part A, which covers inpatient hospital, skilled nursing care, home health, and hospice services, and part B, which covers physician and a wide range of other services, including physical therapy.

enrollees, in contrast to Medicaid's allowance for up to 75 percent publicly insured members.

Applying Managed Care to Disabled Beneficiaries Poses Additional Challenges

Interest in using prepaid managed care programs for disabled Medicaid beneficiaries has prompted concerns about whether this approach is suitable to meet the needs of disabled beneficiaries. One positive viewpoint is that disabled individuals have much to gain from managed care because of its guarantee of access to a primary care practitioner and its potential for coordinating an array of available services. Improved access may particularly benefit segments of the disabled population that have historically been unable to locate practitioners willing to serve them. However, because prepaid plans typically emphasize primary care, limit access to specialty care, and carefully control the utilization of services as ways to control costs and manage care, they are potentially disadvantageous to certain disabled beneficiaries because of their need for extensive services and access to a range of highly specialized providers. For example, compared with nondisabled children in the general population, disabled children use twice as many physician visits and prescribed medications and five times as many other services, such as physical therapy. Among Medicaid children, the average per-person health care costs in 1992 were seven times higher for disabled than for nondisabled children. Other estimates place the per-person cost for moderately disabled individuals at two to three times the cost for nondisabled individuals.

The "medical necessity" standards within many prepaid plans are one example of the potential problems that disabled individuals may face, according to advocacy groups. While not unique to prepaid care, these standards often call for "substantial improvement" or "restoration of function" as conditions for recommending therapies or certain types of medical equipment. However, many disabled people have conditions that preclude making substantial improvement or restoring functions. Advocacy groups worry that medical necessity standards may restrict disabled people from receiving therapy or equipment when they need it basically to maintain their existing level of functioning or to substitute for lost functioning. Advocacy groups have also raised concerns about the potential for managed care plans to disrupt the network of providers that disabled persons have assembled over time.

Another concern that has been raised about using managed care for disabled people is the potential effect on what could be called the “perverse incentives” inherent in a prepaid managed care approach.[18] While incentives in a fee-for-service system may encourage a provider to deliver too many services, prepaid programs may encourage health plans to deliver fewer, or less expensive, services than enrollees need, such as using a physical therapist skilled in sports medicine rather than in specific disabilities such as spinal abnormalities.

Objectives, Scope, and Methodology

The Chairman and Ranking Minority Member of the Subcommittee on Medicaid and Health Care for Low-Income Families of the Senate Committee on Finance asked us to examine (1) the extent to which states are implementing prepaid Medicaid managed care for disabled beneficiaries and (2) what steps states have taken to safeguard the interests of the three major stakeholder groups—disabled beneficiaries, prepaid health care plans, and the government—with a focus on quality assurance and rate-setting mechanisms. On the basis of discussions with subcommittee staff, we focused our review on the delivery of primary and acute medical services. We also focused our work on prepaid managed care programs—thus excluding those types of managed care that are not risk based—because prepayment has the potential to result in underservice to enrolled members.

To identify states with Medicaid managed care programs for disabled beneficiaries, we reviewed HCFA documentation and interviewed national Medicaid experts, including officials at organizations such as the National Academy for State Health Policy and the Medicaid Working Group. From the 17 states identified as having Medicaid prepaid managed care programs for their disabled population,[19] we obtained information on a wide range of topics, including quality-monitoring activities and rate-setting methodologies. We interviewed officials in these states to obtain their views on problems they had encountered serving disabled individuals in prepaid managed care plans and ways they had gone about solving them.

On the basis of what we learned about the states as a whole, we selected three states—Arizona, Oregon, and Massachusetts—for additional study. Arizona and Oregon have relatively long-standing programs that provide a

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[18] Under prepaid managed care, plans are at financial risk—that is, they must cover losses if the cost of providing services to enrollees exceeds the amount received in capitation fees. Conversely, they may keep the excess if the cost of providing services is less than the amount received in capitation.

[19] The 17 states are Arizona, California, Colorado, Delaware, the District of Columbia, Florida, Maryland, Massachusetts, Michigan, New Jersey, Ohio, Oregon, Pennsylvania, Tennessee, Utah, Virginia, and Wisconsin.

degree of operational experience generally not present in other states. Massachusetts has administered for almost 5 years a targeted program for severely incapacitated adults that has served as a model for other state experiments. Our work in these three states included interviewing Medicaid and other state officials, selected providers, and advocacy groups. We obtained and analyzed data provided by the three states, and where they were available, we reviewed existing federal, state, and independent studies of the programs.

During our review, we also interviewed other researchers and knowledgeable officials and reviewed available studies of managed care programs for disabled persons. We performed our work for this study between November 1995 and May 1996 in accordance with generally accepted government auditing standards.

Chapter 2

States Are Moving Toward Managed Care for Disabled Medicaid Recipients

Of the 17 states that enrolled some portion of their disabled Medicaid beneficiaries in prepaid managed care plans, enrollment ranged from less than 1 percent to all of a state's disabled beneficiaries. Six states have programs that are mandatory for some or all disabled beneficiaries. Of the remaining 11 states, 3 operate small-scale, voluntary programs focused specifically on disabled beneficiaries; 7 allow disabled beneficiaries to participate voluntarily wherever prepaid plans for the general Medicaid population are available; and 1 does both.

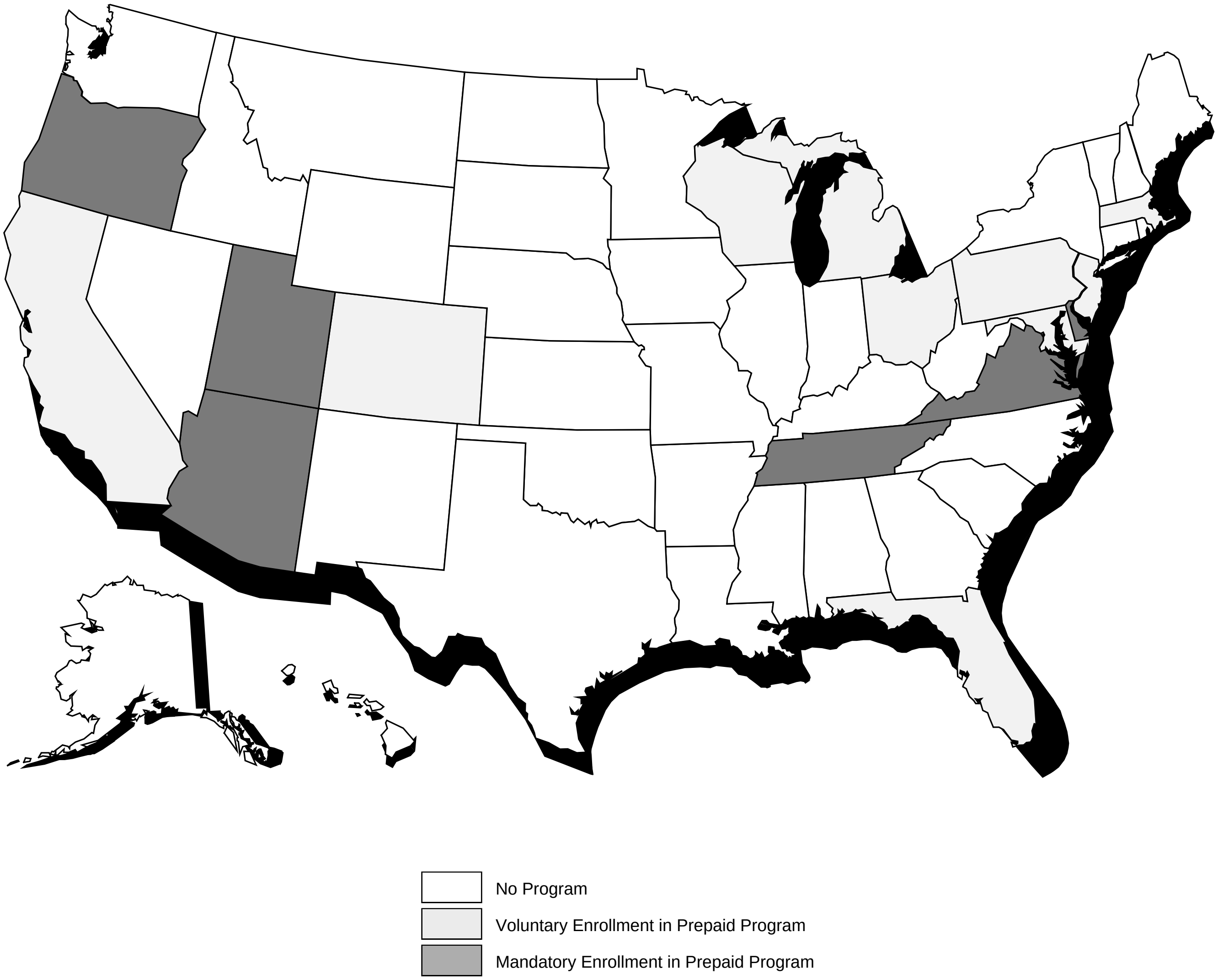
Thirteen states exclude one or both of their more vulnerable disabled populations—those in institutional care and those receiving home and community-based long-term care—from prepaid plan enrollment. However, under certain circumstances, all 17 states include one or more groups of "dually eligible" beneficiaries, who are simultaneously eligible for Medicaid and another federally funded program, such as Medicare. Coordinating enrollment and other requirements for this dually eligible group is difficult, according to state officials.

In addition to the 17 states currently enrolling disabled beneficiaries, more states have plans under way to include them in prepaid managed care. Specifically, 10 additional states have waiver proposals either approved or pending; three of these are for pilot programs to gain experience with the approach.

17 States Have Medicaid Prepaid Managed Care Programs for Disabled Beneficiaries

As of February 1996, 17 states have implemented prepaid managed care programs for disabled Medicaid beneficiaries (see fig. 2.1). Six of 17 mandate prepaid plan enrollment for most or all of their disabled Medicaid beneficiaries. Three states designed small-scale programs specifically for disabled individuals in which participation is voluntary. In seven states, disabled beneficiaries may voluntarily enroll wherever prepaid health care plans are available for the general Medicaid population. The remaining state operates both a small-scale program for disabled individuals and allows beneficiaries to enroll wherever plans are available.

Figure 2.1: States With Prepaid Managed Care Plans for Disabled Medicaid Beneficiaries, February 1996



Note: Washington, D.C. (not pictured), has implemented a targeted voluntary program.

Table 2.1 shows the available comparative data on enrollment for these programs. Limitations in reporting formats preclude comparisons for two states.[20] For the five mandatory programs with available data—Arizona, Oregon, Tennessee, Utah, and Virginia—participation ranged from 15.2 to 100 percent of all disabled Medicaid beneficiaries. Participation by eligible beneficiaries in the voluntary programs targeted exclusively to disabled individuals ranged from less than 1 percent to almost 11 percent, and participation in the remaining voluntary programs ranged from 3 to 20 percent.

