

March 2000

MEDICAID MANAGED CARE

Challenges in Implementing Safeguards for Children With Special Needs



G A O

Accountability * Integrity * Reliability

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Abbreviations

AFDC	Aid to Families With Dependent Children
BBA	Balanced Budget Act
CPT	Current Procedural Terminology
CSHCS	Children's Special Health Care Service
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
FPL	Federal Poverty Level
HCBS	home and community-based service
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HMO	health maintenance organization
HRSA	Health Resources and Services Administration
PCCM	primary care case management
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act of 1996
SSA	Social Security Administration
SSI	Supplemental Security Income
TANF	Temporary Assistance for Needy Families



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Health, Education, and
Human Services Division

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March 3, 2000

The Honorable Charles Grassley
United States Senate

The Honorable Robert Kerrey
United States Senate

The Honorable Daniel Patrick Moynihan
United States Senate

The Honorable Lincoln Chafee
United States Senate

The Honorable Diana DeGette
House of Representatives

Capitated managed care plans, which deliver medical services for a fixed per-person fee, are an increasingly common part of Medicaid, the federal-state health care program for certain low-income individuals, including adults and children in families, and aged, blind, and disabled people. Initially, most states focused on moving families into managed care delivery systems—the nearly 30 million adults and children who account for about 70 percent of Medicaid beneficiaries. However, because over 40 percent of Medicaid payments go for the care of disabled beneficiaries, states are increasing enrollment of this more costly population into capitated health plans.¹ Managed care's emphasis on primary care and control of service use raises concerns for Medicaid's approximately 7 million disabled beneficiaries—many of whom have chronic conditions that require frequent access to specialized providers.

Before the Balanced Budget Act (BBA) of 1997 became law, states could mandate beneficiary enrollment in managed care plans by obtaining a waiver from the Health Care Financing Administration (HCFA), the federal agency within the Department of Health and Human Services (HHS) responsible for Medicaid, of certain Medicaid requirements such as the

¹The Health Care Financing Administration refers to health plans as managed care organizations.

freedom to choose providers. The BBA gave state Medicaid agencies the authority to require managed care enrollment for the majority of beneficiaries without seeking a waiver. The change permitted managed care programs to be established more routinely through an amendment to a state's Medicaid plan. However, the BBA continued to require federal waivers for mandatory programs that include three vulnerable groups—beneficiaries eligible both for Medicare and Medicaid, Indians who are members of federally recognized tribes, and children with special needs. Although there is no consensus definition, children with special needs often have a serious physical or mental disability (such as cerebral palsy or mental retardation), a chronic medical condition (such as diabetes or asthma), or a requirement for significant amounts of medical care or services (such as around-the-clock nursing care). The BBA defined children with special needs by enumerating five federal and state programs likely to include individuals under age 19 with disabilities or chronic conditions. Children covered by these programs receive income support or other services and generally qualify for Medicaid. The five programs, briefly described here, are discussed in greater detail in app. I:

- Supplemental Security Income (SSI) under the Social Security Act,
- a discretionary Medicaid eligibility category known as the Katie Beckett state plan option that covers children living at home who would be eligible for Medicaid had they been institutionalized,
- Maternal and Child Health Services block grants for children with special needs under title V of the Social Security Act,²
- federal foster care or adoption assistance under title IV-E of the Social Security Act, and
- foster care or out-of-home placements funded from other sources.

About a year after enactment of the BBA, the Senate Appropriations Committee elaborated on the need for a waiver requirement. They noted that greater federal scrutiny was required for mandatory programs for children with special needs because the Congress lacked both experience with and knowledge of this vulnerable population.³ Moreover, it expressed an expectation that the federal government would require states to

²While title V uses the term “children with special health care needs,” to avoid confusion we use the term “children with special needs” throughout this report, even when referring to title V coverage.

³See Senate Report 105-300, accompanying Senate Bill 2440, the fiscal year 1999 appropriations bill for the departments of Labor, HHS, and Education, and related agencies.

establish managed care safeguards for this population in order to receive waiver approval. Safeguards are measures intended to encourage the delivery of appropriate, quality care and include requirements for access to specialty providers, care coordination, and certain quality assurance mechanisms. These requirements can be instituted through state Medicaid contracts with managed care organizations or by state or federal Medicaid policies or regulations.

In light of these congressional concerns about protecting children with special needs, you asked us to (1) examine the implications of the BBA provisions defining this population, (2) provide an update on the number of states enrolling children with special needs in capitated health plans, and (3) assess the steps HCFA has taken to establish appropriate safeguards for this population. In conducting this study, we obtained and analyzed pertinent federal data and reports. We also interviewed cognizant officials within HHS agencies including HCFA and the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA), which oversees the title V program. We worked closely with HCFA to identify states with capitated Medicaid programs serving children with special needs as of July 1, 1999. We also interviewed officials at the Social Security Administration (SSA) who manage the SSI program. During the course of our work, we contacted several state Medicaid agencies regarding their managed care programs and their policies regarding enrollment of children with special needs. (Four of these states will be the subject of an in-depth follow-up study addressing their experiences.) Finally, we conducted an extensive survey of the literature on vulnerable populations enrolled in Medicaid managed care, with particular emphasis on children with special needs, and interviewed numerous experts. Our work was carried out between February and December 1999 in accordance with generally accepted government auditing standards.

Results in Brief

Though broad, the BBA definition of children with special needs does not cover some children in Medicaid whose health conditions could merit recognition as exceptional. For example, some children qualify for Medicaid because of high medical expenses but, unlike those covered under the Katie Beckett option, were not included in the BBA definition. Other children who qualify for Medicaid simply because of low income may also have disabilities or chronic conditions whose treatment in a managed care setting deserves to be more closely monitored. The BBA did not address safeguards for such children. Furthermore, even though the five categories used by the BBA include many children acknowledged as having

special needs, those needs can vary considerably. For example, a relatively small percentage of SSI children have high medical expenditures while the remainder have expenditures similar to those of the average Medicaid-eligible child. Additionally, children receiving adoption assistance are considered to have special needs because of characteristics that make them difficult to adopt, and they may not have any special health care needs. The lack of a homogeneous special needs population requires determining how best to apply certain safeguards, such as access to specialists and care coordination of the medical and social services delivered by various providers. Finally, state Medicaid agencies often cannot readily identify some categories of children covered by the BBA definition and served by other programs such as title V and foster care. Improved coordination between state Medicaid agencies and other federal and state agencies that administer these programs would help resolve this problem.

Nationwide data on the number of states with children with special needs in capitated managed care plans are available for only two of the five BBA categories of children with special needs—SSI and foster care. Between 1996 and July 1999, the number of states enrolling SSI children into capitated plans almost doubled, growing from 17 to 32. About the same number of states currently enroll foster children in capitated programs. No similar information is available for Katie Beckett, title V, or adoption assistance beneficiaries. Consequently, HCFA also is unable to determine the number of BBA-defined children with special needs who are enrolled in capitated Medicaid plans. The lack of data is due, in part, to the fact that HCFA had not traditionally required separate identification or tracking of all of the BBA categories of children with special needs. In conjunction with developing appropriate safeguards for children with special needs, HCFA is taking steps to address these data limitations.

In June 1999, HCFA began applying mandatory interim criteria to review state waiver requests that require the enrollment of children with special needs in capitated managed care plans. These interim criteria reflect a new approach: since 1997, HCFA had focused on developing voluntary guidelines and recommendations concerning special needs populations in general. The interim criteria include some generic safeguards that emerged from these earlier efforts as well as some that are specific to children with special needs, such as access to experienced pediatric specialists. However, several safeguards that HCFA identified in earlier efforts were not included in the interim criteria, such as educating health plans and providers regarding issues of particular concern to children with special

needs. The interim criteria also did not specifically address the need to collect individual-level data to monitor the delivery of services or to adopt criteria for the approval of medical services that maintain rather than improve a person's functioning, as recommended in HCFA's earlier efforts. HCFA has indicated that the interim criteria will be revised to become more focused and rigorous as the agency learns more about best practices by states.

Background

In fiscal year 1998, Medicaid spent about \$177 billion to provide health care coverage for over 40 million low-income Americans, more than 50 percent of whom were children. Medicaid expenditures for children who qualify because of a disability represent a disproportionate share of program costs. The 1 million disabled children in Medicaid constituted 7 percent of beneficiaries under age 21, but accounted for 27 percent of the \$26 billion of payments for children.⁴ Most children counted by Medicaid as disabled qualify because they are receiving SSI.

⁴Because 1998 payments are not yet available, our figures for payments for children and the percentage of payments for disabled children are based on 1997 data.

Defining Special Needs Is Difficult

Despite common threads such as presence of a specific health condition or disability and its duration, there is no widely accepted definition of special needs among federal and state programs that target such children.⁵ Thus, there are differences in the type and severity of medical conditions or disabilities used to define this population.⁶ Some approaches look beyond actual diagnoses and take into consideration a child's risk of developing a condition; others emphasize the effect of a condition on a child's ability to carry out everyday tasks.⁷ A high utilization of services can also signal that a child has special needs. Finally, some states have used the presence of a high proportion of children with disabilities or chronic conditions in a program as a proxy for defining this population.⁸

By combining multiple factors to craft a definition, programs help to compensate for the inherent limitations of a single measure of special need. For example, a definition based solely on a condition or diagnosis is limited because of variability in severity, degree of impairment, and service need. A definition based solely on measuring the level of disability leaves out children who maintain their ability to perform daily activities because of medication or special equipment. Moreover, there are substantial problems in the measurement of disabilities in children because of a lack of adequate age-appropriate measurement tools. Used alone, measurement of high service needs in the past may overlook access issues that prevented a child from obtaining needed services.

⁵See Paul W. Newacheck and others, "An Epidemiologic Profile of Children With Special Health Care Needs," *Pediatrics*, Vol. 102, No. 1 (July 1998), pp. 117-123; and Merle McPherson and others, "A New Definition of Children with Special Health Care Needs," *Pediatrics*, Vol. 102, No. 1 (July 1998), pp. 137-140.

⁶Disabilities such as blindness or developmental delay can create special needs because they affect a child's ability to learn and to socialize with others.

⁷Functional status assessments can be used to identify children who, because of their health status, require assistance in the activities of daily living (such as eating, bathing, or dressing).

⁸Eligibility for Medicaid special needs programs often differs by state; for example, children in Michigan must meet the title V definition of special needs, while those in Oregon must receive SSI or be in foster care.

Several examples of different definitions that combine a number of factors illustrate the range of approaches to defining a special needs population. The SSI program has a long list of eligible medical conditions, specifies that the diagnoses must last for a year or longer, and emphasizes the severity of the condition's effect on daily activities. Elevated service need is not a component of this definition. Within the title V program, many states link chronicity with condition or diagnosis lists that may vary—from as few as about a dozen conditions in one state to as many as 2,700 diagnoses in another. Additionally, researchers who were developing a new definition of special needs for the Maternal and Child Health Bureau of HRSA combined the existence of a chronic condition with elevated service need.⁹ Their service-based approach does not require making individual judgments about whether to include each of a large number of childhood chronic conditions and is more succinct than a condition list. Identification of a current elevated service need does not leave out children who function well but need special services to maintain their functional level and obviates the concern about the adequacy of a child's functional measurement. Finally, the BBA linked designation as a child with special needs to five public programs—SSI, the Katie Beckett state plan option under Medicaid, title V services for children with special needs, federal foster care or adoption assistance, and state, funded foster care or out-of-home placement. The five programs reflect these varying approaches to defining special needs.

⁹Recognizing the difficulties caused by considerable interstate variation in title V definitions, HRSA has encouraged the development of a national definition of children with special needs. From 1994 to 1995, the agency convened a group of experts to develop such a definition, which was presented in the July 1998 issue of *Pediatrics*: "Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." Researchers subsequently estimated that about 18 percent of all children under 18 met this definition, exclusive of children who might be at risk for such conditions.

Multiple Ways Exist for Children With Special Needs to Qualify for Medicaid

Many children with special needs qualify for Medicaid through eligibility for federal programs targeted at children with chronic conditions or disabilities. Medicaid eligibility is mandatory for most children who qualify for SSI and for children covered under title IV-E foster care and adoption assistance.¹⁰ States may voluntarily extend Medicaid coverage to children eligible under the Katie Beckett state plan option, home and community-based service (HCBS) waivers, and the medically needy option. Table 1 describes the Medicaid eligibility categories most closely linked to disability.

¹⁰Under Section 1902(f) of the Social Security Act, states are allowed to use their 1972 state assistance eligibility rules in determining Medicaid eligibility for disabled recipients, rather than SSI eligibility. Eleven states do so. (These states are often referred to as 209(b) states because the origin of this requirement was §209(b) of the 1972 Social Security Amendments Act, Pub. L. No. 92-603, 86 Stat. 1381.) The states' definitions of disability or their income/resource standards for Medicaid eligibility tend to be more restrictive than SSI standards, but can be the same as or more liberal. For example, Illinois has substantially lower monthly income requirements than SSI for individuals and couples, while New Hampshire uses a higher monthly income limit for individuals. The 11 states are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. In these states, children who meet federal SSI standards do not automatically qualify for Medicaid.

