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MEDICAID MANAGED CARE

States' Safeguards for Children With Special Needs Vary Significantly



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Abbreviations

ACG	Adjusted Clinical Groups
AFDC	Aid to Families With Dependent Children
AIDS	acquired immunodeficiency syndrome
BBA	Balanced Budget Act
CCR	Continuity of Care Referral Form
CMS	Children's Medical Services
CSHCN	children with special health care needs
CSHCS	Children's Special Health Care Services
DPS	Disability Payment System
ENCC	exceptional needs care coordinator
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HMO	health maintenance organization
IHCP	individualized health care plan
PCCM	primary care case management
PLCC	plan level care coordinator
SNC	special needs coordinator
SSI	Supplemental Security Income



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The Honorable Robert Kerrey
The Honorable Charles E. Grassley
The Honorable Lincoln Chafee
The Honorable Daniel Patrick Moynihan
United States Senate

The Honorable Diana L. DeGette
House of Representatives

Since the mid-1990s, states have accelerated the enrollment of children with special needs in capitated Medicaid managed care programs, which deliver medical services to beneficiaries for a fixed per-person fee. States see capitated managed care, with its emphasis on primary care, restricted access to specialists, and control of services, as both a mechanism to restrain program cost increases and a way to provide the general Medicaid population with consistent preventive and primary health care. However, these same features may be less appropriate for children with special needs, who often require highly specialized and costly medical services. The Balanced Budget Act (BBA) of 1997 continued to require federal approval for state Medicaid programs that mandate that these children enroll,¹ while providing state Medicaid agencies the authority to mandate enrollment for the majority of other beneficiaries without seeking such approval.

Although there is no consensus definition used by states to identify children with special needs, the BBA enumerated four federal programs and a Medicaid optional coverage category that are likely to include individuals under age 19 with disabilities or chronic conditions and refers to these children as having “special needs.”² Children covered by these

¹The BBA also continued to require federal waivers for freedom of choice among participating providers and other statutory provisions for managed care programs that mandate the enrollment of children with special needs and two other vulnerable groups: beneficiaries eligible both for Medicare and Medicaid and Indians who are members of federally recognized tribes.

²See P.L. No. 105-33, sec. 4701, 111 Stat. 489.

programs receive income support or other services and generally qualify for Medicaid:

- *Supplemental Security Income (SSI) under the Social Security Act.* SSI provides cash assistance to low-income adults and children with disabilities, as well as low-income aged individuals. SSI focuses its resources for children on those with a high level of need—that is, those with marked and severe functional limitations.
- *The Katie Beckett state plan option.* This Medicaid coverage category is optional for states. It allows children who need a level of care provided in an institution to be cared for at home.
- *Maternal and Child Health Services Block Grant for children with special health care needs (CSHCN) under title V of the Social Security Act.* Title V is designed to promote coordinated care and community-based systems of services. Though defined differently by each state, title V generally applies to children with physical disabilities, filling in gaps in coverage for services not covered by Medicaid or private health insurance.
- *Federal adoption assistance or foster care programs under title IV-E of the Social Security Act.* These programs provide federal assistance in finding adoptive homes for children who are difficult to place—including those with a physical or emotional disability—and assist foster care families in caring for children from low-income families.³
- *Foster care or out-of-home placements funded from other sources.* States often provide assistance to children who are not eligible for title IV-E assistance because they do not meet income or other standards. The characteristics of these children are similar to those of title IV-E foster children.

About a year after enactment of the BBA, the Senate Appropriations Committee emphasized the need for greater federal scrutiny of mandatory

³Title IV-E adoption assistance is provided to families who adopt a child who is either eligible for SSI or whose biological family's income meets the Aid to Families With Dependent Children (AFDC) eligibility standard in effect 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 as being in a certain situation or having a specific condition—such as being a teenager or having a mental, emotional, or physical handicap—that would prevent placement without special assistance. Title IV-E foster care assistance is available for children whose biological family's income level does not exceed the state's AFDC standards in effect on July 16, 1996.

managed care programs that enroll children with special needs.⁴ The Committee noted that the Congress lacked both experience with and knowledge of this population and expressed an expectation that states would be required to establish managed care safeguards in order to receive federal approval for mandatory enrollment. Safeguards are intended to encourage the delivery of appropriate, quality care and include measures for access to specialty providers, care coordination, and quality monitoring. These safeguards can be instituted through state Medicaid contracts with managed care organizations or by state or federal Medicaid policies or regulations.