Table 2.1: Enrollment of Disabled Beneficiaries in 17 State Medicaid Prepaid Managed Care Programs, February 1996

	Disabled Medicaid beneficiaries			
State	**Total disabled eligibles**	**Total enrolled in prepaid program**	**Percentage enrolled in prepaid program**	**Year enrollment by disabled began**
Mandatory programs				
Arizona	64,456	56,775	88.0[a]	1982
Delaware	12,198	N/A	N/A	1996
Oregon[b]	39,906	28,423	71.2	1995
Tennessee	138,931	138,931	100.0	1994
Utah[c]	17,155	8,158[d]	47.6	1982
Virginia	91,082	13,817[d]	15.2	1995
Voluntary programs targeted only to disabled individuals				
District of Columbia	3,200[e]	8	0.25[f]	1996
Ohio	36,000[e,g]	294	0.82[h]	1995
Wisconsin	22,041[e,i]	2,404	10.9	1994
Voluntary programs for the general Medicaid population				
California	770,067	28,262[j]	3.7	1972
Colorado	45,042	8,842	19.6	1974
Florida	N/A	N/A	N/A	1981
Maryland	83,350	10,496	12.6	1975
Michigan	234,517	42,373	18.1	1972
New Jersey	143,793	4,226	2.9	1983
Pennsylvania	247,902	50,443	20.4	1972
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population				
Massachusetts	164,366	7,935	4.8	1992

(Table notes on next page)

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[20] These two states—Delaware and Florida—do not disaggregate SSI and related categories to distinguish among aged, blind, and disabled beneficiaries.

Note: N/A means the state does not distinguish in enrollment and/or eligibility reports the categories of SSI and related beneficiaries that include aged and disabled.

[a] Medicaid eligible individuals not enrolled in a prepaid plan are Native Americans who live on reservations and who elected to receive care from an Indian Health Service facility.

[b] Oregon allows disabled beneficiaries, under certain conditions, to receive services in managed or nonmanaged fee-for-service settings.

[c] In 1995, the Utah program became mandatory in urban areas only. Enrollment of disabled beneficiaries in the urban areas was phased in and should be completed by July 1996.

[d] Enrollment figures include both mandatory and voluntary participants.

[e] Numbers reflect those eligible to participate in the targeted programs. See table 2.2 for more detail about which disabled beneficiaries may enroll in each program.

[f] Enrollment began in February 1996. As of March 1996, 180 children were enrolled.

[g] Program is limited to three counties.

[h] Enrollment began in one county in May 1995, another in June 1995, and the remaining county in September 1995. March enrollment for the three counties totaled 355.

[i] Program is limited to one county and enrollment is capped at 3,000, making current enrollment 80 percent of capacity.

[j] Enrollment figures are somewhat understated because data from one county do not distinguish between enrollment in prepaid and primary care case management providers.

Sources: State enrollment and eligibility reports for February 1996.

Table 2.2 describes some basic features of the four state programs designed for disabled beneficiaries. Two states—Ohio and Wisconsin—began these specialized programs in selected urban communities to gain experience before expanding their programs statewide. The District of Columbia's program is available to all eligible disabled children who live in the District. The fourth state—Massachusetts—administers a prepaid program to care for severely disabled beneficiaries but also allows disabled beneficiaries statewide to enroll in prepaid plans.[21]

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[21] Two of the four states also have an approved or pending demonstration waiver that would require some or all disabled beneficiaries to participate in prepaid managed care. The District's program, which is an approved demonstration, is voluntary.

Table 2.2: Description of Four State Prepaid Programs Designed Specifically for Disabled Beneficiaries

State	Program name and description
District of Columbia	The Managed Care System for Disabled Special Needs Children is designed to reduce barriers to care faced by disabled children and their families. Begun in February 1996, the program contracts with a single nonprofit managed care plan to serve disabled people 22 and younger and is designed to move them, whenever possible, from institutions into community settings. Each enrolled child is assigned a primary care practitioner—usually his or her current provider—and a case manager who develops an individualized plan of care through a face-to-face assessment and helps coordinate needed medical and social services, including transportation and home adaptation. Enrollment will be phased in over 6 months with the goal of serving a total of about 3,000 within 2 years. Participation is voluntary and enrollees may change primary care practitioners at any time. One goal of the program is to build a comprehensive database profiling each enrollee to determine if caring for children with complex medical needs can be improved through managed care.
Massachusetts	Massachusetts contracts with three prepaid plans that focus on care of people with severe physical disabilities or end-stage AIDS. Combined enrollment in any given month is about 300. The program began in 1992 with a single health plan—now called the Community Medical Alliance (CMA)—which coupled primary care with enhanced home visits and case management. Severely disabled enrollees are screened for each of the following criteria: permanent triplegia or quadriplegia; a need for personal care or other equivalent assistance to maintain independent living; and one of several specified diagnoses, such as spinal cord injury, cerebral palsy, or end-stage muscular dystrophy. AIDS enrollees must meet the clinical criteria of end-stage AIDS. At CMA medical care is provided by a clinical team of physicians and nurse practitioners, with each patient assigned to a nurse practitioner. Care is provided in the most appropriate setting—most often the patient's home—as an alternative to specialty and hospital care.
Ohio	The Accessing Better Care program began enrolling physically disabled and chronically ill beneficiaries under age 65 in three metropolitan areas in 1995. It offers a flexible benefits package that includes home and community-based care as alternatives to institutional care whenever possible and currently enrolls about 300 of the 36,000 eligible beneficiaries. Each area has its own prepaid health care plan, which is a partnership between an HMO and an academic medical center. Care is delivered by an interdisciplinary care team led by a social worker or nurse case manager. Individual care plans for each enrollee are developed from initial assessments. Specialists play active roles on the care teams.
Wisconsin	Designed for disabled beneficiaries over the age of 15, I-Care began operation in 1994 and is a joint venture between a rehabilitation center and an HMO. It currently operates in one metropolitan county and will eventually serve 3,000 beneficiaries. Care coordinators assess initial medical and social needs through an in-home visit, develop an individual care plan jointly with providers and social workers, and assist beneficiaries and their families in selecting and accessing providers. Care coordinators are nurses or social workers knowledgeable about disabilities. All prepaid plan staff are trained in working with people with disabilities. Beneficiaries may select from clinic sites throughout the city. Whenever possible, enrollees' existing primary care practitioners are invited to join the provider panel. Wisconsin hopes to expand the program to two additional counties in 1997.

Six states—Arizona, Delaware, Oregon, Tennessee, Utah, and Virginia—mandate prepaid plan enrollment for some or all of their disabled beneficiaries.

- Arizona, Delaware, Oregon, and Tennessee mandate prepaid enrollment under demonstration waivers for all Medicaid beneficiaries. Oregon allows beneficiaries, in concert with their social service case workers, to select fee-for-service care (either managed—called primary care case management—or nonmanaged) when prepaid care does not best meet their health care needs. As a result, enrollment of disabled beneficiaries in Oregon is about 71 percent, compared with 100 percent in Tennessee.[22] In Arizona, Native Americans who live on reservations may elect to receive health care from either a prepaid plan or Indian Health Service facilities.

- Utah and Virginia mandate prepaid enrollment in selected areas under the program waivers they received from HCFA.

The extent to which these six states with mandatory enrollment adapt their managed care programs specifically for disabled beneficiaries is further discussed in chapters 3 and 4.

Most States Exclude the More Vulnerable From Managed Care

Medicaid covers care for two types of more severely disabled individuals—those in institutional care[23] and those receiving home and community-based long-term care.[24] People meeting these criteria are at least partially unable to care for themselves because of an injury, illness, or other disabling condition. The range of services they need extends beyond primary and acute medical care to include assistance with everyday activities, such as dressing and using the bathroom, that the individual cannot do independently because of his or her disability. Such services include personal care attendants, homemaker services, adult day care, and respite for family caregivers.

Thirteen of the 17 states exclude one or both of these vulnerable populations (see table 2.3). More specifically, 12 exclude disabled beneficiaries who reside in institutions, and 10 exclude those receiving home and community-based long-term care. Under demonstration waivers, two states—Arizona and Tennessee—mandate prepaid plan enrollment of these populations for their primary and acute care needs but provide long-term care under separate arrangements. Specifically, long-term care in Tennessee remains fee-for-service and in Arizona is coordinated by a single contractor—typically a state or county agency—for each county. In Oregon, residents of institutions for the mentally retarded and the

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[22] Demonstration waivers allow states the flexibility to determine health care delivery systems for specified beneficiaries, including giving some a range of managed care alternatives while keeping others in fee-for-service care. Consequently, a state with "mandatory" prepaid enrollment may have certain beneficiaries in other settings. For example, Oregon designated primary care case management as an acceptable managed care alternative.

[23] Institutional care in Medicaid refers to care delivered in nursing facilities, intermediate care facilities for the mentally retarded (called ICF/MR), and, more limitedly, in institutions for those with mental diseases.

[24] Home and community-based care is made available, with HCFA approval, to Medicaid beneficiaries who, in the absence of such services, would be likely to require care in a Medicaid-covered institution.

mentally ill are not enrolled in prepaid plans, while nursing home residents are.

Table 2.3: Extent to Which 17 States Include Severely Disabled Beneficiaries in Medicaid Prepaid Care Programs, February 1996

State	Institutional populations included?[a]	Home and community-based services participants included?[b]
Mandatory programs		
Arizona	NF, ICF/MR, IMD	Yes
Delaware	No	No
Oregon	NF	Yes
Tennessee	NF, ICF/MR, IMD	Yes
Utah	No	Yes
Virginia	No	No
Voluntary programs targeted only to disabled individuals		
District of Columbia	NF, ICF/MR	No
Ohio	No	No
Wisconsin	No	No
Voluntary programs for the general Medicaid population		
California	No	No
Colorado	NF	Yes
Florida	No	No
Maryland	No	No
Michigan	No	No
New Jersey	No	No
Pennsylvania	No	Yes
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population		
Massachusetts	No	Yes

[a] Institutionalized beneficiaries include residents of nursing facilities (NF), intermediate care facilities for the mentally retarded (ICF/MR), and institutions for mental diseases (IMD).

[b] Home and community-based services programs provide a broad range of services to beneficiaries who, in the absence of such services, would require care in Medicaid-covered institutions. Beneficiaries these programs serve include disabled people who might need care in a nursing facility and those who are developmentally disabled or mentally retarded who might need care in an ICF/MR.

Of the 17 states, only the District of Columbia includes long-term care in the set of services covered by capitation payments to health plans.[25] However, a few such programs have existed on a small scale since the 1980s, and HCFA is currently reviewing Colorado's request to implement a pilot program in one county. Integrating primary and acute care into a single prepaid contract with long-term care presents certain challenges. Among them are the lack of generally accepted standards regarding the use of various long-term care services; prepaid plans' lack of experience providing long-term care; the potential for the demise of existing community-based providers with experience in delivering such care; and the difficulty in establishing adequate rates for the combined set of services. Concerns about integrating the two types of care include the potential for medically based prepaid plans to emphasize medical technology or institutional care over the social and supportive services that many beneficiaries prefer. In addition, integration raises concerns about who should perform care needs assessments and case management services—state or prepaid plan staff—given the lack of recognized standards for appropriate long-term care and the fact that in such integrated arrangements a single provider is responsible for major portions of an individual's life needs.