Table 1: Major Medicaid Eligibility Categories for Children With Disabilities

Qualifying category	Program description
Mandatory	
SSI ^a	In most states, children receiving SSI on the basis of disability are automatically eligible for Medicaid. ^b To qualify for SSI, the child must meet the income and resource requirements for the program. ^c To be disabled under SSI, a child under age 18 must have “a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”
Foster care	All children who qualify for title IV-E foster care payments are entitled to Medicaid coverage. ^d Children are eligible for title IV-E payments if their biological family would have been eligible for Aid to Families with Dependent Children (AFDC) on July 16, 1996. States may, but are not required to, extend Medicaid coverage to other foster care children who do not qualify for title IV-E but who are supported with state assistance funds. (Children in foster care often suffer from mental or emotional disabilities due to abuse or neglect.)
Adoption assistance	States that participate in title IV-E adoption assistance are required to provide enrolled children with Medicaid coverage. ^e Title IV-E adoption assistance is provided to families who adopt a child who is either eligible for SSI or whose biological family would have been eligible for AFDC on July 16, 1996, and who is deemed by the state to be a child with special needs. Children with special needs are defined by title IV-E statute as having a specific condition or situation—such as age (teenagers); membership in a minority or sibling group; or a mental, emotional, or physical handicap—that the state deems will prevent placement without special assistance.
Optional	
Katie Beckett option	States choosing this option provide Medicaid coverage for children under age 19 who meet the SSI standard for disability, would be eligible for Medicaid if they were in an institution, and are receiving medical care at home that would be provided in an institution. ^f
HCBS waiver	States may apply for a HCBS waiver under section 1915(c) of the Social Security Act to receive federal Medicaid matching funds to cover the costs of certain populations’ receiving long-term care services in the community. Children receiving services under an HCBS waiver must be eligible for Medicaid if institutionalized and must require the level of care furnished in an institution. States with an HCBS waiver may limit the number of eligible children who participate in the waiver program.
Medically needy (also referred to as spend-down)	A state has the option to extend Medicaid coverage to otherwise qualified persons who may have too much income to qualify under other mandatory or optional eligibility categories, such as SSI. If the child’s family income, minus incurred medical expenses, is less than the state’s medically needy income and resource standards, then the child is eligible for Medicaid. States that elect to include the medically needy in their plan are required to include children under 18 who, but for income or resources, would be eligible under a mandatory category.

^aAdministered by the SSA, SSI was created in 1972 to provide cash assistance to blind and disabled adults and children and to aged individuals who have limited income and resources. SSI provides a uniform federal payment, while optional state programs supplement this assistance. Prior to SSI, states set their own standards for determining eligibility and payment levels for state-operated entitlement programs for the blind and disabled, and the federal government provided matching funds.

^bAs previously discussed, children receiving SSI are not automatically eligible for Medicaid if they live in one of the 11 states that operate under the 1902(f) option.

^cFor children under 18 and living at home, a portion of their parents’ income and all of their resources are considered to be available to the child, while none of the parents’ income or resources are treated as available to the child after he or she has been in an institution for 30 days.

^dTitle IV-E of the Social Security Act authorizes federal matching payments to states to assist in paying the costs of maintaining eligible children in foster care, and for related administrative, child placement, and training costs.

^eTitle IV-E adoption assistance, authorized in the Social Security Act, provides federal matching funds to states which provide payments to adoptive parents of children with special needs.

^fIn order to grant an individual Medicaid coverage under this option, states must determine that the estimated cost to Medicaid of caring for the individual at home does not exceed the estimated cost of institutionalizing the child. Since SSI eligibility rules do not attribute parents' income and resources to disabled children after they have been in an institution for 30 days, this option allows states to reduce the incentive for parents to place their child in an institution in order to qualify the child for Medicaid.

Implications of Managed Care for Children With Special Needs

Managed care includes a variety of approaches that attempt to control or coordinate the use of health services by enrollees. For example, by discouraging providers from furnishing unnecessary services and directing beneficiaries to more cost-effective settings, managed care seeks to control health care expenditures. There are two common models of Medicaid managed care: the capitated model and the primary care case management (PCCM) model. Under the capitated model, a health plan receives a fixed monthly fee per enrollee (the capitation fee) with which to provide or arrange for a specified array of services. The PCCM model are similar to a fee-for-service arrangement except that a primary care provider is paid a monthly, per-capita case management fee to coordinate care for beneficiaries. Although states routinely utilize a mixture of capitated health maintenance organizations (HMOs) and PCCM programs, the latter are often implemented in rural areas and by states where HMOs are less prevalent. From 1993 to 1998, the proportion of the Medicaid population enrolled in capitated and PCCM programs has increased steadily, from over 14 percent to about 53 percent. Compared to PCCM enrollment, about five times as many beneficiaries are enrolled in capitated health plans.

The appropriateness of managed care for children with special needs is a matter of debate. Medicaid managed care has some potential benefits for children with special needs, including linking beneficiaries to a regular care provider and thus improving coordination and continuity of care. Furthermore, incentives exist under capitated arrangements to provide preventive care that can help avoid the onset or exacerbation of conditions requiring more costly services. However, covering children with special needs in capitated arrangements raises some concerns regarding access to providers and medical services. All managed care plans limit the choice of or access to providers to some degree; the more restrictive the provider panel or the provisions for obtaining specialist or out-of-network care, the greater the potential for beneficiaries to receive care from less experienced providers or to experience a disruption in care. Furthermore, capitated plans typically emphasize primary care and cost containment efforts and thus may place limitations on the highly specialized and costly medical services special needs populations often require. Within many capitated plans, coverage of some services and treatments are also generally limited to those that meet medical necessity standards.¹¹ While not unique to capitated care, standards that call for “substantial improvement” or “restoration of function” as conditions for covering services pose additional problems for special needs populations because their conditions often preclude reaching this level of recovery.

In addition to these general concerns about capitated managed care and special needs populations, children with special needs face additional vulnerabilities because they are children. The rapid developmental changes that occur between birth and adolescence and the different type, severity, and frequency of health conditions faced by children highlight the importance of appropriate treatment for children. In order to prevent common childhood conditions, such as ear infections, from becoming long-term problems, such as permanent hearing loss, it is essential that children have a continuous, prompt source of medical care, including access to pediatric specialists and subspecialists (as opposed to adult specialists).

¹¹Medical necessity is a concept that is used (along with other criteria) to determine whether insurers will pay for covered health services.

BBA Changed the Waiver Process and Added New Managed Care Protections

The BBA allowed states to establish mandatory capitated programs for most Medicaid beneficiaries through a state plan amendment rather than through the waiver process. Before the enactment of the BBA in 1997, states could (1) offer managed care to Medicaid beneficiaries on a voluntary basis, or (2) mandate managed care enrollment by obtaining a waiver from HCFA of certain statutory provisions, such as guaranteeing beneficiaries' freedom to choose among participating providers. The two general types of waivers used to establish mandatory Medicaid managed care are program and demonstration waivers. The program waiver, known as the 1915(b) freedom of choice waiver, allows states to require that each beneficiary enroll in either capitated managed care or a PCCM plan. These waivers are initially approved for 2 years and renewable for additional 2-year periods. Demonstration waivers authorized by Section 1115 of the Social Security Act allow states to waive most requirements in Medicaid law in order to test concepts likely to assist in promoting program objectives. Normally granted for a period of 5 years, some demonstration waivers have been renewed and states can request 3-year extensions under the BBA.¹² The nature of HCFA's requirements for and oversight of waiver programs depends on the type of waiver that is authorized—generally 1115 demonstration waivers are subject to more conditions and undergo more oversight. Appendix II describes HCFA's waiver review process in more detail. The BBA created a new section 1932 of the Social Security Act that permits states to enroll Medicaid beneficiaries in managed care on a mandatory basis without applying for or receiving a waiver. Using this new option, states simply amend their Medicaid plans, which HCFA approves after assuring compliance with Medicaid laws and regulations. However, states cannot use this alternative for three categories of beneficiaries (children with special needs, Indians who are members of federally recognized tribes, and beneficiaries eligible for both Medicare and Medicaid); rather, they must continue to apply for waivers.

In addition to changes in states' ability to mandate managed care enrollment, the BBA also strengthened Medicaid beneficiary protections.¹³

¹²The BBA provided that demonstration waivers approved or in effect as of its enactment August 5, 1997, may receive extensions of up to 3 additional years if they are approved under the same terms and conditions.

¹³In September 1998, HCFA published a Notice of Proposed Rule Making to amend Medicaid regulations to implement many of the BBA provisions related to Medicaid managed care. See Medicaid Program; Medicaid Managed Care; Proposed Rule, 63 F. R. 52,021, 52,092 (1998).

HCFA's draft implementing regulations would require states to establish various program standards on access, grievance procedures, and quality assurance for their managed care plans, some of which have particular relevance to children with special needs. For example, the proposed regulations would require plans to perform an initial assessment of health needs for all enrollees and to formulate treatment plans that include direct access to specialists for an adequate number of visits for individuals with complex and serious medical conditions. Appendix II describes existing statutory requirements for Medicaid managed care plans but does not incorporate the proposed regulations, which have not yet been finalized. The BBA also mandated HHS to conduct a study and report to the Congress on safeguards needed to ensure that the health care needs of individuals with special needs are adequately met under Medicaid managed care arrangements.

Implementing the BBA Definition of Children With Special Needs May Not Reach All Those Needing Protections

Though broad, the BBA definition of children with special needs does not cover some Medicaid-eligible children whose health conditions could merit recognition as exceptional and whose treatment in a managed care setting deserves to be more closely monitored. For example, some children qualify for Medicaid because of high medical expenses but, unlike those covered under the Katie Beckett option, were not included in the BBA definition. Other children who qualify simply because of low income may also have disabilities or chronic conditions, but the BBA did not specifically address safeguards for such children. Identification of such children with special needs may be difficult for Medicaid agencies. If well implemented, information on these children could be obtained from the assessment following enrollment that the draft Medicaid managed care regulations would require health plans to perform, or by use of Medicaid's existing screening tool for children—the Early and Periodic Screening, Diagnostic, and Treatment program (EPSDT).¹⁴ However, there currently are no commonly accepted criteria to use during the assessment or screening

¹⁴EPSDT provides comprehensive health screening (for example, physical examinations, health and developmental history, laboratory tests, blood lead level testing, health education), immunizations, vision screening and treatment, hearing screening and treatment, dental screening and treatment, and other necessary diagnostic and treatment services to all categorically needy Medicaid-enrolled individuals under age 21. The benefit is optional for the medically needy population. Periodicity schedules for the medical screenings are set by each state based on recommendations of leading medical organizations involved in pediatric health care.

process to designate a child as having special needs and the EPSDT screening rate is low.

While the BBA's reliance on five programs as a proxy for a definition identifies many children acknowledged as having special needs, those needs vary considerably. For example, some may use relatively few medical services during the course of a year and others may not even have special health care needs. The lack of a homogeneous population will necessitate the development of safeguards that take this variation into consideration. Finally, state Medicaid programs may have difficulty making safeguards available to some children covered by the definition because they rely on other agencies to identify these children, and communication between Medicaid and these agencies is sometimes poor.

Some Children Enrolled in Medicaid but Not Covered by the BBA Definition May Have Special Needs

Children with special needs may qualify for Medicaid but not fall into one of the BBA categories. As a result, these children may not receive the benefit of managed care safeguards intended for children with special needs. For example, some children who qualify for Medicaid under family income standards might be SSI-eligible but not enrolled, and thus may not be protected by safeguards.¹⁵ One study of AFDC-recipient children in California found that only half the children who had a severe disability and were members of AFDC families also received SSI benefits in 1995.¹⁶ A second study concluded that three of every four Medicaid-recipient children with a severe chronic condition in California, Georgia, Michigan, and New York were not receiving SSI.¹⁷

¹⁵Prior to the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996, Medicaid eligibility was directly linked to the AFDC program—an entitlement program that guaranteed cash assistance to needy families with children. PRWORA, however, replaced AFDC with Temporary Assistance for Needy Families (TANF)—a block grant program that stopped open-ended federal funding and eliminated the entitlement to cash assistance for eligible families. While PRWORA eliminated the direct link between eligibility for cash assistance and Medicaid benefits, it also instituted a standard that set a minimum Medicaid eligibility level at AFDC income criteria in effect on July 16, 1996. In doing so, the law ensured that low-income families who would have been eligible for Medicaid prior to welfare reform will continue to qualify for benefits regardless of the states' cash assistance program.

¹⁶Meyers, Marcia K., A. Lukemeyer, and T. Smeeding, "The Cost of Caring: Childhood Disability and Poor Families," *Social Service Review* (June 1998), pp. 209-233.

¹⁷Burwell, Brian, B. Crown, and J. Drabek, *Children with Severe Conditions on Medicaid* (Washington, D.C.: The MEDSTAT Group, December 1997).

In addition, some children with special needs may become eligible for Medicaid through two eligibility categories at the state's option: (1) medically needy or spend-down coverage (currently available in 35 states and the District of Columbia), and (2) Section 1915(c) home and community-based services waiver programs. Given the high level of medical expenses often incurred by families of children with special needs as well as the frequent need for services to prevent institutionalization, both of these options are likely to include some children with special needs. However, any children with special needs enrolled in Medicaid managed care through either of these options are not explicitly afforded the safeguards established through the BBA.