This report is the second of a two-part study we conducted at your request. The first report examined the BBA definition of children with special needs and described the limited data available about their participation in Medicaid managed care.⁵ It also assessed steps taken by the Department of Health and Human Services' (HHS) Health Care Financing Administration (HCFA) to establish safeguard criteria for these children in the agency's waiver review and approval process. This report (1) presents data on the extent to which states are enrolling children with special needs, as defined in the BBA, in capitated managed care plans and (2) assesses the scope and effectiveness of the safeguards these states are implementing to ensure that children with special needs receive appropriate care within Medicaid managed care.

Using the limited data available on state enrollment of children with special needs, we identified 36 states that enrolled SSI children, foster care children, or both in capitated managed care. We surveyed the Medicaid directors of these states to identify their policies on enrolling the categories of children with special needs cited by the BBA and the available safeguards. Additionally, we more closely examined the safeguards operating in Florida, Maryland, Michigan, and Oregon, states that have either included children with special needs in managed care plans along with other beneficiaries or have also created distinct programs to serve some of these children. We conducted our work between September 1999 and September 2000 in accordance with generally accepted government

⁴See S.R. 105-300, accompanying S.B. 2440, the fiscal year 1999 appropriations bill for the Departments of Labor, Health and Human Services, and Education and related agencies.

⁵See *Medicaid Managed Care: Challenges in Implementing Safeguards for Children With Special Needs* (GAO/HEHS-00-37, Mar. 3, 2000).

auditing standards. See appendix I for details regarding our scope and methodology.

Results in Brief

Following the general trend of serving more Medicaid beneficiaries through managed care delivery systems, many states are enrolling a range of children considered to have special health needs in capitated managed care programs. However, the number of children involved is uncertain, because many of the states could not readily report the number of affected children. The 36 states we surveyed enroll some or all of the BBA categories of children in capitated managed care: 14 states mandated enrollment, 11 states allowed families to make a choice between capitated managed care and some form of fee-for-service coverage, and another 11 states had both mandatory and voluntary enrollment for children in different categories or in different parts of the state. Of the six categories of children with special needs identified by the BBA, SSI children are the most likely to be enrolled in capitated plans.⁶ Between 1996 and 1999, the number of states enrolling SSI children in capitated health plans increased from 17 to 31.⁷ Katie Beckett children were the least likely to be enrolled.

Adoption and implementation of safeguards for these children vary significantly across the 36 states we surveyed. Some types of safeguards have been more widely adopted by states than others. For example, 31 of the 36 states have at least one measure designed to ensure adequate pediatric provider capacity. However, 18 states do not inform health plans of the presence of special needs when enrolling children, and 18 do not require health plans to conduct a needs assessment soon after enrollment. Additionally, some safeguards may be less effective because states have made them optional rather than mandatory, have not adopted rigorous approaches in their design and use, or do not target the safeguard specifically for children with special needs. Examples follow.

- While 34 of the 36 states surveyed include a medical necessity definition in their health plan contracts that helps delineate which services will be

⁶Although the BBA cited five categories of children with special needs, we report separately on the foster care and adoption assistance programs under title IV-E of the Social Security Act.

⁷The District of Columbia is included within state totals.

covered, only 19 specifically cover services these children need to maintain, as opposed to improve, their functioning.