Enrollment of Dually Eligible Individuals Creates Challenges

Another consideration for states with Medicaid managed care initiatives is whether to include beneficiaries who are also eligible for medical services or supplies through another federal program. For Medicaid beneficiaries, these programs fall into two categories—Medicare and title V and related school-based programs.

Medicare is a federal health insurance program that covers, among others, all people who have received Social Security disability benefits for 24 months or longer. Medicare and Medicaid provide essential and complementary services to dually eligible beneficiaries. For example, Medicare is the primary provider of inpatient and physician care, while Medicaid generally provides prescription drugs. Some estimate that about one-third of disabled Medicaid beneficiaries nationally are also covered by Medicare, but proportions will vary from state to state. For example, Oregon officials estimate that 45 percent of disabled beneficiaries are also covered by Medicare.

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[25] Long-term care is included because the District's program is designed to help disabled children make the transition from institutional to community-based care. Arizona's long-term care program is primarily operated by state and county agencies that subcontract to separate providers for long-term care and for primary and acute care services, although the Medicaid program does not require them to do so.

Title V of the Social Security Act authorizes state programs to improve the health of mothers and children, including children with special health needs. These programs, which are limited in scope and vary among states, provide and promote state and community-based systems of services for children with special health needs and typically serve children from low- and moderate-income families. Such programs arrange for initial assessments, service plans, outpatient specialty physician services, and therapies and care coordination for children with various chronic conditions. Disabled children may receive various therapies and assistive equipment—speech therapy and wheelchairs, for example—funded from title V as well as from schools that must assure children access to certain medical services that allow them to participate in school. In many cases, these services and equipment are also covered by Medicaid.

The often conflicting or overlapping requirements of Medicaid and other programs, particularly Medicare, have been cited as a barrier to including dually eligible beneficiaries in mandatory prepaid managed care programs. In general, state officials cited the inflexibility of Medicare rules as a deterrent to developing a Medicaid prepaid program that includes those dually eligible for Medicare. Including those eligible for other programs gives rise to the need for negotiations and extensive coordination between the Medicaid staff, HCFA, and representatives from plans and other agencies serving those beneficiaries. Table 2.4 provides examples of barriers states encounter when attempting to include dually eligible beneficiaries.

Table 2.4: Examples of Barriers States Face in Including Dually Eligible Beneficiaries in Medicaid Prepaid Managed Care Programs

Program	Barrier
Medicare	Plans may be unwilling to participate in Medicaid prepaid programs if the addition of dually eligible beneficiaries threatens to raise their percentage of publicly funded enrollees above 50 percent, which would disqualify them from Medicare participation. Medicare rules regarding surrogate decisionmakers—those allowed to make decisions for people not able to make their own—are more restrictive than those of Medicaid, thereby complicating prepaid plan enrollment of dually eligible individuals and affecting who may aid them in selecting a plan. If individuals want to join the same prepaid plan for both their Medicare- and Medicaid-covered services, timing differences between the two programs may require them to remain in Medicare fee-for-service care for up to 2 months after they have enrolled in the Medicaid prepaid plan.
Title V programs	These programs for children with special health care needs are typically administered in states by departments of health, which are often separate from Medicaid agencies. Including these children requires significant interagency coordination.
School-based programs	Conflicts surrounding medical equipment such as wheelchairs or devices to help overcome communicational impairments arise when children receive services through prepaid plans and through school-based programs. In some cases, schools and plans cannot easily agree on whether the equipment is “medically” or “educationally” necessary. In others, schools or plans restrict the use of the equipment to either the classroom or the home, potentially leading to the need to duplicate services.

The nature and extent of coordination barriers between Medicare and Medicaid vary depending on the extent to which states require prepaid plan enrollment and the extent to which Medicare prepaid plans are available. Coordination issues are lessened when dually eligible beneficiaries remain in Medicare fee-for-service care and join a Medicaid prepaid plan for services not covered by Medicare. But coordination issues increase in states where beneficiaries are required to enroll in Medicaid prepaid plans and are to be “locked in” for specified periods. Chief among these are Medicare’s requirement that beneficiaries are free to choose a prepaid plan or to use fee-for-service care and, when in a prepaid plan, are allowed to disenroll at will. As a result, in states restructuring their Medicaid programs under waivers, the potential benefits of coordinated care may elude Medicaid beneficiaries dually eligible for Medicare who may not be enrolled in a single managed care plan for both sets of services or have a single primary care provider—which undermines one goal of a prepaid program.

Although many of the state and federal officials we interviewed described coordination of these programs as a difficult process, most states with prepaid programs for disabled Medicaid beneficiaries are extending enrollment to the dually eligible. In all 17 states, one or both of these groups of dually eligible individuals may elect to enroll in prepaid plans (see table 2.5). For beneficiaries with Medicare eligibility, 12 states open their Medicaid prepaid programs to participation and 5 do not. Three of the 12 states reported allowing enrollment only if Medicare services were obtained in a fee-for-service setting. Another six states reported that coordination between the two programs was not a major issue because the state had no or very few Medicare prepaid plans available to beneficiaries.

Table 2.5: Extent to Which 17 States Include Dually Eligible Beneficiaries in Medicaid Prepaid Care Programs, February 1996

State	Medicare populations included?	Title V populations included?
Mandatory programs		
Arizona	Yes	Yes
Delaware	No	Yes
Oregon	Yes	Yes
Tennessee	Yes	Yes
Utah	Yes	Yes
Virginia	No	Yes
Voluntary programs targeted only to disabled individuals		
District of Columbia	No	Yes
Ohio	No	Yes
Wisconsin	Yes	Yes
Voluntary programs for the general Medicaid population		
California	Yes	Yes
Colorado	Yes	Yes
Florida	Yes	No
Maryland	Yes	Yes
Michigan	Yes	No
New Jersey	Yes	Yes
Pennsylvania	Yes	Yes
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population		
Massachusetts	No	Yes

More States Moving Toward Including Disabled Beneficiaries

Current signs point to increasing movement in the direction of prepaid managed care for disabled beneficiaries, including greater reliance on managed care programs in which their participation is mandatory. Table 2.6 lists additional states with approved and pending demonstration waivers that include disabled beneficiaries.

Table 2.6: Status of Additional Approved and Pending Demonstration Waivers Including Disabled Beneficiaries as of February 1996

State	Date submitted	Date approved	Prepaid enrollment	Current status
Approved and implemented for groups other than disabled individuals				
Minnesota	July 1994	Apr. 1995	Four mandatory pilot programs for disabled individuals	Will enroll disabled individuals in 1997
Oklahoma	Jan. 1995	Oct. 1995	Mandatory (urban providers will be prepaid)	Will enroll disabled individuals in 1997
Vermont	Feb. 1995	July 1995	Mandatory	Will enroll disabled individuals in 1997
Approved, pending implementation				
Kentucky	June 1995	Oct. 1995	Mandatory	Implementation planning under way
Massachusetts	Apr. 1994	Apr. 1995	Mandatory	Awaiting state legislative approval
Ohio	Mar. 1994	Jan. 1995	Mandatory	Will enroll disabled at a future undesignated date
Pending				
Alabama	July 1995		Mandatory—a one-county pilot	Under HCFA review
Illinois	Sept. 1994		Mandatory (urban providers will be prepaid)	Under HCFA review
Louisiana	Jan. 1995		Mandatory	Financing plan disapproved
Missouri	June 1994		Voluntary pilot program for disabled	Under HCFA review
New York	Mar. 1995		Mandatory—to include disabled in year 2	Under HCFA review
Texas	Sept. 1995		Mandatory with managed fee-for-service option	Under HCFA review
Utah	July 1995		Mandatory if income lower than 100 percent of federal poverty level	Under HCFA review

In addition to Arizona, Delaware, Oregon, and Tennessee, which currently mandate prepaid plan enrollment for virtually all their disabled beneficiaries, six other states have received approval to require Medicaid beneficiaries, including those who are disabled, to enroll in prepaid managed care plans.[26] All but two of the six are statewide programs, and four of the six will enroll disabled beneficiaries 1 or more years after enrolling other beneficiaries. Six of the seven states seeking to include disabled beneficiaries in their prepaid programs have sought approval to require prepaid plan enrollment by most or all of their Medicaid beneficiaries, including those who are disabled. Of the seven,

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[26] One of these six—Ohio—is currently experimenting with a voluntary targeted prepaid care program for disabled beneficiaries in three counties.

three—including Utah, which currently mandates enrollment in three urban areas—have sought approval for statewide mandatory programs. Hawaii, which currently mandates enrollment for low-income families under a demonstration waiver approved in 1993, intends to seek approval to include disabled beneficiaries in the near future. Maryland and New Jersey are currently discussing their proposals with HCFA officials.

Quality Assurance Efforts Focused on Care for Disabled Beneficiaries Are Concentrated in a Handful of States

Enrolling disabled Medicaid beneficiaries in prepaid managed care heightens the need for states to ensure the quality of care provided. Prepaid managed care, especially when participation is mandatory, diminishes beneficiaries' ability to "vote with their feet" by changing plans or physicians when they are unhappy with their care. Given disabled people's often extensive need for care, states need an adequate set of mechanisms both to address fears and uncertainties about receiving care in a managed setting and to ensure that health plans are meeting their commitments.

Important aspects of states' quality assurance activities can fall into two main categories: (1) building safeguards into the programs through adequate planning and consensus-building and (2) tailoring various aspects of the program (such as enrollment and monitoring) to meet the specific needs of disabled individuals. To date, most of the efforts have been made by five states with mandatory participation by disabled beneficiaries (Arizona, Delaware, Oregon, Utah, and Virginia) or by four states with programs targeted exclusively for disabled beneficiaries on a voluntary basis (Massachusetts, Ohio, Wisconsin, and the District of Columbia). Among other things, their initiatives include requiring plans to designate advocates or case managers for disabled beneficiaries and to include access to specific types of specialty providers, and developing encounter data and quality-of-care standards for evaluating their managed care programs for disabled beneficiaries. The remaining states (mainly those with voluntary programs for the general Medicaid population) are primarily relying on broadly scoped monitoring actions that may not be sufficient to detect problems with care provided to specialized groups such as disabled individuals.

Adequate Planning and Consensus-Building

Adequate planning and consensus among all the affected parties—health plans, disabled beneficiaries (and their advocates), and state officials—are critical for the development of and transition to an effective Medicaid managed care program, according to officials in the nine states furthest along in tailoring their programs. In particular, they stressed the need to involve beneficiaries and advocates in planning and program design. In two of the three states we visited (Massachusetts and Oregon), advocates and state officials who work with disabled beneficiaries cited the use of consensus meetings, which often involved health plan management and medical staff, as key to the smooth transition to managed care.