Children with special needs who do not receive benefits from one of the five programs included in the BBA definition present an identification issue. The existing EPSDT screening requirement for children enrolled in Medicaid could be used to identify children with special needs but, aside from the five BBA categorical programs, HCFA lacks criteria to designate a child as having special needs. EPSDT requires that all children receiving Medicaid-covered services be screened according to a regular schedule and that any diagnosed needs be treated in a timely fashion. Available evidence, however, indicates that EPSDT does not reach a substantial part of the pediatric Medicaid population. Based on HCFA's annual EPSDT participation report for fiscal year 1997, 58 percent of all children who were due an EPSDT screen in that year actually received at least one screen. Additionally, only about 21 percent received a dental assessment, 15 percent received a vision assessment, and nearly 14 percent received a hearing assessment. HCFA officials told us that because managed care organizations are not reporting encounter data, the agency allows the states to report proxy data for EPSDT involving managed care enrollees.¹⁸ The combination of low EPSDT utilization rates and the use of proxy data within managed care suggests that there may be unidentified children with special needs enrolled in Medicaid managed care.

¹⁸Currently, states may use specific Current Procedural Terminology (CPT) codes instead of documented, complete EPSDT screens. Prior to this change, states with managed care used sampling or other methods to estimate complete EPSDT screens for managed care enrollees. Encounter data are individual-level data for each service provided to each enrollee. These data allow states to identify the care received by any individual, including the provision of any procedure.

HCFA's proposed regulations for Medicaid managed care plans, published on September 29, 1998, would establish a new screening mechanism. They would require Medicaid managed care plans to conduct an initial health assessment of all enrollees within 90 days. For enrollees with complex and serious medical conditions, the assessment must be conducted within a shorter period of time, as specified by the state. Furthermore, the proposed regulations would require states to ensure that plans have procedures in place to identify enrollees with complex and serious medical conditions in a timely manner, and that an appropriate treatment plan be implemented.¹⁹ Assuming timely or expedited screening for new enrollees, EPSDT-like periodic screenings would remain important for identifying conditions that develop after an initial health plan assessment. However, neither the screening requirement of the proposed regulations nor EPSDT has criteria defining children with special needs for the purpose of protecting them in managed care.

**Use of Proxy Definition
Results in States Addressing
Safeguards for Children
With a Wide Array of Needs**

While the BBA definition generally includes individuals with chronic health conditions or disabilities, it collectively covers children with a wide array of needs. Thus, the BBA covers some children whose health care expenditures are relatively low, who do not currently have a chronic condition, or whose program eligibility is not based on a health care need.

¹⁹Several surveys specifically intended to identify children with special needs, using various criteria, are under development or are being tested. The Maternal and Child Health Bureau within HRSA is supporting research efforts to create a shortened version of the Questionnaire for Identifying Children with Chronic Conditions, and is also supporting development of a questionnaire by the Foundation for Accountability and the National Committee for Quality Assurance. Both surveys, which would allow managed care organizations to identify enrolled children with special needs and are generally intended for quality assessment purposes, rely on the HRSA definition of children with special needs published in 1998, though they do not attempt to identify at-risk children. In addition, the National Association of Children's Hospitals & Related Institutions is developing the Categorical Classification of Congenital and Chronic Health Conditions for Children, an instrument that uses data regularly collected by health plans and Medicaid agencies. This assessment tool defines a chronic illness to be a physical, emotional, behavioral, or development disorder expected to last 12 months or longer and to require regular treatment and monitoring.

SSI. The SSI program supports children with impairments that result in marked and severe functional limitations. Even so, these functional limitations do not necessarily translate into frequent use of medical services. A relatively small percentage of children who qualify for SSI have high medical expenses. A 1998 analysis of 1992 Medicaid expenditure data from four states showed that fewer than 13 percent of SSI children could be characterized as high-expenditure cases.²⁰ Nevertheless, these SSI children with high costs accounted for between 63.4 percent and 81.0 percent of Medicaid expenditures for SSI children in these states. Conversely, average Medicaid expenditures on the majority of SSI children in the four states were relatively modest—for example, \$1,275 in Tennessee and \$1,748 in Michigan. Nationally, Medicaid spent about \$960 per low-income child in 1992. The researchers recognized that 1996 changes in SSI disability determinations may slightly increase average expenditures because some children with low medical costs may have lost eligibility.²¹

Title V. Because states have broad discretion in targeting services for the Maternal and Child Health Block Grant program under title V, there is considerable variation in how state title V programs define special needs. Generally, states define eligibility by developing (1) broad, state-specific medical criteria; (2) lists of covered and excluded conditions/services; and (3) income limits. However, at least eight states and the District of Columbia include children who are considered at risk for developing a chronic condition as potentially eligible to receive title V services. For example, Iowa includes children at risk for chronic illness, disability, or a health-related educational or behavioral problem in its medical eligibility criteria. Oregon includes “developmental delay or at risk of becoming disabled” as an eligible condition. The variety of state approaches is evident in appendix III, which compares the definitions used by Florida,

²⁰The four states are California, Georgia, Michigan, and Tennessee. Those children whose medical costs exceed \$10,000 annually, in 1992 dollars, were considered high-expenditure cases. Average annual Medicaid spending on their behalf in these four states ranged from \$28,470 in Tennessee up to \$45,434 in California. Karen Kuhlthau, James Perrin, Susan Ettner, Thomas McLaughlin, and Steven Gortmaker, “High-Expenditure Children With Supplemental Security Income,” *Pediatrics* (September 1998), pp. 610-615.

²¹The PRWORA of 1996 (1) changed the definition of disability for a child from an impairment comparable to one that would prevent an adult from working to one that results in “marked and severe functional limitations,” (2) eliminated the individualized functional assessments that had been used to award benefits to children whose impairments were not severe enough to qualify under the SSAs medical listings, and (3) removed maladaptive behavior as a discrete criterion for assessing a child’s personal and behavioral functioning.

Maryland, Michigan, and Oregon—states whose programs we plan to report on in a follow-up study currently underway.

Adoption Assistance/Foster Care. All children receiving adoption assistance are considered to have special needs because of health or other characteristics that make them hard to place in an adoptive home. Some children suffer from a mental, emotional, or physical disability; others are classified as special needs due to age (teenagers), having brothers or sisters also needing placement, or their minority status. While research suggests that the prevalence of children with special health care needs is higher among foster children than among those from a similar socioeconomic background, children do not have to have a special health care need to receive assistance.²² Similar to the variation in the title V definition, policies for placement in foster care may differ across states and localities, leading to variation in the characteristics of the population from state to state and from locality to locality.

Because of the variation in health care needs of children who come under the BBA definition of special needs, it may not be necessary to provide the same safeguards to all of them. For example, requirements for care coordination for SSI children with multiple chronic conditions could be very different from those for children in foster care who do not have any special health care needs.

Identifying Some Children Covered by the BBA Definition May Be Challenging for Medicaid Programs

State Medicaid agencies do not manage foster care, adoption assistance, or title V programs; and coordination and communication between Medicaid and these programs is not consistent, leading to problems in readily identifying these children. For example, Medicaid agencies may not always be able to identify foster children due to the sometimes weak lines of communication with child welfare agencies responsible for managing foster care programs. Similarly, Medicaid agencies may not be aware if a Medicaid-enrolled child also receives title V services. HRSA officials

²²In addition to higher rates of serious emotional or behavioral problems due to abuse or neglect, foster children have higher rates of chronic physical disabilities, birth defects, and developmental delays. See Committee on Early Childhood, Adoption, and Dependent Care, American Academy of Pediatrics, "Health Care of Children in Foster Care," *Pediatrics*, Vol. 93, No. 2 (February 1994), pp. 335-338; and Tony Dreyfus and Carol Tobias, *Financing Managed Care for Children in Foster Care* (Portland, ME: National Academy for State Health Policy, May 1998).

confirmed that state title V programs do not routinely provide state Medicaid agencies with data on the children they serve.

Along with the concerns regarding title V communication and coordination, the interpretation of the BBA definition may lead to further problems identifying title V children. HCFA gave states the option of adopting a definition of children with special needs that is broader than those in receipt of title V services.²³ Given that many state Medicaid agencies do not know the names of children receiving title V services, the additional identification issues involved with such a decision raise a question about how those states that adopt this broader definition will identify children eligible under it. HRSA's official position is that states should have been required to adopt a broader definition. They indicated that the relevant provisions of the Social Security Act establish two purposes for the title V program—some children with special needs directly receive services provided by state programs, while others benefit from the community-based systems of care that have been developed and/or enhanced by the state programs. HRSA believes that the BBA's exemption encompasses both these groups of children. In contrast, HCFA permits the second group to be included in the definition at state option.

²³According to a HCFA official, the BBA language “described in section 501(a)(1)(D)” does not delineate a group of individuals but certain types of grant programs funded under title V of the Social Security Act. HCFA gave states the choice of either limiting the definition or applying it more broadly. HCFA's interpretation of the phrase indicates that state Medicaid agencies must, *at a minimum*, take steps to identify Medicaid-eligible children under age 19 “receiving services through a family-centered, community-based, coordinated care system receiving grant funds under section 501(a)(1)(D) of Title V.” A state may not opt for a definition that is *narrower* and fails to encompass all Medicaid-eligible children in receipt of such services. However, the state Medicaid agency may choose to include *a more extensive* group than those receiving the specified title V services. Additionally, the state Medicaid agency may develop a process whereby individuals not identified through the initial title V-related exemption process could request exemption based on special needs as defined in the title V plan.

A Growing Number of States Are Enrolling Children With Special Needs in Capitated Plans, but HCFA Has Limited Data on These Programs

Although the number of states with SSI children enrolled in mandatory or voluntary capitated Medicaid programs has grown significantly over the past 3 years, HCFA has only limited information concerning state managed care programs for SSI children and other categories of children with special needs as defined in the BBA. In part, the lack of data on state enrollment policies for children with special needs can be attributed to the imprecise match between the BBA categories and HCFA's data reporting requirements. HCFA's recent introduction of new reporting requirements for capitated programs that enroll children with special needs should, over time, help to provide more data on these programs.

Available national data are limited to two BBA categories of children with special needs—SSI and foster children—and include several elements: (1) the number of states that enroll such children in capitated health plans, (2) whether enrollment is mandatory or voluntary, (3) the type of waivers under which these programs operate, and (4) whether the programs cover the entire state or just a portion of it. However, HCFA does not know how many SSI and foster care children are actually enrolled in states' capitated plans. Even the limited data available were not readily accessible and had to be compiled from different sources that were sometimes inaccurate or contained conflicting information. Moreover, the agency also has no information on state managed care programs for the other BBA categories of children with special needs—Katie Beckett children, children receiving adoption assistance, or children covered by title V services.

In 1996, we reported that 16 states and the District of Columbia included both adults and children receiving SSI in capitated health plans.²⁴ As of July 1999, that number had increased to 31, plus the District of Columbia. Of these, 22 have mandatory capitated programs, up from six states just 3 years earlier.²⁵ Of the states with mandatory programs, seven also allow voluntary enrollment of SSI children in some areas of the state. Another 10 states have only voluntary capitated Medicaid programs for SSI children (see figure 1). In 1999, almost the same number of states (30) and the District of Columbia included foster children in their capitated Medicaid programs (see appendix IV). However, seven states that enroll SSI children do not enroll foster children, while six states do the opposite.²⁶ A review of state programs and SSA data suggests that the enrollment of SSI children in managed care may be significant. In nine states that enroll SSI children statewide in mandatory capitated programs, the SSA reports that there are nearly 100,000 SSI children; all of these children should be enrolled in managed care.²⁷