- Many of the states we surveyed have limited requirements for health plans to provide ready access to specialty or out-of-network providers. Instead, states often permit health plans to decide whether to use pediatric specialists as primary care providers; allow standing referrals to specialists; and let children use pediatric, as opposed to adult, specialists.
- Although all states surveyed make at least some children with special needs eligible for services that coordinate care provided by various providers, 14 states leave the decision regarding actual receipt of these services to the sole discretion of the health plan, and most states could not identify the number of children actually receiving care coordination services.
- Only 17 states adjust rates paid to health plans to reflect the health status or expected utilization of services of the children enrolled.
- Only five of the states we surveyed target their managed care plan monitoring activities in ways that allow them to focus on the experience of children with special needs. Rather, states rely on more generalized monitoring activities to help assess whether Medicaid beneficiaries in managed care have adequate access to and quality of care. Because children with special needs are usually a small proportion of the overall Medicaid population, general monitoring may not capture sufficient information to adequately assess such children's care.

Background

Medicaid is a joint federal-state entitlement program that annually finances health care coverage for more than 40 million low-income individuals, over half of whom are children. Many children with special needs qualify for Medicaid through eligibility for federal programs targeted at children with chronic conditions or disabilities, such as SSI. Most states' Medicaid programs offer a wide array of therapies and services that are important for children with special needs. These benefits, such as physical, occupational, and speech therapies, as well as rehabilitative and case management services, are all commonly offered to Medicaid-eligible individuals.

In designing and implementing Medicaid managed care programs for children with special needs, various experts and advocates identified six areas as important safeguards to provide adequate and appropriate care. As described in table 1, these safeguards are:

- program development,

- enrollment procedures,
- provider networks,
- care coordination,
- reimbursement, and
- targeted quality monitoring.

Table 1: Descriptions of Safeguards for Children With Special Needs Enrolled in Capitated Medicaid Managed Care That Were Identified by Experts and Advocates

Safeguard area	Description
Program development	<p>Public input</p> <ul style="list-style-type: none"> • Involve key stakeholders, such as advocacy groups and families, in program development, implementation, and monitoring. <p>Medical necessity</p> <ul style="list-style-type: none"> • Include the concept of maintenance of function in the definition of necessary medical services (medical necessity) in health plan contracts, because medical necessity standards that require substantial improvement or restoration of function can conflict with the needs of children with special needs.
Enrollment procedures	<ul style="list-style-type: none"> • Identify children's special needs before or soon after enrollment to ensure that children benefit from safeguards. • Educate beneficiaries about accessing services and available protections in managed care and provide assistance in choosing a health plan. • Allow children with special needs to change plans or opt out of managed care when appropriate.
Provider networks	<ul style="list-style-type: none"> • Ensure that health plans develop provider networks that are sufficient to meet the anticipated needs of children with special needs, for example, by including pediatric specialists. • Institute various requirements, such as standing referrals, to ensure access to specialized providers both within health plan networks and through arrangements for out-of-network care if needed.
Care coordination	<ul style="list-style-type: none"> • Provide beneficiaries assistance to organize and facilitate access to relevant services, either through independent entities or through requirements for health plans.
Reimbursement	<ul style="list-style-type: none"> • Adjust payments to plans to reflect the varying health needs of enrollees, design payment methods to minimize incentives for underservice and to protect plans from extraordinary financial risk, or both.
Targeted quality monitoring	<ul style="list-style-type: none"> • Target quality-monitoring activities, such as beneficiary satisfaction surveys, focused clinical studies, and analyses of complaints and grievances or disenrollments from health plans, toward children with special needs.

HCFA has addressed each of these safeguard areas, to varying degrees, in its guidance to states with mandatory capitated Medicaid managed care programs for children with special needs. In order to mandate the enrollment of children with special needs in managed care, states must apply to HCFA to receive a waiver of certain federal statutory requirements, such as the requirement to guarantee beneficiaries' freedom to choose among participating providers. In June 1999, HCFA implemented the first requirements for states applying for or renewing federal waivers to enroll children with special needs in mandatory capitated managed care programs. The "Interim Review Criteria for Children with Special Needs"

include requirements that states implement certain safeguards when requiring capitated managed care enrollment of children with special needs.⁸ The interim criteria, summarized in appendix II, cover 11 areas, including access to specialists, payment methodology, and provider capacity. However, as we reported earlier, the interim criteria are not as specific as those outlined in previous HCFA guidance on using managed care for populations with special needs, particularly in such areas as determining medical necessity, involving the public in program implementation and oversight, and collecting encounter data.⁹ The criteria are brief and self-contained; there are no accompanying standards, guidelines, or definitions for the criteria, and they do not address how best to apply the safeguards in light of the multiple and divergent care requirements of children with special needs. HCFA plans to release revised criteria in the fall of 2000 that will be more specific and reflect recent research.