Oregon's experience is an example of how these consensus meetings worked. For more than a year before bringing disabled beneficiaries into managed care, Oregon's Medicaid staff held weekly meetings with health plan representatives, beneficiary representatives, and state social service agencies (from whom most disabled residents received case management services). These meetings covered such topics as building a common set of definitions for terms like "case management" and "case workers"—terms each group routinely used with different meanings. The need to arrive at such definitions was not unique to Oregon: An official in another state said coordination meetings were needed to define "disabled" because health plans anticipated diabetic or asthmatic enrollees, not quadriplegics or other individuals with medically complex needs.

Officials in the three states also noted the importance of ongoing meetings among stakeholders to address issues as they arose. They said that once the programs had been implemented, Medicaid staff met routinely with health plan management, medical directors, and advocacy and social service agency representatives to discuss such issues as rates, data reporting, and matters related to health care. These groups sometimes formed subcommittees to study specific problem areas. For example, in Oregon and Arizona the Medicaid and health plan medical directors have subcommittees to develop practice guidelines and study issues concerning disabled children. To date the state and health plan medical directors in Oregon have adopted practice guidelines for preventive care, cerebral palsy, spina bifida, and cleft palate. Guidelines for cystic fibrosis, Down's syndrome, pediatric asthma, and sickle cell disease are being developed. One of Arizona's subcommittees evaluates new treatments and technologies; it granted approval for the use of certain prescription drug treatments for cystic fibrosis and multiple sclerosis.

Tailoring Programs Specifically to Meet the Needs of Disabled Beneficiaries

The same nine states have taken action in a number of other ways to better adapt aspects of their managed care programs to address the concerns of disabled beneficiaries. These actions include addressing concerns about disabled individuals' ability to continue seeing established caregivers, helping disabled individuals and their families decide which plan to select, providing access to a range of available services, and monitoring the quality of services provided.

Resolving Concerns About Medical Necessity

Among the most important issues regarding access to services that need resolution is how the concept of "medical necessity" will be applied in prepaid care situations involving disabled enrollees. Definitions vary widely in their sensitivity to the needs of disabled individuals: Some include the need for improvement or restoration of function within a specified number of treatments or time period (often 60 days), while others include consideration of preventing the progression of adverse health conditions or the cost-effectiveness of the treatment.

The strict application of a narrow definition of medical necessity can conflict with disabled enrollees' needs, particularly in the case of services that offer little hope for improvement but can help to maintain existing quality of life. For example, people with neuromuscular disabilities may need physical therapy to prevent deterioration and reduce discomfort even when restoration or functional improvement is not possible. Conversely, state officials also pointed out that, in applying the concept of medical necessity, health plans' flexibility can provide an opportunity for them to supply services over and above those available in the fee-for-service program. For example, in one state a child received a technologically enhanced bed (not covered under the state's fee-for-service program) because health plan officials decided the bed was likely to reduce hospitalizations for pressure sores and infections.

The three states we visited address concerns about medical necessity primarily through the appeal process, giving the medical director of the Medicaid program authority to overturn health plan decisions regarding what is medically necessary for an individual recipient. However, advocates for disabled individuals said reliance on the complaint and grievance process puts an undue burden on beneficiaries because (1) the process requires a significant amount of self-advocacy on the part of beneficiaries who may not be capable of it and (2) the process can be extremely time-consuming.

Some states are beginning to include a definition of medical necessity in health plan contracts and to supplement this definition with guidance on or monitoring of its application. For example, Arizona approached the issue by including the concept of "habilitation" (the extent to which treatment helps to maintain a recipient's current ability to function) in its monitoring of health plan services. Similarly, Oregon issued guidance for health plans to use in approving various therapies and equipment emphasizing such nonmedical outcomes as enhancement of independent living.

Addressing Concerns Through Enrollment and Related Programs

Among states that offer prepaid managed care to disabled beneficiaries, only those with mandatory enrollment have significant percentages of their populations participating. The low participation in other states may reflect, among other things, concerns of disabled individuals about relying on a prepaid care system. When prepaid plan enrollment can be required of beneficiaries, state decisions about enrollment—such as who will enroll recipients, what sorts of education programs will be involved, and how beneficiaries will be assigned to a health plan if they do not choose one—become more prominent among the concerns of disabled beneficiaries, according to advocates in the states we visited. States we contacted reported using various approaches to enrollment, assignments, and exceptions to remain in the fee-for-service system.

Client Enrollment

Some states view the process of enrolling beneficiaries in Medicaid managed care programs as an important opportunity to educate and counsel beneficiaries—sometimes individually—about both managed care and the need to choose from among participating health plans. The three states we visited generally applied many of the steps they use for other beneficiaries when they enrolled disabled beneficiaries.[27] Other steps included the following:

- Oregon sends disabled beneficiaries (1) a booklet that the state developmental disabilities council created to educate beneficiaries about managed care and (2) a chart comparing the features of available health plans. The booklet contains worksheets to help beneficiaries identify their health care needs and detail their existing provider network so that they can better select an appropriate health plan.
- In Massachusetts advocates were concerned that managed care might disrupt the existing provider networks from which disabled beneficiaries receive care.[28] State staff and advocates adopted a health needs assessment that enrollment staff use to help beneficiaries select existing or other appropriate providers. The state also adopted a more flexible approach allowing specialists to serve as primary care providers for their

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[27] Examples of such steps include sending beneficiaries materials informing them of their rights and responsibilities under managed care, sending summary information about participating health plans, and making materials prepared by health plans available for beneficiary consideration. In these three states, the materials sent to beneficiaries contained lists of participating clinics and hospitals but not individual primary care practitioners (except in one instance) or specialty care practitioners. However, in all three states, beneficiaries could contact state enrollment staff or participating health plans to obtain primary care practitioner lists.

[28] Massachusetts' program waiver requires all beneficiaries—including disabled beneficiaries—to select either a prepaid plan or a primary care case manager. In October 1995, HCFA approved state officials' request to begin assigning beneficiaries to a prepaid plan.

disabled patients and allowing beneficiaries to enroll with providers outside their geographic service areas.

Although each state makes educational materials available, state staff familiar with cognitively impaired beneficiaries in two states reported that written materials were seldom helpful to this population. Instead, for these beneficiaries, education largely occurs through the one-on-one relationships between case workers and beneficiaries and their families.

To ensure that needed equipment and supplies are provided without interruption while a beneficiary's enrollment is processed and a primary care provider is selected, Oregon also developed a process to inform the selected plan in advance about an individual's health care needs. "Continuity of care referral" forms alert prepaid plans to life-sustaining, ongoing treatment needs of individuals enrolling. Social service agency case workers, who enroll disabled beneficiaries in the prepaid plans they select, complete a form for each individual with life-sustaining needs—such as oxygen supplies—and forward it directly to the plan's care coordinator. Delaware and Virginia also require plans to either maintain existing plans of care or develop transition plans for people with ongoing care needs.

Exceptions

States with mandatory prepaid plan enrollment face decisions about whether, or if, to allow exceptions for certain beneficiaries to receive fee-for-service care. Delaware, Tennessee, Utah, and Virginia—four of the six states with mandatory programs—essentially do not allow exceptions, though individuals may receive care in a fee-for-service setting for a short time while eligibility and enrollment forms are processed. In Arizona, Native Americans living on reservations may elect not to enroll in prepaid care. Oregon allows case workers, in concert with beneficiaries and their families, to decide whether prepaid managed care is the best delivery system. Most exceptions involve an ongoing relationship with a practitioner who does not participate in any of the managed care networks, while others are for situations in which the beneficiary is involved in an ongoing treatment regime or when changing practitioners could seriously harm the individual.[29] Some exceptions are short-lived, delaying enrollment by up to 1 year; others may be permanent. Oregon Medicaid officials monitor exceptions granted by case workers to determine, among other things, whether any trends develop.

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[29] Oregon also grants exceptions for religious or Indian heritage reasons.

Assignment

States with mandatory enrollment programs for broader segments of the population, such as low-income families, often develop systems that automatically assign beneficiaries to a health plan if they do not select one for themselves. This assignment is usually based on geographic proximity. The three states we visited each took a different approach to assigning disabled enrollees. Oregon decided against assigning disabled beneficiaries, relying instead on each social services case worker selecting a plan in consultation with beneficiaries or their families. In Arizona, severely disabled recipients who receive both acute and long-term care do not have a choice among providers because only one contract is awarded in each county. Less severely disabled beneficiaries are assigned to plans, when they do not choose from among those available, based on results of the state's competitive bidding process, with the lowest-cost plans receiving proportionately more assignments. In Massachusetts, nurse review panels analyze beneficiaries' claims histories to determine the health needs of those who do not choose health plans so that assigned plans are more likely to have the capacity to meet their needs. Enrollment staff try to contact beneficiaries after assignment to ask about their satisfaction and help them select another provider if the relationship is unsatisfactory.

Active Management of a Disabled Beneficiary's Care

Most of the nine states furthest along in tailoring their programs have also taken steps to ensure that disabled beneficiaries receive coordination of services through a process called "case management." The four small-scale programs aimed exclusively at disabled individuals have included specific requirements for case management services. Examples of such requirements are (1) coordination of a range of needed services, such as transportation, community support services, and primary and specialty care; (2) development of individual plans of care that ensure continuity and coordination of care among various clinical and nonclinical settings; and (3) stipulation that case managers be social workers or nurses with specific training in working with disabled people. In Wisconsin's program, if case managers do not perform a needs assessment within 55 days of enrollment, the beneficiary is automatically disenrolled from the program.

Among the mandatory programs, Arizona and Delaware have also taken steps regarding case management. Arizona's program for the more severely disabled requires contractors to provide case management services, although no such requirement exists for health plans serving the less disabled. Arizona requires case managers to perform a needs assessment within 15 days and complete a plan of care within 30. Failure to meet these requirements can result in a financial penalty. For the severely disabled, Arizona also established maximum ratios of 1 case manager to 40 community-based enrollees and 1 case manager to 120 institutionalized enrollees. Delaware requires plans to provide case managers for disabled children. These case managers visit children in their homes to assess the children's needs in concert with their families.

Requiring Plans to Provide Staff Advocates or Access to Specific Specialties

Several other actions are similar to case management in that they are directed at ensuring that disabled enrollees receive appropriate care. One of these actions is a requirement for a "designated advocate." Oregon and Wisconsin require health plans to have designated contact staff available for disabled enrollees and their families. These staff, called "exceptional needs care coordinators" in Oregon and "Medicaid advocates" in Wisconsin's targeted program, function as advocates for enrolled beneficiaries and must meet specific requirements for experience or training in working with those who are disabled. Oregon also created a state-level ombudsman to serve as a contact point for disabled beneficiaries and to help coordinate the activities of the plan-based care coordinators. Advocates for disabled individuals in Oregon said the coordinators perform a vital role in educating health plans on appropriate care for disabled enrollees.