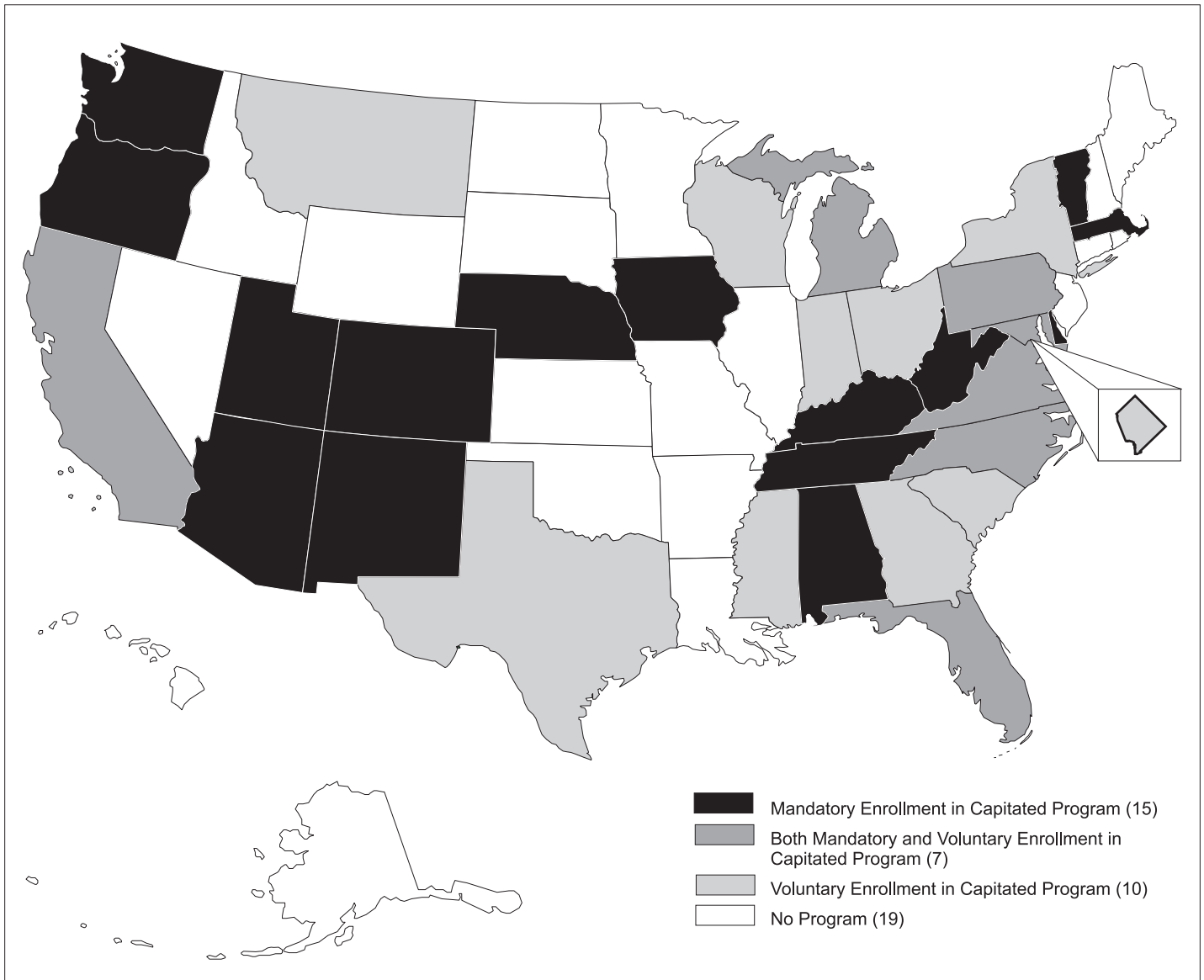
²⁴*Medicaid Managed Care: Serving the Disabled Challenges State Programs* (GAO/HEHS-96-136, July 1996). The 16 states were Arizona, California, Colorado, Delaware, Florida, Maryland, Massachusetts, Michigan, New Jersey, Ohio, Oregon, Pennsylvania, Tennessee, Utah, Virginia, and Wisconsin, plus the District of Columbia. New Jersey has since discontinued enrolling SSI children in capitated Medicaid managed care.

²⁵Only 18 states have no capitated Medicaid programs that enroll SSI children—Arkansas, Connecticut, Hawaii, Idaho, Illinois, Kansas, Louisiana, Maine, Minnesota, Missouri, Nevada, New Hampshire, New Jersey, North Dakota, Oklahoma, Rhode Island, South Dakota, and Wyoming. Alaska has no Medicaid managed care program.

²⁶Alabama, Georgia, Indiana, Iowa, Michigan, Texas, and Virginia enroll SSI children but do not enroll foster children in capitated managed care. Connecticut, Hawaii, Maine, Minnesota, Missouri, and New Hampshire enroll foster children but not SSI children in capitated arrangements.

²⁷These nine states are Arizona, Delaware, Iowa, Kentucky, Massachusetts, New Mexico, Oregon, Tennessee, and Vermont. Separately, in a 1999 report on Medicaid managed care, the National Academy for State Health Policy (NASHP) provided data on the enrollment of SSI children in risk-based managed care (including partially capitated PCCM programs) for only 10 states—Arizona (17,816), Delaware (2,946), Florida (6,247), Montana (2,635), New York (8,157), North Carolina (533), Oregon (4,925), Tennessee (26,912), Utah (2,586), and Wisconsin (266)—and the District of Columbia (2,015). NASHP staff informed us that they made no further attempt to obtain information from states that did not provide data.

Figure 1: State Enrollment of SSI Children in Capitated Medicaid Managed Care, July 1, 1999



As noted previously, the current ability of some states to report data on all five categories of BBA children with special needs is limited. For example, Oregon's Medicaid agency can identify SSI and foster children enrolled in its mandatory capitated program, but is not able to identify children

receiving title V services. Another state, Michigan, targets its program for children with special needs to those who meet its title V eligibility criteria, but does not separately identify Medicaid-eligible children receiving adoption assistance. In a follow-up study currently underway, we plan to report the results of a survey of all states that enroll children with special needs in capitated health plans, including an estimate of the number of children with special needs that states can identify as being enrolled.

HCFA's Managed Care Oversight Evolving to Include Safeguards Focused on Children With Special Needs

In June 1999, HCFA released a four-page document, entitled "Interim Review Criteria for Children with Special Needs," that constituted the first set of mandatory requirements for states enrolling such children and was effective immediately for certain waiver renewals. Eventually, the criteria will be applied to all states that require the enrollment of children with special needs in capitated programs. The interim criteria were based on HCFA's 1998 planning guidance and the analysis contained in a draft report to the Congress and incorporate most of the same types of safeguards. Nonetheless, they are less specific than this earlier guidance. HCFA said that the requirements were interim because the agency had little information regarding appropriate safeguards and states' best practices for children with special needs in managed care. Therefore, the agency plans to release a revised version of the criteria that integrates the results of state case studies and the findings of its report to the Congress. As of November 1999, HCFA had approved waivers that included children with special needs for five states and had 10 others under review.

Interim Criteria Are First Mandatory Requirements Developed for Children With Special Needs

A 1998 Senate report expressed concern that HCFA had not yet developed special review standards or model waiver applications for states that are enrolling children with special needs in managed care through waiver programs.²⁸ In response to congressional concern, HCFA developed “The Interim Review Criteria for Children with Special Needs” (interim criteria), shared in draft with states and advocacy organizations in June 1999.²⁹ The interim criteria represent the first mandatory safeguards targeted specifically to children with special needs enrolled in state Medicaid managed care programs. Prior to the implementation of the interim criteria, HCFA’s review and monitoring of special needs populations in Medicaid managed care programs was limited, and most guidance to states was focused on special needs individuals generally, rather than on children with special needs.³⁰

HCFA will use the interim criteria to review state waiver applications that include children with special needs in managed care on three levels: (1) state responsibility to develop safeguards; (2) state efforts to monitor application of these safeguards; and (3) managed care organizations’ strategies to address the needs of these children. For each of the five categories of children with special needs a state plans to enroll, the state will be required to describe safeguards meeting each requirement. For example, if a state plans to enroll SSI and foster children, it must detail how it plans to address all of the requirements for each of the two groups.

²⁸See Senate Report 105-300 accompanying Senate Bill 2440.

²⁹The interim criteria were officially issued to states on October 1, 1999, when HCFA released a letter to state Medicaid directors transmitting a revised preprint for 1915(b) capitated waivers that included the interim criteria as an addendum.

³⁰There was no explicit mention of special needs safeguards in waiver applications until a May 1999 revision of the form for 1915(b) capitated program waivers. The revised waiver application reflected BBA changes and included a new section allowing states to provide information on program elements related to special needs populations; however, states were not required to complete this section. As a result of the BBA, HCFA increased waiver requirements for section 1115 demonstration waivers that include special needs beneficiaries. Nevertheless, according to HCFA the requirements are more likely to relate to adult special needs populations or those with a specific diagnosis, such as persons with Acquired Immune Deficiency Syndrome, than to children with special needs.

The interim criteria were grouped into 11 categories of safeguards, including identification of children with special needs, provider capacity, access to specialists, and quality of care.³¹ However, there are no accompanying standards, guidelines, or definitions. For example, the capacity safeguard requires “experienced” providers but provides no guidance to identify a sufficient experience level. The criteria also do not address how best to apply safeguards in light of the multiple and divergent requirements of children with special needs. Moreover, the interim criteria do not refer states to any supporting documents, such as HCFA’s previous efforts related to special needs populations. This situation suggests that review of the interim criteria alone may not be sufficient to guide a state in developing an adequate response. Table 2 summarizes the interim criteria; the complete text is included as appendix V.

³¹HCFA also included several existing safeguards that are required for all Medicaid beneficiaries enrolled in managed care programs; however, the interim criteria require states to specifically identify how they will address these safeguards for each category of children with special needs. These safeguards relate to enrollment and disenrollment from managed care plans, specifically the right to disenroll for cause and the prohibition on termination of enrollment or transfer to another health plan because of an adverse change in the enrollee’s health.

Table 2: Summary of Interim Review Criteria for Children With Special Needs

Types of safeguards	Requirements for state managed care programs
Public process	<ul style="list-style-type: none"> Stakeholders such as advocates, providers, and consumer groups are included during waiver development.
Definition of children with special needs	<ul style="list-style-type: none"> Definition includes at least the BBA categories of children with special needs.
Identification	<ul style="list-style-type: none"> Children with special needs are identified and specific data are collected on these children.
Enrollment/disenrollment	<ul style="list-style-type: none"> Enrollment includes outreach activities and assistance from specially trained personnel, and children with special needs can disenroll or re-enroll in another plan for good cause. The auto-assignment process assigns these children to an existing or otherwise capable provider.^a
Provider capacity	<ul style="list-style-type: none"> Health plans should have sufficient experienced providers to serve children with special needs and the state will monitor their capacity.
Specialists	<ul style="list-style-type: none"> Capacity standards are set for specialists to whom children with special needs have direct access or can use as primary care physicians. Specific specialist types are either included in health plan networks or children are allowed to see specialists not in the networks.
Coordination	<ul style="list-style-type: none"> Children with special needs must receive a needs assessment and subsequent treatment plan, along with case management services. Coordination is required among agencies, advocates, and other systems of care or funding sources serving children with special needs.
Quality of care	<ul style="list-style-type: none"> Specific performance measures and performance improvement projects addressing children with special needs are developed.
Payment methodology	<ul style="list-style-type: none"> A payment methodology accounts for children with special needs enrolled in capitated managed care.
Plan monitoring	<ul style="list-style-type: none"> Access to specialists and to services, quality of care, coordination of care, and enrollee satisfaction are monitored. Americans with Disabilities Act access standards are monitored. Medical necessity is defined for health plans and its application is monitored.
BBA guidance	<ul style="list-style-type: none"> The state has adequately addressed HCFA guidance regarding relevant BBA provisions.

^aAuto-assignment is the process by which individuals who do not select a health plan or a provider within a designated time limit are automatically assigned to a plan or provider.

While HCFA did not include written standards or guidelines with the interim criteria, officials said the agency will review waiver requests using several standards that are similar to ones already in use. For example, in determining whether a state sufficiently meets capacity standards for specialists, HCFA is adapting the standard it currently uses for primary care providers—that numbers of providers (now specialists) must be similar under managed care to the numbers available in fee-for-service Medicaid.³² Additionally, HCFA attempted to identify existing safeguard processes or requirements for other programs that are familiar to states and relevant for children with special needs. For example, the requirement to develop a public input process is new for 1915(b) program waivers, but is drawn from 1115 demonstration waiver requirements.

Compared to Other HCFA Guidance, Interim Criteria Omit Some Safeguards and Are Less Specific

HCFA officials told us that the interim criteria are based on previous work that focused broadly on special needs populations as a whole. Even though these earlier documents are not specifically focused on children with special needs, they identify many of the same safeguards as the interim criteria. In October 1998, the agency released “Key Approaches to the Use of Managed Care Systems for Persons With Special Health Care Needs,” a voluntary guide that includes recommendations intended to assist states in the development of Medicaid managed care programs. At about the same time it released the interim criteria in June 1999, HCFA circulated a first draft of the “Report to Congress: Safeguards for Individuals With Special Health Care Needs Enrolled in Medicaid Managed Care,” a BBA-mandated study that is to identify the safeguards needed to ensure that the health care needs of persons with disabilities enrolled in Medicaid managed care are adequately met.³³ Although the report was not finalized, the interim

³²In 1997 we reported that assessing the availability of specialty providers is problematic for at least two reasons: (1) there are no criteria or standards—in fee-for-service or managed care—for the number and mix of specialists needed to serve a population, nor for when and how often referrals to specialists should be made; and (2) because some specialists are available only outside of managed care physician networks, states cannot readily assess their availability to beneficiaries when needed. See *Medicaid Managed Care: Challenge of Holding Plans Accountable Requires Greater State Effort* (GAO/HEHS-97-86, May 16, 1997), pp. 10-11.

³³A second draft that added some proposed recommendations and consolidated others was developed in July 1999. This analysis is based on the July draft. A number of stakeholders participated in the development and review of the draft report. These stakeholders included children’s advocates, advocates for special needs populations, representatives of state Medicaid agencies and managed care organizations, and members of various national associations. HCFA plans to deliver the final report to the Congress in 2000.

criteria are based in part on its analysis. The three documents recognize similar concepts, even when they use different terminology. For example, the criteria adapt from the draft report to the Congress and Key Approaches the requirements of ensuring that children with special needs have access to experienced providers, that specialists are directly available, and that enrollment personnel are trained to assist in selecting health plans and providers based on medical needs.

The interim criteria do not address all of the safeguards suggested in Key Approaches and the draft report to the Congress. For example, the criteria do not address targeting education about managed care to children with special needs and their families or assisting them in navigating managed care systems. Furthermore, there is no criterion to provide education for health plans and providers regarding issues of particular concern to these children—especially those regarding developmental needs, adaptation of medical equipment, and other available networks of care.