Another way in which states can help ensure access to appropriate care is to require health plans to provide enrollees access to specific specialty services. For example, Utah requires prepaid plans that serve disabled children to provide timely access to pediatric subspecialty consultation and care, and rehabilitative services from professionals with pediatric training. For selected disabling conditions such as spina bifida and cerebral palsy, children must have timely access to coordinated multispecialty clinics for their disorder. Delaware requires health plans to consider disabled enrollees' requests for specialists to serve as primary care practitioners, including requests for specific specialists not affiliated with the prepaid plan. Denials of these requests may be appealed to the Medicaid agency. As of April 1996, two requests for pediatric specialists had been granted, both of which were for specialists not affiliated with the plan. Prepaid plan response to such requests is included in periodic state monitoring.

Monitoring Plans for Compliance With Contractual Requirements

Another category of quality assurance mechanisms is the compliance monitoring normally performed for all Medicaid prepaid care plans. This monitoring helps to assure the state that health plans are delivering the health services they are paid for and doing so in accordance with state and federal requirements. However, most of this monitoring activity is not specifically targeted to any eligibility group. Without some form of adjustment (a step some states are beginning to take), this monitoring will have limited effectiveness in systematically identifying problems that disabled beneficiaries may be having with their care.

Federal regulations promulgated by HCFA are the basis for much of the monitoring activity. They require, for example, that prepaid plans allow enrollees, to the extent possible, to choose their health practitioners and maintain a program that allows enrollees to voice complaints and provides for speedy resolution. States may establish performance measures to determine compliance with federal access standards. For example, as measures of access to care, states may set standards for time frames for linking enrollees with primary care practitioners, waiting times for scheduled appointments, enrollee travel time to a provider, and capacity ratios of providers to enrollees. The following are additional examples of HCFA requirements for access and quality:[30]

- Health plans must offer enrollees health services comparable to those available for non-enrolled beneficiaries in the same locale.
- Health plans may not discriminate against enrollees on the basis of their health status or need for health services.
- Health plans may not terminate enrollment because of an adverse change in the enrollees’ health.
- Emergency services must be available 24 hours a day, 7 days a week.
- The state must provide for annual external reviews conducted by an independent reviewer.
- Health plans must maintain an internal quality assurance program.

States typically monitor compliance with these and other state and federal requirements through periodic (usually annual) site visits and reviews of health plan policies and procedures. Some data, such as disenrollments and complaints and grievances data, are collected and reviewed quarterly. In addition to these requirements, some states survey enrollees periodically to determine their level of satisfaction with the care received from participating plans.

Monitoring activities specifically related to disabled enrollees were limited. Of the 17 states with prepaid programs that include disabled

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[30] Other federal requirements pertain to health maintenance plan organization and administration, data systems, financial solvency, marketing, member services, and utilization review. These requirements are specified in sec. 1903(m) of the Social Security Act and 42 C.F.R. 434.

Medicaid beneficiaries, 9 reported no specific monitoring efforts designed to assess quality of and access to care for this population.[31] For example, only those states with programs targeted specifically to disabled beneficiaries analyzed complaints and grievances by eligibility category to learn the views of disabled enrollees. Also, two states we visited reported using the results of their monitoring efforts to apply incentives and sanctions to influence health plan behavior. However, neither state had encountered treatment of disabled enrollees that would warrant the use of sanctions.

Among those nine states without specific monitoring efforts for disabled enrollees, there was acknowledgment that more needed to be done. Officials in eight of these states said more focused efforts would be needed as more disabled beneficiaries enrolled in prepaid plans. For example, these states currently rely heavily on disabled recipients' freedom to disenroll from or transfer among prepaid plans and the existence of a complaint and grievance program. However, disabled beneficiaries may choose to disenroll rather than complain about the care they receive and, even if they complain, their concerns may be masked by a low overall complaint rate for all eligibility categories unless complaints are analyzed by eligibility group. Thus, without more focused effort, such measures will not reveal systemic problems in care for disabled enrollees.

Current monitoring programs do have the potential to provide more information about care delivered to disabled beneficiaries, as the following examples indicate:

- States could extend their current efforts to assess specific aspects of health care delivery to disabled enrollees. Some states that do not assess care for disabled individuals do conduct assessments of maternal and child care. States that conduct reviews of prenatal, well child, or asthma care could require studies of care for specific disabling conditions present among the plan's enrollees. For example, a Massachusetts prepaid plan, on its own initiative, studied the management of pressure sores, a common cause of hospitalization, as an area of quality improvement. One result was the development of a variety of methods, including new screening protocols for earlier intervention and an accelerated schedule for wheelchair seating evaluations, to further improve care.

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[31] One of these nine (Delaware) has taken specific steps to allay concerns of disabled beneficiaries about relying on prepaid plans and to help ensure access to appropriate providers, some of which have been discussed in this chapter. However, as of April 1996, the state had no specific measures to assess care received by disabled enrollees.

- Consumer surveys could include questions about eligibility status, and samples could be designed to ensure that sufficient numbers of disabled beneficiaries were included. States could also request disenrollment or utilization data reported by eligibility category to allow comparisons with other eligibility groups or across health plans. States might, as one reported, interview individuals requesting disenrollment to gather more in-depth information about the care received. In 1996, Virginia will conduct a survey of all disabled beneficiaries who disenrolled during the year.
- States have great flexibility in deciding how to structure required external reviews, which represent an opportunity for closer scrutiny of issues facing disabled individuals. Oregon, the District of Columbia, and Virginia are seeking proposals from external professional review contractors for studies specifically designed to measure the quality of care for disabled enrollees.

The steps taken to monitor plans once they are up and running need not be limited to modifying existing Medicaid oversight requirements. Targeted quality-of-care studies and quality improvement goals have been instituted by one or more of the eight states.

Targeted Quality-of-Care Studies

Arizona, the District of Columbia, Ohio, and Virginia will begin in 1996 to conduct additional quality-of-care studies focused specifically on care for disabled enrollees. Arizona's studies will include outcome measures, such as the frequency and reasons for hospitalizations and emergency room visits, rates and changes in pressure ulcers, and changes in functional abilities. Since 1990, Arizona staff have also visited a random sample of developmentally disabled beneficiaries in their homes to determine satisfaction with services and progress in fulfilling individualized plans of care developed by their health plans. The District of Columbia, Ohio, and Virginia are collecting encounter data from health plans and will evaluate care beginning in 1996 or 1997. A fourth state—Wisconsin—is scheduled to release by December 1996 an evaluation of its program conducted by independent researchers.

Quality Improvement Goals

Massachusetts uses quality improvement goals and contractor selection specifications to build health plan capacity to meet the needs of Medicaid beneficiaries. Each year, the state identifies quality improvement goals for all health plans and requires each plan to select additional goals. Twice annually, Medicaid staff meet with health plans to review progress in meeting stated goals. For each contracting cycle, the state identifies capabilities it expects successful contractors to possess. These goals and specifications have included developing capacity to serve disabled individuals. For example, one health plan elected to develop and implement a program for enrollees with human immunodeficiency virus (HIV) or AIDS to provide case management and access to specialists trained in infectious diseases. Selection criteria for 1995 required prepaid plans to demonstrate how they provided reasonable access to services for enrollees with physical and communicational disabilities as measured, in part, by enrollee satisfaction.

Programs Can Be Strengthened by Analysis of Encounter Data

Under a fee-for-service approach to Medicaid, states have ready access to data on services performed because they reimburse providers for those services. These data—called claims data in fee-for-service systems and encounter data in prepaid managed care—consist of such information as the patient's identity, type of service, date of delivery, diagnosis, and provider. In a prepaid care setting, states do not need such data for reimbursement purposes. Many plans have—and use—this information, but unless states specifically request it, the information can largely disappear from view.

This information can play an important role in quality assurance, estimations of future service use, research, and program planning. It can also play an important role in rate-setting, the subject of the next chapter. However, state experience to date shows that a substantial investment of time and effort is needed to assemble a workable encounter database, although the potential applications appear to make the effort worthwhile.

Encounter Data Have Had Limited Use to Date

When Arizona, Oregon, and Tennessee received approval to implement statewide Medicaid mandatory managed care programs, HCFA required them to collect and validate encounter data, mainly for use in independent evaluations of the programs. These states, which have had significant experience in collecting such data, all had difficulty obtaining information of sufficient quality and comprehensiveness to use in quality assurance reviews. The problems were numerous: The data were not readily available, health plans used a variety of data systems, and definitions varied from plan to plan.

- Arizona has had by far the most experience in collecting and using this information for quality assurance purposes. However, the state spent over 10 years and $30 million getting to the point that the Medicaid department could use encounter data for quality analysis.

- Oregon and Tennessee are experiencing collection and validation problems similar to those Arizona experienced initially. In each of these states, staff spent considerable time editing the data, working with health plans to overcome problems, working to resolve significant data reject and coding problems, and implementing validation strategies. In Oregon and Tennessee, relatively complete and usable data elements were not available until almost 2 years after enrollment began.[32]

State use of encounter data in quality reviews is also limited to some extent by the lack of a recognized standard for what level of care is considered appropriate for people with disabilities. In addition, quality measures for chronic and disabling conditions are just now being developed. Current federal and privately funded research and development in the field of quality analysis will provide states with more definitive criteria to use in their analyses.

Encounter Data Analysis Shows Potential in Quality Control Applications

While assembling adequate databases is difficult and expensive, the effort can yield substantial results in terms of the ability to monitor programs. The types of studies that could be conducted using person-level encounter data include tracking patterns of services by health plan or eligibility group, identifying providers serving special needs populations, and tracking the movement of high-cost patients among health plans. Encounter data could also be analyzed to reveal patterns of under- or overutilization. Although linking such patterns to quality of care in all cases is limited by the lack of recognized standards, patterns of service use can reveal access problems. For example, Arizona officials analyzed encounter data and found very low use of dental services among all beneficiaries. The access problem was resolved when state officials removed the requirement that beneficiaries receive a referral from their primary care provider before obtaining dental care.

Encounter data for Oregon's disabled enrollees are just becoming available for analysis.[33] As a result, no studies are yet under way. However, state officials listed the following as possible uses for encounter data:

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[32] Some other states are also collecting encounter data but are not attempting to use them in this way as yet. Florida and Maryland reported collecting encounter data, but neither reported using such data, at present, in studies of care for disabled enrollees. California collects encounter data in one county. Delaware, Pennsylvania, Utah, and Virginia have either just begun or will within the next year collect such data.

[33] Enrollment by disabled beneficiaries was phased in over 9 months beginning in February 1995. As a result, the collection and availability of encounter data for disabled beneficiaries lag behind data for previously enrolled groups of beneficiaries.

comparing utilization to adopted practice guidelines to assess the extent to which they had been implemented; identifying providers serving special needs populations; identifying and tracking high-cost enrollees; identifying areas of underservice for selected services; identifying gaps in follow-up care or preventive care for selected enrollees; and analyzing enrollment to detect adverse selection by selected diagnoses.