The criteria are not as specific as the draft report to the Congress and the Key Approaches in certain areas. For example, the interim criteria require states to devise and monitor the application of a medical necessity definition. However, the criteria do not indicate that the definition should address two issues important to children with special needs. First, the draft report to the Congress notes that medical necessity has specific importance for children with special needs in that both the written definition, and application of the definition, should reflect EPSDT-required access to services.³⁴ Second, both the Key Approaches and the draft report to the Congress point out that the medical necessity definition should require access to health care services that maintain or substitute for loss of functioning rather than merely following the traditional medical models which focus more on the issue of improvement or restoration of functioning. For many children with special needs, specific health services are important to maintaining a reasonable level of functioning, but may not lead to significant improvement.

³⁴In addition to specific screening requirements, the EPSDT program also includes other health care, diagnostic services, treatment, and other measures described in Sec. 1905(a) of the Social Security Act that are necessary to correct or ameliorate defects and physical and mental illnesses and conditions discovered through screening, whether or not those services are covered by the state's Medicaid plan.

Furthermore, the interim criteria require a state to have a process to involve stakeholders for children with special needs during waiver development, and to seek stakeholder participation in the process. The Key Approaches, in contrast, suggest that a state create a Key Stakeholders Advisory Committee to be involved in both the development and implementation processes of the managed care program. The draft report to the Congress further suggests involving stakeholders in the evaluation of managed care initiatives for special needs populations. In 1996, we reported that states that have successfully addressed special needs issues have found that involving beneficiaries and advocates in the planning and design of the program, and on an on-going basis after program implementation, is critical for operating an effective Medicaid managed care program.³⁵

Finally, states are required to track the criteria by each of the five categories of children with special needs. However, the interim criteria do not specify the collection of encounter data, which Key Approaches recommends for evaluating managed care performance. In 1996, we also reported that this information about the health care services provided to patients with disabilities is essential for effective monitoring.³⁶ The information can play an important role in quality assurance, estimates of future service use, research, and program planning. Developing comprehensive, consistent data on services provided under capitated managed care takes time and effort, and can be expensive. However, it 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. A comparison of selected safeguards outlined in the interim criteria and these other documents is provided in appendix VI.

³⁵ *Medicaid Managed Care: Serving the Disabled Challenges State Programs* (GAO/HEHS-96-136), pp. 35-36.

³⁶ *Medicaid Managed Care: Serving the Disabled Challenges State Programs* (GAO/HEHS-96-136), pp. 45-47.

Waivers in Nearly 20 States May Face Interim Criteria Review by 2001

The BBA limited HCFA's authority to mandate safeguards for children with special needs by generally exempting existing waivers from new terms and conditions until they come up for renewal.³⁷ Because children with special needs are enrolled in managed care through different types of waivers with different renewal timeframes, they will be afforded safeguards at different times in various states.³⁸ As of November 1999, five states—Arkansas, California, Colorado, Texas, and Washington—had received approval for waivers under the interim criteria and HCFA reported that waiver proposals from 10 states had addressed the criteria and were under review (see table 3). HCFA has identified additional waivers in 10 states that it expects will have to meet the interim criteria when the waivers are submitted for renewal, through December 2000.³⁹

³⁷For 1915(b) waivers, the interim criteria apply to new and renewal applications; for 1115 demonstration projects, the interim criteria generally only apply to new waiver applications. HCFA further limited application of the interim criteria to mandatory, capitated waivers that include any of the five categories of children with special needs identified by the BBA. It excluded PCCM waivers because the greatest concern for children with special needs in managed care has focused on capitated programs, which have potential issues of withholding or delaying high-cost care that do not exist with the PCCM fee-for-service programs. Additionally, HCFA does not have the authority to require waiver applications for states' voluntary managed care programs. As a result, the interim criteria will more often be applied to 1915(b) waivers both because they are more numerous than 1115 waivers (29 enrolling some children with special needs mandatorily compared to 14 Section 1115 waivers) and because their 2-year term means that they face renewal sooner.

³⁸For example, in six states (Arizona, Delaware, Massachusetts, Oregon, Tennessee, and Vermont) and the District of Columbia, SSI children now are enrolled exclusively through existing Section 1115 waivers (see app. IV, table 6). In Maryland, SSI children are enrolled only under Section 1115 or voluntary programs. New York enrolls children through Section 1115 and Section 1915(b) waivers and in voluntary programs. Alabama and Kentucky enroll children through a combination of Section 1115 and 1915(b) waivers. In five other states—California, Florida, Michigan, North Carolina, and Pennsylvania—SSI children are enrolled under a combination of Section 1915(b) and voluntary programs. The remaining 16 states enroll SSI children either through 1915(b) waivers or through voluntary programs.

³⁹States that have separate managed care programs based in counties or regions, or separate specialty services such as mental health or substance abuse, often have multiple waivers. For example, those states for which HCFA anticipates reviewing additional, multiple waivers include California (four waivers), Florida (two waivers), and Texas (five waivers).

Table 3: States With Waivers Approved, Under Review, or Pending Review Using Interim Criteria as of November 1999

Waiver status	1915(b) Waivers ^a	1115 Demonstration waivers
Approved	Arkansas, ^b California, Washington, Texas (2) ^d	Colorado ^c
Under review	California (2), Florida, Kentucky, Michigan, Nebraska, New Jersey, Pennsylvania, Texas (2), Utah, West Virginia	
Expected review through 2000	California (4), Colorado, Florida (2), Georgia, Indiana, Michigan, Nebraska, New Mexico, Texas (5), Virginia	

^aIf a state has more than one waiver approved or under current or expected review, the number of waivers is indicated in parentheses after the state's name.

^bArkansas was the first state to receive approval for a waiver for a mental health services program enrolling each of the five categories of BBA-exempt children with special needs.

^cColorado's new Section 1115 demonstration program waiver also included children with special needs and was approved in September 1999. However, HCFA officials said the state has indicated that it plans to withdraw its application because the program's sole health plan has decided not to participate.

^dTexas' waiver for medical care services in the Dallas area was approved, though HCFA subsequently determined it should not be subject to the criteria because enrollment of children with special needs is voluntary, rather than mandatory.

A HCFA official acknowledged that states may find the interim criteria demanding, but the agency believes that the criteria are fair and reasonable in terms of waiver standards to meet the congressional interest in greater safeguards for children with special needs. In fact, many states currently may be using these types of safeguards for children with special needs, but they often are not validating the results or identifying their approaches through reports or evaluations, the official said. Furthermore, to facilitate states' compliance with the interim criteria, HCFA is providing technical assistance through conference calls to individual states to review each component of the criteria, and is providing written feedback on state applications. This technical assistance is in addition to a 2-day training session HCFA conducted on how it intends to apply the criteria. The agency also met with national advocacy groups and conducted a short seminar on the interim criteria. Officials noted that they expect their review process to improve as they gain more experience, and that this is likely to result in more terms and conditions imposed on specific waivers. Moreover, HCFA officials said that they expect the criteria to become more rigorous and focused over time. The waiver criteria were issued as "interim" because HCFA had not completed either the report to the

Congress or a special study of six states intended to identify and assess state application of appropriate safeguards for the populations. Therefore, HCFA expects to issue a revision to reflect the report's findings and lessons learned from state experience in serving these children in managed care. HCFA did not have a proposed date for releasing a revised set of interim criteria to states.

Conclusions

Both HCFA and the states face significant challenges implementing safeguards for children with special needs mandatorily enrolled in capitated Medicaid managed care. Complying with the BBA may be difficult for some states, which will have to expand their existing definitions of children with special needs to include all of the BBA categories. On the other hand, some states may wish to go further than the BBA categories in order to provide safeguards to all children with special needs enrolled in Medicaid managed care. An additional challenge is the need to assess whether and how to adapt generic safeguards for special needs populations to the unique needs of children. HCFA is making progress in tailoring its waiver review to require states to explicitly focus on children with special needs as a discrete population. As HCFA recognizes, continued research and examination of state best practices can assist the agency in improving its waiver review criteria and in providing technical assistance to states regarding the most useful safeguards for this uniquely vulnerable population of children.

Agency Comments

HHS was given an opportunity to review a draft of this report. The Department generally concurred with our findings (see app. VII). They acknowledged that the BBA definition may exclude some children who have special health care needs, while including others who have no such needs. HHS also agreed that identification of children with special needs is the first step to ensuring that their health care needs are met. Our report discusses the challenges faced by Medicaid agencies in coordinating with other agencies to identify children with special needs. HHS noted that it will encourage state Medicaid agencies and title V agencies to work collaboratively to identify and coordinate services for children with special needs.

In their comments, HHS highlighted other related initiatives in process, including development of a resource book that will provide HCFA and state Medicaid agencies with resources on caring for children with special needs

in managed care, along with creation of sample purchasing specifications to guide and assist state Medicaid agencies and managed care organizations on approaches for providing quality care. Additionally, HHS plans to implement a survey to gather national and state prevalence data on children with special needs in the summer of 2000, with data available late in 2001. HHS evaluations of Medicaid managed care statewide programs in Oregon and Tennessee include a specific focus on disabled children; the agency will have results from these evaluations by summer 2000.

HHS commented, and we agreed, that although our report focused on Medicaid managed care, these same issues apply to children with special needs who are enrolling in the new State Children's Health Insurance Programs. HHS expressed concern that our report discussed its draft report to the Congress, "Safeguards for Individuals With Special Health Care Needs Enrolled in Medicaid Managed Care," that is required by the BBA. We acknowledge that the report has not received final departmental clearance, and note throughout that the report remains in draft. Nevertheless, we feel it is appropriate to discuss the report because, even though in draft, it was used to develop the interim criteria that have been the basis for reviewing state applications to mandate the enrollment of children with special needs in capitated managed care programs since June 1999. In addition, the draft report was provided to a broad selection of stakeholders for review and comment, including advocates for children with special needs, representatives of state Medicaid agencies and managed care organizations, advocates for other special needs populations, and representatives of various national associations. Finally, though it was scheduled to be issued prior to the publication of our report, the target date for issuance of HHS' report has changed several times. While recognizing the sensitivity of reporting on a document that had not been finalized, we also believe that because the draft report had been made available for comment and was already being used to shape HCFA's decision-making criteria, it deserves to be included in our analysis of HCFA's evolving efforts on this issue. In addition, we incorporated other HHS technical comments as appropriate.

As arranged with your offices, unless you release its contents earlier, we plan no further distribution of this report until 30 days after its issuance date. At that time, we will send copies to the Honorable Donna E. Shalala, Secretary of Health and Human Services; the Honorable Nancy-Ann Min De Parle, Administrator of HCFA; the Honorable Claude Earl Fox,

Administrator of HRSA; appropriate congressional committees; and other interested parties.

If you or your staff have any questions about this report, please call me at (202) 512-7118 or Walter Ochinko, Assistant Director, at (202) 512-7157. Other major contributors are listed in appendix VIII.



Kathryn G. Allen
Associate Director, Health Financing
and Public Health Issues

Key Characteristics of Programs Used by the BBA to Define Children With Special Needs

The Balanced Budget Act of 1997 (BBA) linked designation as a child with special needs to four public programs and a Medicaid optional coverage category—Supplemental Security Income (SSI), the Katie Beckett state plan option under Medicaid, title V services for children with special needs, federal foster care or adoption assistance, and state-funded foster care or out-of-home placement. In basing the definition of children with special needs on programs with high concentrations of Medicaid-eligible children with chronic and disabling conditions, the Congress chose not to develop a new definition of special needs. The five programs reflect the varying approaches to defining special needs, such as diagnosis, degree of functional impairment, frequent use of services, or severity of disability, and include children with a wide range of needs. For example, the Katie Beckett option under Medicaid allows states to offer coverage to children with severe disabilities living at home who otherwise would be ineligible for Medicaid unless they entered an institution, such as a nursing home. Children who receive adoption assistance have a special need which makes placement in an adoptive home difficult; in this instance, special needs include not only mental, emotional, or physical disability, but also conditions or situations such as age and minority status. Eligibility criteria for the programs often both overlap and complement one another. For example, a child may be eligible for both SSI and title V. On the other hand, many children receiving SSI have mental impairments while title V emphasizes physical disability. With the exception of title V and state-funded foster care, Medicaid coverage is generally guaranteed by eligibility for these other programs. Table 4 describes key characteristics of these programs.