We also identified other innovative uses of data systems for more limited quality or access reviews:

- Arizona monitors case management for certain disabled Medicaid beneficiaries through on-line systems. The state provides case managers with the terminals and software with which they record the individuals' plan of care and progress in meeting stated goals. This information is then transmitted to the Medicaid department for immediatiate review.
- The contracting health plan in the District of Columbia also plans to use an on-line system for its own and the District's monitoring of care for enrollees. For case managers providing 24-hour medical access to beneficiaries and their families, the system gives access to care plans, service authorizations, and even scanned-in photographs of the children.
- In Massachusetts, the Medicaid department compared managed care aggregated utilization data with fee-for-service claims data to determine whether mental health services were underutilized. The state took immediate action to work with prepaid plans that needed to correct utilization problems.

Risk-Adjusted Rates and Risk-Sharing Can Help Reduce Incentives to Underserve Disabled Beneficiaries

Adequate quality-of-care safeguards provide some protection against the potential risks of prepaid managed care. Paying health plans a capitation rate in advance to provide enrollees a set of services creates an incentive to improve efficiency by eliminating unnecessary services. However, it simultaneously creates certain risks. First is a risk of underservice, because plans can profit by reducing the number or quality of beneficial services. Second is the risk that when the same capitation rate is paid for enrollees with different health care needs, plans will seek to enroll the healthier, less expensive individuals. These risks may be greater when plans feel financial pressure from actual or potential losses from serving enrollees with extreme needs.

States are examining ways to reduce these incentives and pressures in prepaid care plans that have a disproportionate share of beneficiaries with high-cost medical needs, such as severely disabled people. States' efforts have been of three main types:

- Using risk-adjusted capitation rates to more closely match the reimbursement rates with anticipated costs of treating individual recipients.
- Sharing financial risk by providing retrospective adjustments (called "reinsurance") to reimburse plans for losses resulting from very high-cost individuals or disproportionate numbers of enrollees with above-average costs.
- Establishing funding agreements with "risk corridors" that reimburse plans for a portion of losses but also require plans to return part of the profits exceeding a specified level.

For the 17 states we contacted with managed care programs for disabled beneficiaries, most state activity to date has centered on reinsurance. Initiatives to establish risk-adjusted rates for disabled enrollees or to set up risk corridors in funding agreements are fewer in number and have much shorter track records. Risk-adjusted rates—currently implemented in only two states—are seen as potentially beneficial by many states but also as administratively difficult to develop and maintain. As the only mechanism that specifically limits health plan profits, risk corridors appear to have the greatest potential for reducing plans' incentives to underserve or to enroll only the healthier beneficiaries. To date, five states have taken steps to build risk corridors into their payments to plans.

Traditional Rate-Setting Approach Does Not Address Negative Incentives and Pressures

In setting capitation rates, states make an effort to account for differences in expected costs for broad categories of beneficiaries. To do this, they frequently divide the eligible population into subgroups, or cells, of individuals with similar characteristics. Of the 17 states we contacted, 16 established rate cells according to Medicaid eligibility category, such as all disabled people or all children in AFDC-eligible families, with some adjustment for age or the geographic area in which the beneficiaries reside.[34]

Setting capitation rates in this way meets HCFA requirements and provides appropriate payments to plans as long as each plan's enrollment mix of beneficiaries with complex health care needs is comparable with the mix of the population used to set the rates.[35] The money saved serving enrollees with lower-than-average costs pays the cost of serving enrollees with higher-than-average costs. However, plans may not enroll disabled people with health care needs comparable with those included in setting the rates. While some disabled enrollees may require little medical treatment, others may have disabilities, such as quadriplegia, that require extensive treatment. The identifiability of such groups and the high costs associated with their care heighten the incentives for health care plans to avoid enrolling such individuals.

In most state programs, the rate-setting methods do not take into account the cost variation associated with different types of disabling conditions. Researchers have identified significant variation in medical costs within different subcategories of conditions. For example, using 1992 fee-for-service claims data divided along clinical diagnoses, researchers found average annual costs ranging from nothing (for the 5 percent of the disabled population that had no medical claims during the year) to $35,000 per year in one state for an individual diagnosed with quadriplegia. Similarly Oregon found tremendous variation in 1993 health care costs among its 199 highest-cost children. The 6-month group average was $21,472, but amounts varied from a high of $410,420 to a low of $5,014. In

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[34] For example, Oregon's 1996 (January through September) average rate for categorically eligible children in families under the federal poverty level is $126.15 per month, while its average rate for blind or disabled individuals who have no Medicare coverage is $521.81 per month.

[35] Richard Kronick, Zhiyuan Zhou, and Tony Dreyfus, "Making Risk Adjustment Work for Everyone," Inquiry, Vol. 32 (Spring 1995).

1995, Oregon's average 6-month capitation rate for disabled individuals in the cell that includes these children was $3,023.[36]

High-Cost Cases Strengthen Pressure to Seek Healthier Enrollees

With such a broad range of costs within the category of disabled enrollees, a health plan being paid on the basis of average costs may make profits or experience losses unrelated to its ability to provide high-quality health care services efficiently. Instead, these profits or losses may be a function of how many high-cost cases it does or does not enroll. A health plan with a disproportionate number of high-cost cases that result in unanticipated losses is said to be experiencing "adverse selection," while a plan with few high-cost cases is said to be experiencing "favorable selection."

The greater the difference between the high- and low-cost recipients in each cell, the greater the pressure on plans to avoid enrolling high-cost recipients or to underserve the high-cost beneficiaries who do enroll. Favorable selection may happen unintentionally in that, as research suggests, some people—often those with few health care needs—may be more prone to select prepaid care when given the option. But, plans can also avoid enrolling high-cost members by using a variety of methods that may be difficult for states to detect.

- Manipulating the panel of providers. Health plans can avoid high-cost recipients by dropping providers that attract high-cost patients. For example, a former health plan official told us that the health plan she worked for identified a specific provider who was responsible in large part for the plan's attracting a significant number of enrollees with AIDS—a condition that frequently requires extensive and expensive treatment, especially in its later stages. This plan dropped the provider from its panel in favor of an AIDS treatment clinic and saw its AIDS caseload decrease. The decision to drop the provider may have been for other reasons, in that by adding the clinic and dropping the individual provider, the health plan may have improved its capacity to treat people with AIDS and the quality of care they would receive. The outcome demonstrates, however, recipients' attachment to specific providers and health plans' ability to (1) identify specific providers as magnets for high-cost recipients and (2) reduce the cost to treat these recipients by dropping or replacing certain providers.
- Limiting access to information about specialty providers. Health plans can also make it difficult for prospective enrollees to find out which specialty

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[36] Because (1) Oregon lacked a systematic approach to case management for these children and (2) plans have limited flexibility in providing low-cost in-home care, the most "medically fragile" of these children were taken out of prepaid care and are being served on a fee-for-service basis with case management by state staff.

providers are available through the plan. In one state we studied, the state and health plans initially resisted distributing a handbook produced by an advocacy group designed to help disabled Medicaid recipients select a health plan that could best meet his or her particular needs. The booklet contained a worksheet for individuals to detail their specialty care requirements. The state and health plans were concerned about the possibility of adverse selection and felt that, without this information, the high-cost cases would be more evenly distributed among the various health plans.

- Using marketing efforts to discourage enrollment. Some states have allowed plans to conduct direct marketing as a way of enrolling beneficiaries in managed care. However, through direct marketing, health plans can also attempt to deliberately influence the distribution of high-cost enrollees. For example, they may seek information on a person's health status or discourage—or not aggressively market to—those likely to have more expensive needs. Consequently, several of the states in our review prohibited or severely limited the amount and content of marketing by health plans.
- Remaining silent about new treatment approaches. The wide gap between the relatively healthy and the sick within a rate cell also discourages the dissemination of information about health plans that have found innovative and successful ways to treat enrollees with difficult conditions. One health plan official told us that when the plan develops innovative and successful ways to treat the chronically ill, it does not advertise this fact because the resulting increase in enrollment of chronically ill individuals could be financially devastating. This health plan had success in managing asthma, and as word of its success spread, the number of asthmatics enrolling in the plan increased dramatically. This increase had such a negative financial impact on the health plan that it asked the state to cap its enrollment to prevent additional high-cost recipients from enrolling. When the incentive of health plans to develop innovative treatments decreases, disabled individuals are adversely affected in that they may miss out on new and effective treatments.

Determining whether a health plan is facing adverse selection goes beyond reviewing the plan's financial statements to see if there is a profit or loss. Health plans that do poorly managing care may lose money and blame it on adverse selection even though they may in fact be the beneficiary of favorable selection. Alternatively, plans actually experiencing adverse selection may limit services to such an extent they are still able to show a profit. Medicaid officials told us it is not uncommon for all participating health plans to describe themselves as victims of adverse selection, an impossible situation. However, these states had limited ability to verify or refute such claims with any certainty.

States Could Experience Adverse Selection and Lose Money With Managed Care

Health plans are not the only players in the Medicaid managed care marketplace that can face adverse selection and financial risks. When prepaid managed care plan enrollment is voluntary (as it is in 11 of the 17 states now using prepaid care for some or all of their disabled beneficiaries), the state may experience adverse selection. Specifically, where participation is voluntary, beneficiaries with relatively few health care needs (who may have few, if any, existing relationships with specialists) may choose prepaid care, while beneficiaries needing more expensive care (who may have long-standing relationships with specific providers) may choose to remain in fee-for-service care. When enrollment is mandatory but exceptions are allowed, a state may similarly face adverse selection.

Enrollment patterns in which the users of the most expensive medical services are in fee-for-service care and the relatively healthy in prepaid managed care are not problematic if the rate the state pays the health plans is adequately adjusted for the health status of the enrollees. However, in many cases, the rates paid to health plans are based on the average cost of providing care to an entire eligibility category and may not appropriately account for those that do not elect prepaid care. Consequently, the state pays the full cost of treating the expensive beneficiaries through fee-for-service care and too high a rate for the lower-cost health plan members. This problem may be compounded in that it is likely that future capitation rates would be based on the costs of serving those remaining in fee-for-service care—individuals who are likely to be less healthy and consequently more costly.

Just as it is difficult to tell if a health plan is experiencing adverse selection, it is very difficult to determine whether a state is experiencing adverse selection. An Oregon Medicaid official suspects that the state's enrollment exemption process for disabled individuals, which allows case workers to determine if prepaid managed care is appropriate for individual beneficiaries, may be resulting in adverse selection for the state.

Risk Adjustment and Reinsurance Have Some Impact on Incentives for Favorable Selection or Underservice

To address the concerns associated with adverse and favorable selection, some states are beginning to experiment with risk-adjusted methods for setting capitation rates. Risk adjustment is an attempt to match the rates paid to health plans with the expected costs of providing appropriate services to individual recipients. It essentially groups beneficiaries according to expected future expense and narrows the gap between the highest-and lowest-cost individuals in any given rate cell. This reduces the payoff for selecting only the healthiest recipients and provides better assurance that the state is not paying too much for individuals who are relatively healthy or too little for individuals who need such complex and expensive care that health plans are at best unwilling to attract and at worst unwilling or unable to accommodate them.