**Appendix I
Key Characteristics of Programs Used by the
BBA to Define Children With Special Needs**

Table 4: Program Characteristics

Program	Eligibility definition and program focus	Leads to Medicaid eligibility	Estimated federal program expenditures on children	Number of children receiving benefits
SSI	SSI provides federal payments to low-income individuals with disabilities, including children and adults, and to older Americans. Regarding children, the program focuses resources on those with a high level of need—that is, marked and severe functional limitations. A high percentage of children have mental disorders.	Yes (except for 11 states using 1902(f) option ^a)	\$4.9 billion (FY 1998)	887,066 (December 1998)
Katie Beckett	Katie Beckett children must need a level of care provided in institutions, and generally have long-term disabilities or complex medical needs. As of 1996, 20 states and the District of Columbia used this eligibility category. The number of Katie Beckett children may have dropped as a result of Medicaid eligibility expansions for children resulting from both federal mandates and state choices to peg eligibility to higher percentages of the federal poverty level; these factors moved some children into the regular Medicaid eligibility categories.	Yes (if state offers program)	[Not readily available]	4,000 (1993) ^b
Title V children with special health care needs	Each state determines eligibility for the title V children with special needs program. States generally use title V to fill gaps in services not covered by their Medicaid benefits package. Services for physical disabilities are generally emphasized over those for mental disabilities, and children with mental retardation/developmental disability diagnoses generally are excluded.	No	\$179.6 million ^c (FY 1997)	875,648 ^d (FY 1997)
Title IV-E:	Title IV-E of the Social Security Act governs eligibility for assistance to children who have been adopted or who are still residing in foster care arrangements.			
Adoption assistance	Eligibility is based either on SSI eligibility, or on a child's biological family's income meeting the state's Aid to Families with Dependent Children (AFDC) eligibility standard as of 7/16/96. In order for a family to receive adoption assistance, their child must be designated as having special needs because of health or other characteristics that make him or her hard to place in an adoptive home ^f	Yes	\$427 million (FY 1996)	122,657 ^e (1996)

Continued

**Appendix I
Key Characteristics of Programs Used by the
BBA to Define Children With Special Needs**

Program	Eligibility definition and program focus	Leads to Medicaid eligibility	Estimated federal program expenditures on children	Number of children receiving benefits
Foster care	State child welfare agencies place children in out-of-home arrangements (foster care) when parents or guardians are unable to care for their children. With respect to children in foster care, title IV-E funding is only available to children whose biological parents have income levels that do not exceed the state's AFDC standards in effect on 7/16/96. (Mental illness and emotional disturbance are common conditions among foster children.) The population varies according to state and local philosophy about the importance of keeping children with their biological parents.	Yes	\$3.114 billion (FY 1996)	266,977 ^g (1996)
Non-title IV-E foster care and out-of-home placement	Because the income of some biological parents exceeds the state's AFDC standards in effect on 7/16/96, or because the homes do not meet state licensure requirements, not all foster children qualify for title IV-E funding. As a result, states use their own revenues and/or title IV-B and title XX funds to support these children. ^h Children receiving non-title IV-E funding are not automatically eligible for Medicaid. The characteristics of these children, including reasons for placement, are generally similar to those of title IV-E foster children.	At state option	Title IV-B—unavailable ⁱ Title XX—\$29 million (FY 1995) ^j	Approximately 250,000 ^k

Continued from Previous Page

^aSee footnote 10 for a list of these states.

^bThis estimate, from a January 1993 report, is the most recent available. At that time, 17 states offered Katie Beckett eligibility, but by 1996, the number had grown to 20 and the District of Columbia.

^cIn fiscal year 1997, federal, state, local, and other expenditures for children with special needs totaled just over \$1 billion. Total title V expenditures are distributed among programs serving pregnant women, infants, and children along with children with special needs. In FY 1997, total title V expenditures were \$2.77 billion, with \$513 million provided by the federal government. Every \$4 of federal title V money must be matched by at least \$3 of state and local money. At least 30 percent of title V federal funds are earmarked for services for children with special health care needs.

^dThis total includes some children who are not eligible for Medicaid. However, it is not possible to estimate the percentage of children who are not Medicaid eligible.

^eThis figure represents the average monthly number of children served in 1996.

^fFor a child to qualify for federal adoption assistance, the state must assure that the child cannot or should not be returned to the biological family and that reasonable efforts have been made to place the child without providing adoption assistance.

^gThis figure represents the average monthly number of children served in 1996.

^hTitle IV-B of the Social Security Act, the Child Welfare Services Program, authorizes 75-percent federal matching grants to states for services that protect the welfare of children. There are no federal income eligibility requirements for receipt of title IV-B services. Title XX of the Social Security Act, the Social Services Block Grant program, allocates funds to states on the basis of population—without a state matching requirement—for a variety of social policy goals, including child day care, protective services and foster care for children, home-based services, and case management. According to officials at the Administration for Children and Families, state-only expenditures are the largest source

Appendix I
Key Characteristics of Programs Used by the
BBA to Define Children With Special Needs

of non-title IV-E funding. Appropriations for federal funding are capped and have generally been declining in recent years. Despite the 75-percent federal match available under the Child Welfare Services Program, the allocations are small and states consistently provide more funds than required by the matching formula.

ⁱFederal expenditures under the Child Welfare Services Program totaled \$502 million in FY 1996. The portion devoted to support of foster children is not readily available.

^jIn 1995, 41 states used title XX funds for foster care for children. In aggregate, their spending on foster children accounted for 10.4 percent of title XX spending, or about \$29 million.

^kA total of 520,000 children were in foster care in 1998, but in 1996 only 266,977 children received title IV-E foster care assistance. Based on these numbers, we estimate that about 250,000 children are in foster care placements not supported by title IV-E.

Major Federal Requirements for Approving and Monitoring Quality and Other Aspects of Medicaid Managed Care Programs

Whether they are implemented through a state Medicaid plan amendment or through a waiver, states must comply with certain federal statutory and Health Care Financing Administration (HCFA) requirements for the development and oversight of managed care programs. For both plan amendments and waivers, HCFA monitors compliance by reviewing state contracts with managed care plans. Additionally, monitoring of state Medicaid plans includes the review of independent evaluations and of state-submitted information on expenditures, medical services, and enrollment data, which HCFA requires all states to report periodically.

HCFA's primary oversight of Medicaid waivers generally occurs when states submit a waiver application and when they apply for an extension or renewal. Applications enumerate the specific requirements to be waived and provide an overview of the program. HCFA's central office scrutinizes Section 1115 demonstration waiver applications and subsequent operational plans required prior to implementation. The central office takes the lead in approval for Section 1915(b) program waivers, though the agency's regional offices also play a significant role. Other agencies, such as the Office of Management and Budget and HHS' Substance Abuse and Mental Health Services Administration, also participate in reviews of both waiver types.

HCFA also examines waiver programs when extensions are requested—every year for the continuation of Section 1115 demonstration waivers and every 2 years for the renewal of 1915(b) program waivers. For renewals and continuations, states are required to summarize their programs' accomplishments. States with Section 1115 demonstrations must provide quarterly and annual reports and encounter data, while some also must provide an independent evaluation. States with 1915(b) waiver programs are required to provide independent assessments for the first two waiver cycles.

In order to promote the quality of managed care programs developed either under state Medicaid plans or through waivers, the federal government requires the use of several quality assurance tools. For example, all plans must have an internal quality assurance system, must undergo an annual medical audit, and must have procedures for appeals and grievances that meet certain standards. Table II.1 describes the major federal requirements currently in place for Medicaid managed care programs. Quality assurance measures proposed in HCFA's draft regulations on Medicaid managed care, issued in September 1998, are not reflected in the table because they were not yet finalized.

**Appendix II
Major Federal Requirements for Approving
and Monitoring Quality and Other Aspects of
Medicaid Managed Care Programs**

Table 5: Major Federal Requirements for Monitoring Medicaid Managed Care Programs

Program	Requirement	Detail
Federal requirements		
All Medicaid managed care	Internal quality assurance system	Plans must have a quality assurance system that is consistent with Medicaid utilization control requirements and provides <ul style="list-style-type: none"> • for review by appropriate health professionals of the process followed in providing health services, • for systematic data collection of performance and patient results, and • for interpretation of these data to practitioners and for making needed changes. 42 C.F.R. § 434.34 (1999)
	Grievance and appeals	States must provide an opportunity for a fair hearing to any individual whose Medicaid claim is denied or not acted upon with reasonable promptness. 42 U.S.C. § 1396a(a)(3) (1999) Managed care contractors must provide an internal grievance procedure that <ul style="list-style-type: none"> • is approved in writing by the state Medicaid agency, • provides for prompt resolution of grievances, and • assures the participation of individuals with authority to require corrective action. 42 C.F.R. § 434.32
	Periodic medical audits	States must <ul style="list-style-type: none"> • conduct audits at least once a year for each contractor, • identify and collect management data for use by medical audit personnel, and • ensure that data include reasons for enrollment and termination and use of services. 42 C.F.R. § 434.53
All Medicaid managed care except prepaid health plans	Annual external quality review	States must use, with limited exception, a utilization and quality control peer review organization to conduct an independent, external review of the quality of services furnished, and the results must be made available to the state and certain federal officials. 42 U.S.C. § 1396a(a)(30)(C)
HCFA requirements		
Section 1915(b) program waiver	Independent assessments	States must conduct an assessment of cost, quality, and access for the whole program that is <ul style="list-style-type: none"> • performed on a 2-year cycle, and • required only for the first two waiver renewals.
Section 1115 demonstration waiver	Encounter data	HCFA requires all states with these waivers to collect all encounter data.
	Terms and conditions	The initial terms and conditions of approval contain HCFA's specific monitoring requirements for section 1115 waiver states.

State Examples of Title V Eligibility Criteria, Services, and Conditions for Children With Special Needs

Florida

Program Name	Children's Medical Services
Children With Special Needs Served	51,102 in 1997
Medical Eligibility Criteria	Children whose serious or chronic physical or developmental conditions require extensive preventive and maintenance care beyond that required by typically healthy children. Health care utilization by these children exceeds the statistically expected usage by the normal child, adjusted for chronological age. These children often need complex care requiring multiple providers, rehabilitation services, and specialized equipment in a number of different settings.
Eligible Conditions	Does not use list of eligible conditions
Excluded Conditions	None specifically excluded
Eligible Services	All medically indicated treatment services, including case management
Excluded Services	None specifically excluded
Financial Eligibility	Pregnant women and infants—185% Federal Poverty Level (FPL) (same as Medicaid); ages 12 months to 6 years—133% FPL (same as Medicaid); ages 6 years to 21 years—100% FPL. Individuals are “eligible without financial participation” (that is, at no cost) at or below these levels.

Maryland

Program Name	Children's Medical Services
Children With Special Needs Served	14,125 in 1997

**Appendix III
State Examples of Title V Eligibility Criteria,
Services, and Conditions for Children With
Special Needs**

Medical Eligibility Criteria	Children with disabilities and handicapping conditions, chronic illness and conditions, health-related educational or behavioral problems, and those at risk
Eligible Conditions	Eligible conditions include but are not limited to chronic asthma; chronic renal disease; cystic fibrosis; diabetes, hemophilia, and immune deficiencies; juvenile rheumatoid arthritis; childhood cancers; phenylketonuria; chronic anemia; biliary artresia; broncho-pulmonary dysplasia; tracheal esophageal fistula; ulcerative colitis; brain tumors; cerebral palsy; high-risk neonates; closed head injuries; hydrocephalus; medical aspects of learning disabilities; attention deficit disorder; medical aspects of mental retardation and developmental disability including Down syndrome and other mental retardation syndromes; muscular atrophies and dystrophies; myelomeningocele; seizure disorders; musculotskeletal impairments; cardiac anomalies; orofacial and malocclusive conditions; vision, hearing, language, and speech abnormalities
Excluded Conditions	Mental health services
Eligible Services	Durable medical equipment, orthoses, prostheses, formula and medication to correct metabolic and physiologic disorders, approved therapies, medications, selected dental services; hearing aids and augmentive devices
Excluded Services	None specifically addressed
Financial Eligibility	The annual adjusted gross salary varies by family size: 1=\$13,620; 2=\$18,204; 3=\$22,788; 4=\$27,384; 5=\$31,968; 6=\$36,552; 7=\$41,148; 8=\$45,732. In addition, there is a family contribution toward yearly service costs.

Michigan

Program Name	Children's Special Health Care Services (CSHCS)
Children With Special Needs Served	28,439 in 1997

**Appendix III
State Examples of Title V Eligibility Criteria,
Services, and Conditions for Children With
Special Needs**

Medical Eligibility Criteria	Factors considered include type of condition (diagnosis), severity of the condition, long-term effects of the condition on the child and family (chronically), treatment plan recommended by CSHCS specialists (need for specialty treatment)
Eligible Conditions	Eligible diagnostic groups include certain diseases peculiar to newborn infants and congenital anomalies; diseases of blood and blood-forming organs; diseases of circulatory, digestive, genitorunrinary, musculoskeletal (and connective tissue), nervous (and sense organs), and respiratory systems; diseases of skin and subcutaneous tissue; endocrinal, nutritional, and metabolic diseases; infective and parasitic diseases; injury and poisoning, and neoplasms.
Excluded Conditions	Autism, dyslexia, emotional disorders, learning disabilities, mental retardation
Eligible Services	Care coordination, dental care, equipment and supplies, home health, inpatient hospital, lab tests, medication, nutrition counseling, outpatient care, therapies (physical therapy, occupational therapy, speech and hearing), respite nursing, surgery, vision services, X-rays
Excluded Services	Experimental care (certain organ transplants), medical social work, mental health, skilled nursing and intermediate care facilities
Financial Eligibility	Families with adjusted income \geq 250% FPL share in the cost of treatment

Oregon

Program Name	The Child Development and Rehabilitation Center
Children With Special Needs Served	6,254 in 1997
Medical Eligibility Criteria	Children who have disabling conditions that are expected to be chronic, involve multiple physical defects/disabilities/ handicaps, are amenable to treatment, and create a need for long-term, highly specialized medical care, including rehabilitation; chronic conditions are those expected to last longer than 1 year or to be lifelong.