However, the actual application of risk-adjustment methods to the development of capitation rates for disabled Medicaid beneficiaries is very limited.[37] To date, only two states (Massachusetts and Ohio) have implemented any risk-adjustment methods, and only one other state (Missouri) has active plans to do so. Other states told us that risk adjustment was too administratively difficult to implement and that they looked to reinsurance to protect plans that experience adverse selection. Reinsurance does not, however, affect plans' incentive to seek favorable selection.

Risk Adjustment Is Largely Untested for Disabled Enrollees

The three states experimenting with risk-adjusted rates have based their adjustments on a beneficiary's prior utilization of medical services or a beneficiary's clinical diagnosis. Researchers point out that such measures may better predict future costs since disabled individuals, compared with the population as a whole, have a higher percentage of their health care costs related to chronic (recurring or consistent) conditions than to acute (random) conditions. Still, for risk-adjustment methods to be useful, attention must be paid to whether the predictive measures are sufficiently reliable and administratively feasible to collect.

Risk Adjustment Using Prior Utilization Rates

Utilization-based risk adjustment attempts to predict a person's future health care costs based on a measure of prior use, such as the costs of services or the number of hospital days used in a previous period. For example, a health plan could be paid a higher-than-average amount if the

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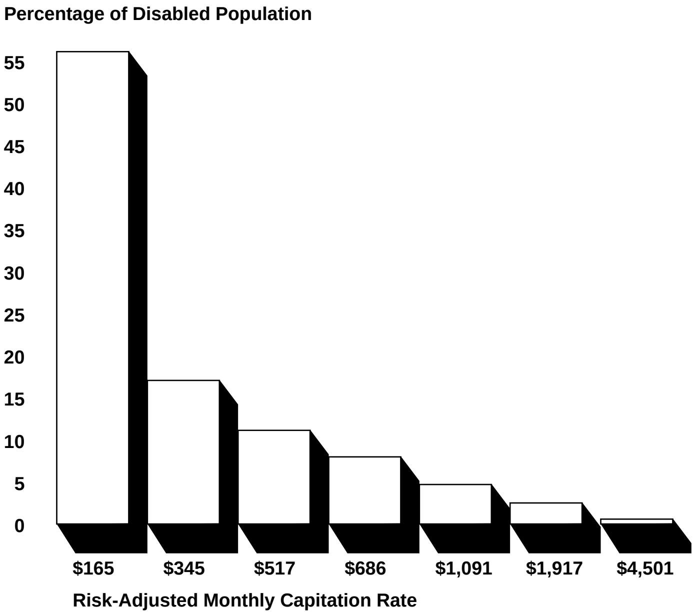
[37] To date, research on risk-adjustment mechanisms has concentrated more extensively on the Medicare population. We examined risk-adjustment mechanisms among the Medicare population in two reports, Medicare: Changes to HMO Rate Setting Method Are Needed to Reduce Program Costs (GAO/HEHS-94-119, Sept. 2, 1994) and Medicare Managed Care: Growing Enrollment Adds Urgency to Fixing HMO Payment Problem (GAO/HEHS-96-21, Nov. 8, 1995).

person spent several days in the hospital in the last year or a lower-than-average rate if the person spent no time in the hospital or did not visit the doctor in the last year.

To set capitation rates for its disabled population, Ohio is moving forward with a pilot project that uses a beneficiary's prior utilization (measured in dollars) in the fee-for-service system. This program, called Accessing Better Care, uses eight rate cells for the disabled population. Seven of the cells are based on prior expenditures, and the eighth is for newly eligible beneficiaries. Monthly capitation rates range from $165 (for beneficiaries with prior annual costs of $1,000 or less) to $4,501 (for beneficiaries with prior annual costs of $50,000 or more). Figure 4.1 shows how Ohio's disabled beneficiaries are distributed among the seven prior-expenditure categories.[38] More than half of all disabled beneficiaries are in the lowest-cost cell.

Figure 4.1: Ohio's Risk-Adjusted Capitation Rates and the Percentage of Disabled Population at Each Rate



Risk Adjustment Using Clinical Diagnosis

Another approach predicts future health care costs using beneficiaries' individual clinical diagnoses. Various methods to identify or classify diagnoses can be used, employing inpatient data, outpatient data, or both.

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[38] The distribution is an average from 1991 and 1992 fee-for-service data.

Some methods rely on an individual's primary diagnosis, and others incorporate measures of the severity of the primary diagnosis as well as the existence of secondary diagnoses of conditions that may aggravate the individual's health status.

Massachusetts is one of two states working with a diagnosis-based approach. It has identified a few disabling conditions that warrant higher rates and, as a result, has created a three-celled, diagnosis-based risk-adjustment system for its disabled Medicaid population. Severely disabled beneficiaries and those with end-stage AIDS (in both cases meeting clinical criteria detailed by the state and receiving an enhanced benefits package) have capitation rates of about $1,500 and $4,400 per month, respectively, compared with about $500 per month for beneficiaries in the general disabled category.

Missouri is currently developing a diagnosis-based methodology as part of a prepaid care program for disabled Medicaid beneficiaries scheduled to begin in 1997. Their methodology adjusts the capitation rate paid for an individual recipient according to both the type of diagnosis and its severity. The state identified approximately 400 distinct diagnoses and computed a rate-adjustment factor for each. The rate for an individual is the sum of the adjustment factors for each of the individual's diagnoses. The methodology accounts for multiple diagnoses: the capitation rate for an individual with diagnoses of muscular dystrophy and mild mental retardation would be higher than the rate for a mildly retarded individual with no additional disabling diagnoses. Table 4.1 shows an initial estimate of the resulting base rate along with a sample of the diagnoses identified and the associated capitation adjustment.

Table 4.1: Missouri Sample Diagnostic Categories and Rate Adjustments

Base rate, per month: $143

Sample diagnostic categories	Adjustment
Hemophilia, other clotting factors	$1,495
Cystic fibrosis, respiratory failure	1,108
Quadriplegia	517
Muscular dystrophy/paraplegia	263
Mild and moderate mental retardation	74

Note: Rate adjustments are additive. For example, the rate for an individual with muscular dystrophy and mild mental retardation would be $480 per month ($143 for the base rate plus $263 for muscular dystrophy and $74 for mild mental retardation).

Source: Missouri Division of Medical Services.

Risk-Adjustment Methods Must Be Accurate, Free From Manipulation, and Workable

Although risk-adjustment mechanisms are designed primarily to prevent adverse and favorable selection, implementing a risk-adjustment scheme involves a number of other considerations. Risk-adjustment methodologies must not only be reasonable predictors of future health care costs, they must also be relatively insulated from manipulation by health plans or providers, and they must be feasible in terms of administrative and data requirements.

To prevent adverse or favorable selection, a risk-adjustment mechanism must be able to predict health care costs. Researchers have demonstrated that prior utilization and diagnosis-based methodologies can both have predictive power superior to that of rates based on eligibility category. Some prior utilization models are able to explain nearly 40 percent of the variation in health care costs for disabled individuals, and diagnosis-based models have been able to explain about 25 percent. However, even the best predictors of health care costs explain less than half the variation in costs of providing care. Plans then still have an incentive to avoid the higher-cost members of a rate cell.

The basis selected for risk adjustment can affect the behavior of health plans.

- With utilization models that use cost as a measure, health plans have less of an incentive to hold down costs because less efficient health plans may be rewarded with higher capitation rates as participants are characterized as high use. Conversely, a plan that manages its enrollees’ care very efficiently may be penalized with lower capitation rates in the future. Moreover, a prior utilization method based on the number of hospital admissions affects health plan behavior in a different way than one based on the number of days an individual spends in the hospital. In both cases, the health plan could manipulate the measure affecting future rates without necessarily losing much in terms of efficiency.[39]
- With diagnosis-based risk-adjustment methods, “upcoding” exists in which providers and plans record the most severe diagnosis—the diagnosis associated with the greatest capitation adjustment—of those available for an individual’s symptoms. The use of multiple diagnoses as factors in the rate-setting methodology creates a situation in which providers could record unwarranted diagnoses to raise future capitation rates.

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[39] To account for the effects of adverse selection, some states are considering making retrospective adjustments to capitation rates based on utilization. Such an adjustment can ease the effects of a large number of high-cost cases, but it may also strengthen the incentive for health plans to act inefficiently. With a retrospective adjustment, plans would be rewarded for their inefficient behavior in the current year, rather than having to wait for higher rates in the future.

To be useful, risk-adjustment methodologies must also have feasible administrative and data requirements. Measures of health status, collected through surveys, may help predict the need for future health care but may be too administratively burdensome to be practical. Risk-adjustment methods based on information about the use of services are more practical. However, while such information was routinely available in fee-for-service claims, states need a new source, such as encounter data, to classify individuals enrolling in health plans.

The lack of fee-for-service data is not a problem limited to states that adjust their capitation rates by risk. Any state that moves most or all of its Medicaid population into managed care will find that prior rate-setting methods based on averaging fee-for-service claims will be unsuitable. While rates calculated using older fee-for-service data might be trended forward using any of a variety of factors, over time such trending may cause rates to be unrepresentative of the health care services being used. To address these difficulties, some states are using or evaluating individual-level encounter data as a basis from which they can generate capitation rates in the future.

Reinsurance Relieves Financial Pressure on Plans but Not Negative Incentives

State officials we contacted recognized the benefits of prospectively risk-adjusting capitation rates but—with the exceptions of Ohio, Massachusetts, and Missouri—were reluctant to do so in their programs because they felt it was too difficult administratively. Instead, officials rely on reinsurance to decrease the pressure on health plans serving high-cost individuals. With reinsurance, the reinsurer (sometimes the state) protects health plans against adverse selection or unexpectedly high-cost cases. To obtain coverage, the plan pays a reinsurance premium.

Reinsurance programs come in many forms. Most programs involve a reinsurance threshold, or deductible, with health plans being responsible for all the costs of serving a group or an individual up to that amount. Once the threshold is met, the state shares the cost of treating the group or individual with the health plan. Table 4.2 shows the range of reinsurance options Oregon offers in its current health plan contracts.

Table 4.2: Oregon's Reinsurance Levels and Rates, 1995-97

Annual deductible per person before state will participate	Percentage of liability over the deductible to be paid by the plan	Reinsurance premium as a percentage of capitation
$10,000	5	29.9
15,000	10	19.7
30,000	20	9.3
50,000	20	4.1

Source: Oregon Office of Medical Assistance Programs.

State Medicaid officials told us that, by protecting health plans from extraordinary costs, reinsurance also helps build health plan capacity. For example, new health plans and plans with small enrollments need time to absorb spikes in service costs and the cash flow fluctuations inherent in prepaid managed care. With reinsurance available, these plans can participate and compete in the programs.

While reinsurance relieves some pressure on health plans faced with expensive cases, it does not remove the negative incentives discussed earlier. Plans still may benefit from enrolling the healthiest eligibles or from underserving the high-cost cases that do enroll. Reinsurance compensates plans only after they lose money on a case or on all their enrollees. While reinsurance may relieve some pressure on plans facing losses, it may not affect the incentives plans create with individual providers to limit services. These incentives set out in the provider's contract may not automatically adjust when the costs of a provider's patient reach the reinsurance threshold.

In some areas, Medicaid managed care reinsurance may not be readily available in the private market and may not be available at all for small health plans. Consequently, state Medicaid agencies become de facto insurance companies with the associated risk and resource requirements. As reinsurers, states face the challenge of setting appropriate reinsurance premiums—inappropriate premiums could lead either to plans paying too much, and thus increasing the pressure to underserve, or plans paying too little, which leaves the state in a money-losing position.

Risk Corridors Have Greatest Impact on Negative Financial Incentives

Five states—the District of Columbia, Massachusetts, Ohio, Utah, and Wisconsin—are building risk corridors into their contracts to help mitigate the potentially negative incentives affecting health plans' treatment of disabled enrollees.[40] Unlike reinsurance, risk corridors work in two directions, sharing both losses and profits with health plans below and above preestablished ratios.

As the only mechanism that specifically limits health plan profits, risk corridors have the greatest impact on incentives facing health plans to either reach for the lowest-cost recipients in any given rate cell or to underserve the high-cost enrollees they cannot avoid. The point at which profit and loss sharing begins—the width of the risk corridor—varies from state to state, as does the degree to which profits and losses are shared. Table 4.3 shows the risk corridor arrangement Massachusetts has in its current contract with a plan that provides prepaid care for the severely disabled.

Table 4.3: Massachusetts Risk Corridors for Plan Providing Prepaid Care to the Severely Disabled

Situation at end of contract period	Outcome
Plan has medical expenditures totaling more than 10% below capitation payments	The difference above 10% reverts to the state
Plan has medical expenditures between 0 and 10% below capitation payments	Plan keeps 40% of the difference; 60% reverts to the state
Plan has medical expenditures between 0 and 10% above capitation payments	State pays 50% of the difference
Plan has medical expenditures totaling more than 10% above capitation payments	State pays 75% of the difference

Source: Massachusetts Executive Office of Health and Human Services.

By reducing the potential for profits, the state is affecting implicit health plan calculations regarding the costs and benefits of restricting services. When $1 saved from restricting service translates to $1 of profit, a health plan may be willing to risk losing enrollees who are dissatisfied with health plan service. With risk corridors, however, $1 saved may only translate to 30 or 40 cents in profit, reducing the benefit side of the equation. Because health plans understand how risk corridor arrangements operate before entering into Medicaid prepaid care agreements, corridors also have the unique feature of being a retrospective adjustment with a prospective impact. Risk corridors and their profit limits may affect health plan risk arrangements established with individual

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[40] In addition to these five states, Tennessee has limited profits for certain of its managed care organizations to 10 percent but plans to discontinue the practice in December 1996.

providers in a way that reinsurance does not. In their provider contracts, plans may limit the incentives to reduce services when their profits will be limited.

Chapter 5

Observations, Conclusions, and Comments

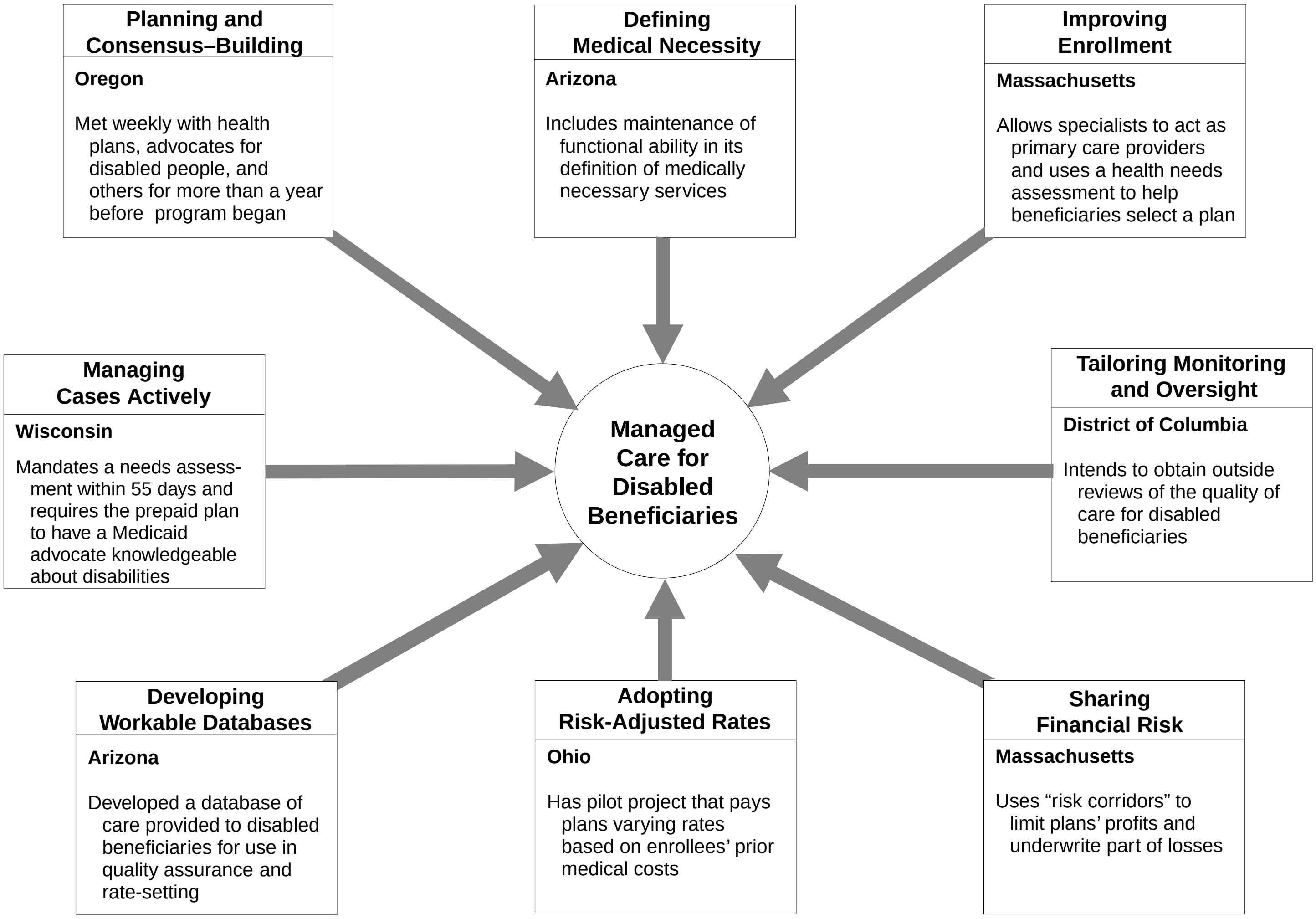
Enrolling disabled beneficiaries in prepaid managed care is a growing trend in Medicaid. Moreover, because much of the proposed expansion is directed toward mandatory managed care, the future expansion of prepaid care for disabled Medicaid beneficiaries appears likely to be even more sweeping in its effect. Thus far, two-thirds of the states providing prepaid care for disabled beneficiaries offer it on a voluntary basis. By contrast, 12 of the 13 states with newly approved or pending Medicaid managed care waivers intend to mandate participation by disabled beneficiaries.

The implications of this shift toward mandatory programs are substantial. Prepaid care has operated in both the public and private arenas as a system based on averages. For example, populationwide averages drive the expectations of what services should be provided and how much they will be used. Likewise, prepaid rates are calculated on average costs, and quality has been monitored, in part, using aggregated average utilization rates. To adequately safeguard the interests of disabled beneficiaries, however, state programs must recognize that these beneficiaries are quite distinct from the general Medicaid population. Not only are their health needs greater than those of the general population, but included among them are a small number of highly vulnerable individuals whose needs are extensive and critical to the prevention of death or further disability. Not addressing these differences heightens the risk that prepaid care plans will try to hold down their costs by (1) discouraging enrollment from high-cost segments of the disabled population or (2) inadequately serving those high-cost beneficiaries they cannot avoid.

Thus far, actions at the state level do not reflect a widespread acknowledgment of the changes in approach that should occur when applying managed care to disabled beneficiaries rather than the general population. In most states, the level of effort to anticipate and accommodate the needs of the various stakeholder groups (disabled individuals and their advocates, the health care plans, and the government) in their current programs has been limited largely because participation in these programs has been voluntary. The efforts have tended to be most extensive in those few states that have already put mandatory or targeted programs in place.

No clear blueprint has yet emerged for how to incorporate disabled beneficiaries into Medicaid managed care plans. The limited efforts to date have not been in place long enough to allow definitive conclusions about how effective they are. At this relatively early stage, however, several key areas are emerging that merit consideration by all parties seeking to develop effective prepaid programs. These key areas, and examples of state actions to address them, are illustrated in figure 5.1.

Figure 5.1: Key Approaches for Including Disabled Beneficiaries in Medicaid Managed Care and Examples of State Initiatives



To date, few states have significant, long-term experience with programs that mandate enrollment by their disabled population. Even fairly extensive experience with voluntary programs may not fully prepare health plans and state officials if, as research suggests, those who select prepaid care in voluntary situations tend to be healthier than those who do not. A state may find it useful to develop and operate a targeted or relatively small-scale program before moving to any large-scale effort to mandate the enrollment of disabled beneficiaries. Small-scale programs would allow health plans, beneficiaries, and state staff to gain experience with meeting the diverse and complex needs of disabled individuals in a prepaid setting.

For states that elect to move immediately into a large-scale program, the areas shown in figure 5.1 are even more critical. Adequate preparation, consensus-building, and program safeguards assume greater significance when substantial numbers of people are being added, particularly if their ability to change plans readily is limited.

Understanding the various approaches currently being tried will provide states with a good starting point for planning their own efforts. Making prepaid managed care work for disabled individuals will be achieved only through the combined and continuing efforts of states, health plans, and beneficiaries and their advocates.

Agency and Other Comments

We provided a draft of this report to the Administrator, HCFA. The draft report was reviewed by officials in HCFA's Office of Managed Care, Office of Research and Demonstrations, and the Medicaid Bureau. HCFA officials had no technical or other comments on the report draft. In addition, we provided relevant sections of the draft report to Medicaid staff from the 17 states in our report. All but one state responded with comments, generally agreeing with the accuracy of the information. Officials in Arizona commented that the draft report seemed to suggest prepaid managed care is not suitable for people with disabilities. We believe, instead, that given the limited state and health plan experience with serving disabled individuals in prepaid care and the medical complexity of their health care needs, careful attention is required in designing, implementing, and monitoring programs for this population.

In addition to requesting comments from HCFA and state agencies, we provided the draft report to several independent researchers from the National Academy for State Health Policy, the Medicaid Working Group, MEDSTAT, and Fox Health Policy Consultants. These researchers generally agreed with the accuracy and comprehensiveness of our presentation of the issues and programs. We incorporated technical and clarifying comments from states and external researchers as appropriate.

Appendix I

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