**Appendix III
State Examples of Title V Eligibility Criteria,
Services, and Conditions for Children With
Special Needs**

Eligible Conditions	Asthma, cardiovascular impairments, communication impairments, cystic fibrosis, developmental delay or at risk of becoming disabled, external body impairments (including oral-facial-cranial and burns requiring specialized care and/or long-term habilitation), genetic disorders, hearing impairments, hemophilia, inborn errors of metabolism, juvenile rheumatoid arthritis, nervous system or orthopedic impairments, prenatal conditions (for example, advanced maternal age with family history or risk of a prenatally diagnosable condition with an abnormal serum alpha-fetoprotein screen or abnormal ultrasound)
Excluded Conditions	AIDS (except for limited services for hemophiliac patients), blindness, cancer, gastrointestinal conditions, renal/liver conditions
Eligible Services	Home health; assistive appliances and supplies; consultative services; continuing outpatient supervision, evaluation, and management; genetic evaluation and counseling; in-patient hospital surgical treatment; nutritional, physical, and occupational therapies; psychological/psychiatric evaluation; specialized dental care; specialized prescription drugs; speech pathology; audiology; transportation, lodging, meals, parking costs, and interpreter for family and child
Excluded Services	Glasses; occasional minor costs such as charges for supplies, equipment, replacement parts, repair and replacement of equipment, and drugs less than \$25 each and occurring less frequently than once per month; organ transplants and related anti-rejection drugs; primary care; research or experimental services; primarily cosmetic surgery
Financial Eligibility	Full financial assistance if family income is less than or equal to 300% FPL

Note: All four states indicate, with varying wording, that title V is the payor of last resort.

Source: Institute for Child Health Policy, University of Florida, *Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services*, 1998 Edition (August 1998).

SSI and Foster Children: States With Mandatory and Voluntary Enrollment in Capitated Medicaid Programs, July 1, 1999

SSI children are enrolled in capitated health plans in 31 states and the District of Columbia—22 of which have mandatory enrollment. Ten states have only voluntary enrollment, while seven others have a combination of mandatory and voluntary enrollment. There are 30 states and the District of Columbia that enroll foster care children in capitated Medicaid programs. Tables IV.1 and IV.2 illustrate enrollment of SSI and foster care children in Medicaid capitated managed care across the states.

States enrolling SSI and foster children in capitated programs may have multiple waivers of the same type (1915(b)), differing types (1915(b) and 1115), or may even have a voluntary program that does not require a waiver. We identified 43 1915(b) and 14 Section 1115 waivers being used to enroll either SSI or foster children in the 31 states and the District of Columbia that have mandatory or voluntary managed care programs for such children. For example, California has six separate 1915(b) waivers as well as a voluntary program. Some of these programs are statewide, some are county-based, and still others cover multiple counties. In addition to two capitated 1915(b) waivers and a voluntary program, New York also has a 1115 waiver. Some states use separate waivers for their mental health and substance abuse services. For example, Colorado has a statewide medical care 1915(b) waiver and a separate mental health 1915(b) waiver.

Table 6: SSI Children

State	Type of enrollment		Type of capitated program			Scope of program	
	Mandatory	Voluntary	1915(b) Waiver	1115 Demonstration	Voluntary program ^a	Statewide	Less than statewide
Alabama	X		X	X			X
Arizona	X			X		X	
California	X	X	X		X	X	X
Colorado	X		X			X	X
Delaware	X			X		X	
Washington, D.C.		X		X		X	
Florida	X	X	X		X	X	X
Georgia		X			X		X
Indiana		X			X		X
Louisiana	X		X			X	
Kentucky	X		X	X		X	
Maryland	X	X		X	X	X	X

Continued

**Appendix IV
SSI and Foster Children: States With
Mandatory and Voluntary Enrollment in
Capitated Medicaid Programs, July 1, 1999**

State	Type of enrollment		Type of capitated program			Scope of program	
	Mandatory	Voluntary	1915(b) Waiver	1115 Demonstration	Voluntary program ^a	Statewide	Less than statewide
Massachusetts	X			X		X	
Michigan	X	X	X		X	X	X
Mississippi		X			X		X
Montana		X			X		X
Nebraska	X		X			X	X
New Mexico	X		X			X	
New York		X	X	X	X		X
North Carolina	X	X	X		X		X
Ohio		X			X		X
Oregon	X			X		X	
Pennsylvania	X	X	X		X		X
South Carolina		X			X		X
Tennessee	X			X		X	
Texas		X	X				X
Utah	X		X				X
Vermont	X			X		X	
Virginia	X	X	X				X
Washington	X		X				X
West Virginia	X		X				X
Wisconsin		X			X	X	X

Continued from Previous Page

Source: HCFA.

^aVoluntary capitated programs require neither 1915(b) waivers nor 1115 demonstration waivers, since enrollees are not compelled to enroll.

**Appendix IV
SSI and Foster Children: States With
Mandatory and Voluntary Enrollment in
Capitated Medicaid Programs, July 1, 1999**

Table 7: Foster Children

State	Type of enrollment		Type of capitated program			Scope of program	
	Mandatory	Voluntary	1915(b) Waiver	1115 Demonstration	Voluntary program ^a	Statewide	Less than statewide
Arizona	X			X		X	
California	X	X	X		X	X	X
Colorado	X	X	X			X	X
Connecticut	X		X			X	
Delaware	X			X		X	
Washington, D.C.		X	X			X	
Florida	X	X	X		X	X	X
Hawaii	X			X		X	
Kentucky	X		X	X		X	
Maine		X	X				X
Maryland	X	X		X	X	X	X
Massachusetts	X			X			X
Minnesota	X	X		X		X	X
Mississippi		X			X		X
Missouri	X		X				X
Montana		X			X		X
Nebraska	X		X			X	X
New Hampshire		X			X	X	
New Mexico	X		X			X	
New York		X	X	X	X		X
North Carolina	X	X	X		X		X
Ohio		X		X		X	
Oregon	X			X		X	
Pennsylvania	X		X				X
South Carolina		X			X		X
Tennessee	X			X		X	
Utah	X		X				X
Vermont	X			X		X	
Washington	X		X				X
West Virginia	X		X				X
Wisconsin			X		X	X	X

Continued

**Appendix IV
SSI and Foster Children: States With
Mandatory and Voluntary Enrollment in
Capitated Medicaid Programs, July 1, 1999**

^aVoluntary capitated programs require neither 1915(b) waivers nor 1115 demonstration waivers, since enrollees are not compelled to enroll.

Source: HCFA.

Interim Criteria Currently Used to Review Waiver Applications for Mandatory Capitated Programs

Interim Review Criteria for Children with Special Needs June 4, 1999

When addressing these criteria, please provide the following information by each appropriate subset of children with special needs:

- The State's responsibilities in managed care programs enrolling children with special needs.
- The State's requirements for MCOs/PHPs enrolling children with special health care needs.
- How the State monitors its own actions and that of its contracting MCOs and PHPs.
- For foster-care children only, the provisions which address the broader, unique issues occurring because of out-of-home, out-of-geographic area placement.

State Responsibilities for Managed Care Programs Enrolling Children with Special Needs

• **Public Process**

The State has in place a public process for the involvement of relevant parties (e.g., advocates, providers, consumer groups) during the development of the waiver program and has sought their participation in that process.

• **Definition of Children with Special Needs**

The State has a definition of children with special needs that includes at least these five subsets :

1. Blind/Disabled Children and Related Populations (eligible for SSI under title XVI);
2. Eligible under section 1902(e)(3) of the Social Security Act;
3. In foster care or other out-of-home placement;
4. Receiving foster care or adoption assistance; or
5. Receiving services through a family-centered, community-based coordinated care system that receives grant funds under section 501(a)(1)(D) of title V, as is defined by the State in terms of either program participant or special health care needs.

• **Identification**

- The State identifies and/or requires MCOs/PHPs to identify children with special needs. The State collects, or requires MCOs/PHPs to collect specific data on children with special needs. The State explains the processes it has for identifying

**Appendix V
Interim Criteria Currently Used to Review
Waiver Applications for Mandatory Capitated
Programs**

each of the special needs groups described above.

- **Enrollment/Disenrollment**

The State performs functions in the enrollment/disenrollment process for children with special needs, including:

- Outreach activities to reach potential children with special needs and their families, providers, and other interested parties regarding the managed care program.
- Enrollment selection counselors have information and training to assist special populations and children with special health care needs in selecting appropriate MCO/PHPs and providers based on their medical needs.
- Auto-assignment process assigns children with special health care needs to an MCO/PHP that includes their current provider or to an MCO/PHP that is capable of serving their particular needs.
- A child with special needs can disenroll and re-enroll in another MCO/PHP for good cause.
- If an MCO/PHP requests to disenroll or transfer enrollment of an enrollee to another plan, the reasons for reassignment are not discriminatory in any way -- including adverse change in an enrollee's health status and non-compliant behavior for individuals with mental health and substance abuse diagnoses -- against the enrollee.

- **Provider Capacity**

- The State ensures that the MCOs/PHPs in a geographic area have sufficient experienced providers to serve the enrolled children with special needs (e.g., providers experienced in serving foster care children, children with mental health care needs, children with HIV/AIDS, etc.).
- The State monitors experienced providers capacity.

- **Specialists**

- The State has set capacity standards for specialists.
- The State monitors access to specialists.
- The State has provisions in MCOs'/PHPs' contracts which allow children with special needs who utilize specialists frequently for their health care to be allowed

**Appendix V
Interim Criteria Currently Used to Review
Waiver Applications for Mandatory Capitated
Programs**

to maintain these types of specialists as PCPs or be allowed direct access to specialists for the needed care.

- The State requires particular specialist types to be included in the MCO/PHP network. If specialists types are not involved in the MCO/PHP network, arrangements are made for enrollees to access these services (for waiver covered services only).

- **Coordination**

- The State requires an assessment of each child's needs and implementation of a treatment plan based on that assessment.
- The State has required the MCOs/PHPs to provide case management services to children with special needs.
- The State has developed and implemented a process to collaborate and coordinate with agencies and advocates which serve special needs children and their families.
- The State has a process for coordination with other systems of care (for example, Medicare, HRSA Title V grants, Ryan White CARE Act, SAMHSA Mental Health and Substance Abuse Block Grant Funds) or State/local funding sources.
- The State requires the MCO/PHP to coordinate health care services for special needs children with: providers of mental health, substance abuse, local health department, transportation, home and community based waiver, developmental disabilities, and Title V services.

- **Quality of Care**

- The State has some specific performance measures for children with special needs (for example, CAHPS for children with special needs, HEDIS measures stratified by special needs children, etc.).
- The State has specific performance improvement projects that address issues for children with special health care needs.

- **BBA Safeguards**

- To the extent appropriate, the State has adequately addressed Balanced Budget Act (BBA) guidance that HCFA has issued to date.

**Appendix V
Interim Criteria Currently Used to Review
Waiver Applications for Mandatory Capitated
Programs**

- **Payment Methodology**

- The State develops a payment methodology that accounts for special needs populations enrolled in capitated managed care.

- **Plan Monitoring**

- The State has in place a process for monitoring children with special needs enrolled in MCOs/PHPs for access to services, quality of care, coordination of care, and enrollee satisfaction.

- The State has standards or efforts in place regarding MCOs'/PHPs' compliance with ADA access requirements for enrollees with physical disabilities.

- The State defines medical necessity for MCOs/PHPs and the State monitors the MCOs/PHPs to assure that it is applied by the MCOs/PHPs in their service authorizations.

Comparison of Selected HCFA Requirements, Guidance, and Findings for Special Needs Populations in Medicaid Managed Care

Table VI.1 compares HCFA waiver review requirements, guidance, and proposed regulations for Medicaid managed care. It focuses on four areas that are commonly identified in the literature as important: identification of special needs populations, access to specialists, payment methodology, and quality of care. In each case, the recommended safeguards are addressed to special needs populations in general unless children with special needs are directly referenced.

The publications we compared include

- Interim Review Criteria for Children with Special Needs, issued to states in June and formally published in October 1999 as a series of requirements for new and renewal 1915(b) (and eventually Section 1115) waivers that mandatorily enroll children with special needs in capitated managed care;
- Notice of Proposed Rule Making for Medicaid Managed Care, published in the Federal Register September 29, 1998, and incorporating BBA Medicaid managed care requirements into regulation;
- Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs, a nonmandatory guidance for states developing managed care programs that include special needs populations, published in October 1998; and
- Report to Congress: Safeguards for Individuals with Special Health Care Needs Enrolled in Medicaid Managed Care (draft), a BBA-mandated study to identify safeguards for special needs populations; the report was under development when the interim criteria were issued.

The interim criteria currently are required of states enrolling children with special needs through certain waivers. The managed care regulations were not finalized, while the other documents contain no mandates for states.

**Appendix VI
Comparison of Selected HCFA Requirements,
Guidance, and Findings for Special Needs
Populations in Medicaid Managed Care**

Table 8: Selected Safeguards for Special Needs Populations Enrolled in Medicaid Managed Care Contained in HCFA Publications

Safeguard	Interim criteria (required)	Proposed regulations	Key approaches (optional guidance)	Draft report to the Congress^a
Identification of special needs individuals/ children	<p>The state or health plan</p> <ul style="list-style-type: none"> • identifies children with special needs, and • collects specific data on these children. <p>The state must explain its identification processes.</p>	<p>A health plan must have procedures to</p> <ul style="list-style-type: none"> • identify, in a timely manner, individuals with complex and serious medical conditions, • assess the conditions, and • identify appropriate treatment or monitoring. <p>Medicaid Program; Medicaid Managed Care; Proposed Rule, 63 Fed. Reg. 52,021, 52,083 (1998) (to be codified at 42 C.F.R. § 438.306(e)(3)(ii))</p>	<p>States should consider</p> <ul style="list-style-type: none"> • identifying potential beneficiaries through outreach and bringing them into Medicaid, • facilitating beneficiaries' enrollment into the most appropriate care delivery system, and • whether and how approaches for children and adults should vary. 	<p>States should</p> <ul style="list-style-type: none"> • use various data to identify persons to health plans, including children with special health care needs and children in foster care, • require health plans to screen state-identified persons for special needs, • require screening by health plans of all other Medicaid enrollees within 90 days of enrollment to assess for the presence of special needs, • require plans to identify enrollees that develop such needs after enrollment, and • routinely report numbers enrolled by special needs category. <p>HCFA will provide technical assistance to states on approaches to identify individuals. HHS will support research in methods to identify special needs individuals.</p>

Continued

**Appendix VI
Comparison of Selected HCFA Requirements,
Guidance, and Findings for Special Needs
Populations in Medicaid Managed Care**

Safeguard	Interim criteria (required)	Proposed regulations	Key approaches (optional guidance)	Draft report to the Congress^a
Access to specialists	<p>The state</p> <ul style="list-style-type: none"> • sets capacity standards for specialists, • monitors access, • includes contract requirements for designation of specialists as primary care providers or allowances for direct access to specialists, and • requires particular specialist types in health plan networks or requires out-of-network access. 	<p>Health plans must assure that they offer access to specialty services appropriate for the needs of the population being served.</p> <p>Medicaid Program; Medicaid Managed Care; Proposed Rule, 63 Fed. Reg. 52,021, 52,081 (1998) (to be codified at 42 C.F.R. § 438.110(b)(1))</p>	<p>States should consider</p> <ul style="list-style-type: none"> • systems to permit specialists to serve as primary care providers, • procedures to permit standing referrals to specialists in and out of health plan networks, and • ways of determining appropriate training and experience. 	<p>States should</p> <ul style="list-style-type: none"> • require health plans to include providers with experience serving special needs persons, including providers with experience in pediatric populations, • require health plans to have out-of-network referrals if an appropriate provider is not available within the network, and • ensure that providers are physically accessible. <p>HCFA will monitor state implementation of BBA requirements for access to specialists.</p>
Payment methodology	<p>The state will develop a payment methodology accounting for the enrollment of special needs populations in capitated managed care.</p>	<p>No requirement</p>	<p>States should consider</p> <ul style="list-style-type: none"> • ensuring rates of payment adequate for enrollment of special needs population, • reimbursement methodologies to address adverse selection, • whether new pharmaceuticals or treatments are included in the capitation rate, and what adjustments are necessary if they are, and • providing financial incentives to providers/health plans to encourage appropriate care delivery. 	<p>States should</p> <ul style="list-style-type: none"> • use mechanisms such as risk-adjusted capitation and risk sharing, and • collect and validate health plan encounter data to help develop payment rates. <p>HCFA will provide technical support to states to develop risk adjustment approaches.</p>

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**Appendix VI
Comparison of Selected HCFA Requirements,
Guidance, and Findings for Special Needs
Populations in Medicaid Managed Care**

Safeguard	Interim criteria (required)	Proposed regulations	Key approaches (optional guidance)	Draft report to the Congress^a
Quality of care	<p>The state</p> <ul style="list-style-type: none"> • has some specific performance measures (such as CAHPS^b survey or HEDIS^c measures), and • has specific performance improvement projects. 	States must ensure that health plans comply with requirements for identification, assessment, monitoring and treatment of individuals with complex and serious medical conditions. Medicaid Program; Medicaid Managed Care; Proposed Rule, 63 Fed. Reg. 52,021, 52,083 (1998) (to be codified at 42 C.F.R. § 438.306(e)(3)(iii))	States should consider <ul style="list-style-type: none"> • monitoring health plan compliance with state and federal requirements, • assuring complaint and grievance processes expedited for those with life-threatening conditions, • requiring HEDIS measures and assessing the need for measures specific to special needs populations, • creating consumer satisfaction surveys for this population, • assessing specific aspects of quality of care for this population, including targeted studies or investigations, • incorporating continuous quality improvement goals in health plan contracts, • evaluating patterns of referrals to specialists and subspecialists, and • developing safeguards on conflict-of-interest issues for enrollment, guardianship, or eligibility determination agencies. 	Health plan internal quality assessment and performance improvement programs should assess and improve quality of care. States should monitor and take action to improve care to the population as part of BBA-required quality assessment and performance improvement strategies. HCFA will monitor state quality and performance improvement strategies, fair hearing systems, and state oversight of health plan grievance systems for the population. HHS will lead development or adaptation of performance measures for the population.

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Note: Boldfaced sections contain a specific reference to children with special needs.

^aThe draft report to the Congress includes a series of recommendations collected under eight issue areas. These recommendations are followed by chapters describing the evidence upon which the proposals are based and providing additional explanation and examples. Only the abbreviated text of the recommendations is provided here.

^bThe Consumer Assessment of Health Plans (CAHPS), sponsored by the Agency for Health Care Policy and Research, is a survey intended to provide information to allow consumers and purchasers to assess and choose a health plan.

^cThe Health Plan Employer Data and Information Set (HEDIS), developed by the National Committee for Quality Assurance, is a set of standardized performance measures for health plans.

Comments From the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

FEB 14 2000

Ms. Kathryn G. Allen
Associate Director
Health Financing and Public Health Issues
United States General
Accounting Office
Washington, D.C. 20548

Dear Ms. Allen:

Enclosed are the Department's comments on your draft report, "Medicaid Managed Care: Federal and State Challenges in Implementing Safeguards for Special Needs Children." The comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department also provided extensive technical comments directly to your staff.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely,

Michael Mangano
for June Gibbs Brown
Inspector General

Enclosure

The Office of Inspector General (OIG) is transmitting the Department's response to this draft report in our capacity as the Department's designated focal point and coordinator for General Accounting Office reports. The OIG has not conducted an independent assessment of these comments and therefore expresses no opinion on them.

Comments of the Department of Health and Human Services
on the General Accounting Office Draft Report
“Medicaid Managed Care: Federal and State Challenges in
Implementing Safeguards for Special Needs Children”

General Comments

The Department of Health and Human Services (Department) appreciates the opportunity to comment on the General Accounting Office’s (GAO) draft report. The Department shares GAO’s concern about ensuring that appropriate safeguards are in place for children with special health care needs being provided with managed care by the Medicaid program. This report provides valuable information to Federal and State policymakers on the challenges faced in implementing safeguards for special needs children. In general, we concur with GAO’s findings and conclusions.

Managed care includes a variety of approaches that attempt to control or coordinate the use of health services by enrollees. One of the potential benefits of managed care for special needs children is linking beneficiaries with a gatekeeper or medical home, and thus improving coordination and continuity of care. This type of coordination is endorsed by the American Academy of Pediatrics and provides children with special needs with care that is accessible, comprehensive, continuous, coordinated, compassionate and culturally competent. It is essential that children have a continuous, available source of medical care, including access to pediatric specialists and sub-specialists.

The Department has consistently recognized a number of key factors that must be present to safeguard children with special health care needs in managed care. These include quickly identifying special needs children as they enter managed care, providing access to appropriate health care professionals, coordinating care, monitoring quality and providing sufficient funding, while educating and involving stakeholders.

The Department has taken a number of steps to identify these special needs children and provide appropriate safeguards.

- In October 1998 the Department’s Health Care Financing Administration (HCFA) issued a guide to States on safeguarding children with special health care needs entitled “*Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs.*” The HCFA also began to study safeguards for people with special health care needs as required by the Balanced Budget Act of 1997 (BBA).
- Over the last 6 years the Department’s Health Resources and Services

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Administration (HRSA) has provided funding for a number of organizations to research and evaluate the issues of children with special needs receiving managed care. This research and evaluation has provided a wealth of information on ways of protecting special needs children; including identification tools, quality assurance mechanisms, and family satisfaction surveys. The HRSA is currently in the process of developing a resource book that will provide HCFA and State Medicaid agencies with valuable resources on caring for children with special health care needs in managed care.

- The HRSA, in collaboration with the Department's National Center for Health Statistics, has developed a State survey to gather national and State prevalence data on children with special health care needs. The survey will be implemented beginning in the summer of 2000 and data will be available late in 2001.
- The HCFA in collaboration with the Department's Assistant Secretary for Planning and Evaluation is evaluating statewide Medicaid managed care demonstrations in Oregon and Tennessee. Children with special needs are enrolled in managed care in both States. Each evaluation has a disability component that includes a survey of disabled Medicaid enrollees with a sub-sample of disabled children. Results from these evaluations should be available in the spring and early summer of 2000.
- The HCFA, in collaboration with the Department's Assistant Secretary for Planning and Evaluation, is conducting case studies in six States to assess interim review criteria. In June 1999 the Department shared with the States the draft criteria that we are using when reviewing new waiver applications under 1915(b) and 1115 and for 1915(b) waiver renewals. This study, due to be completed in March of 2000 is intended to test interim review criteria and provide information to us in making the criteria final. The HCFA will need time to review the results of the case studies prior to revising the criteria. As a result, HCFA is revising the time line to complete the criteria revisions and will advise GAO when the new time line is established.

The Department concurs with GAO's conclusion that the BBA definition of special needs children is not adequate for identifying all children with special health care needs. The five programs referred to in the BBA: 1) the Supplemental Security Income program, 2) the Katie Beckett State plan option under Medicaid, 3) the Maternal and Child Health Services block grants for special needs children under title V of the Social Security Act, 4) the Federal foster care or adoption assistance program under title IV-E

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of the Social Security Act, and 5) the foster care or out of home placement program do not represent the entire population of children with special needs. We agree there needs to be a consensus on defining special needs; however, this is extremely difficult due to the types and severity of medical conditions or disabilities affecting these children. The Department is working toward achieving a common definition for Federal and State programs that target these children. In working toward this goal, HRSA and the American Academy of Pediatrics have worked collaboratively to establish an operational definition of children with special needs.

On the other hand, we believe the exemption categories in the BBA provide a useful starting point to identify children who should be screened. We agree that identification is the necessary first step to ensuring that their special health care needs are met. Because not all children with special health care needs are in these groups, we anxiously await the refinements of the instruments currently under development to provide additional tools to identify these children.

The GAO report states there are no commonly accepted criteria to use during the assessment or screening process to designate a child as having special needs. However, in addition to the Department's Early and Periodic Screening, Diagnostic and Treatment program there are two other tools that can assist managed care organizations identify special needs children: 1) the Questionnaire for Identifying Children with Chronic Conditions developed by R.E. Stein and 2) the FACT/CAHMI Tool for Identifying Children with Special Needs from the Children's Health Measurement Initiative developed by the Foundation for Accountability.

The GAO report discusses the challenges faced by Medicaid agencies in working with other agencies to identify special needs children. The Department agrees that some State title V programs do not routinely provide State Medicaid agencies with data on children they serve. However, this lack of data sharing is often not due to a lack of willingness to share the data, but rather due to a lack of communication between the agencies. The Department will encourage State Medicaid agencies and State title V agencies to work collaboratively to identify and coordinate services for special needs children. This could be accomplished through a joint letter from HRSA and HCFA to State Medicaid Directors and State title V Directors, similar to the November 25, 1998 letter on coordination and collaboration sent to Ryan White agencies.

The Department, with assistance from the George Washington University Center for Health Service Policy Research, is developing sample purchasing specifications for children with special health care needs in Medicaid managed care. These purchasing specifications will provide guidance and technical assistance to State Medicaid agencies and managed care organizations on approaches for providing quality care to children with special needs. These specifications will contain illustrative language relating to

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benefits, including identification, care coordination services and coverage determination, and the delivery of care, including enrollment, provider selection, provider network, access standards and quality measurement. The specifications should be finalized by late spring of 2000.

The Department must provide for adequate reimbursement of managed care organizations and providers to ensure special needs children receive quality services. As part of the review process under interim criteria, States must develop a payment methodology that accounts for special needs populations enrolled in capitated managed care. However, the Department recognizes that the state of the art for risk adjustment methodologies for children with special health care needs is still in its infancy. The Department will address rate setting issues for special needs populations, including children, in their forthcoming Report to Congress and the final regulations implementing the BBA Medicaid managed care requirements.

We do wish to express our concern that GAO has chosen to use information from our draft report to Congress: "Safeguards for Individuals with Special Health Care Needs Enrolled in Medicaid Managed Care." This is a BBA-mandated study that identifies the safeguards needed to ensure that the health care needs of persons with disabilities enrolled in Medicaid managed care are adequately met. Our draft report was provided to a limited set of stakeholders for their review and comment. Throughout the process of conducting our study and developing our report, we shared information with GAO staff. We invited GAO staff to meetings with stakeholders to provide them the benefit of discussions surrounding this subject. On those occasions, we stressed the sensitivity surrounding our documents until a final report was released by the Secretary to the Congress. Since our report has not received final departmental clearance, we do not believe it is appropriate to include this information in GAO's report.

Finally, although GAO's report focused on Medicaid managed care, it is important to highlight that these same issues apply to children with special health care needs who are enrolling in the new State Children's Health Insurance Program. Several of these programs build on Medicaid managed care programs, and thus address the same issues for children with special health care needs.

GAO Staff Acknowledgments

In addition to those named in the report, Karen Doran, Richard Hegner, Behn Miller, Mike Piskai, and Michelle Rosenberg made key contributions to this report.

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