As of June 2000, HCFA had used the interim criteria in reviewing 15 waiver applications in 12 states (states may have multiple waivers, used for different counties or populations). Waiver requests are reviewed when a new application is submitted or when existing waivers are under consideration for renewal. Waivers are granted for 2- or 5-year periods, depending on the statutory provisions being waived, and the BBA granted a 3-year extension to waivers being considered for renewal if there are no proposed changes (see app. II). At the time of our survey (October 1999), few states had been required to use HCFA's interim criteria safeguards for children with special needs because their waivers had been approved before the criteria's June 1999 effective date. Therefore, survey responses generally reflected safeguards that states had chosen to implement for children with special needs prior to the HCFA mandate.

⁸When states allow voluntary enrollment in managed care, they do not have to seek a waiver from HCFA.

⁹See GAO/HEHS-00-37, Mar. 3, 2000, pp. 29-31.

Many States Are Enrolling BBA-Defined Children With Special Needs in Capitated Plans

Our survey of 36 states that enroll SSI or foster children or both in capitated Medicaid health plans—the only two categories of children with special needs tracked by HCFA prior to the BBA—found that half enroll children with special needs in multiple BBA categories. The number of mandatory programs slightly exceeds those that are voluntary. The number of states that enroll SSI children—the largest and most consistently tracked group of children with special needs—grew from 17 to 31 between 1996 and 1999. Katie Beckett children are the least likely to be enrolled, with only 11 states including them in capitated managed care. While many children with special needs are enrolled in capitated plans, there is no measure of the total number because some states could not readily provide counts by each of the BBA-defined categories.

States Enrolled Most Categories of Children With Special Needs in Capitated Managed Care but Did Not Report the Number Enrolled

The variety of enrollment policies makes it difficult to generalize about state managed care programs for children with special needs. States vary with regard to whether enrollment is mandatory or voluntary, how many of the categories of children with special needs they enroll, and whether policies allowing or mandating enrollment apply statewide or only to selected areas. Of the 36 states we surveyed, 14 have only mandatory enrollment, 11 have only voluntary enrollment, and 11 have mandatory enrollment for some groups and voluntary enrollment for others. The 11 states with both mandatory and voluntary enrollment either have mandatory programs in certain counties and voluntary programs in others or mandate enrollment for certain categories of special needs children, leaving enrollment for others as voluntary.¹⁰ (See table 2.)

¹⁰States may have different enrollment arrangements for the BBA categories in different areas of the state. For example, California has some county-based waivers (such as for Caloptima and the Health Plan of San Mateo) that mandatorily enroll SSI children and other county-based waivers (such as for Sacramento Geographic Managed Care and the Two-Plan Model Program) that voluntarily enroll SSI children.

Table 2: State Enrollment Policies for Children With Special Needs as of October 31, 1999 (36 states)

Program type	Number of states	States
Mandatory	14	Arizona, Connecticut, Delaware, Hawaii, Kentucky, Maryland, Nebraska, New Mexico, Oregon, Tennessee, Utah, Vermont, Virginia, West Virginia
Voluntary	11	Colorado, Florida, Georgia, Maine, Minnesota, Mississippi, Montana, New Hampshire, New York, South Carolina, Wisconsin
Mandatory and voluntary	11	California, District of Columbia, Indiana, Massachusetts, Michigan, Missouri, North Carolina, Ohio, Pennsylvania, Texas, Washington

Note: States may have both mandatory and voluntary enrollment because (1) programs in some states are county-based, which may result in mandatory programs in certain counties and voluntary programs in others, or (2) some states mandate enrollment for certain categories while enrollment for others is voluntary.

Source: GAO survey of state Medicaid directors.

SSI and title V, the categories with the largest number of beneficiaries, are most often included in either a mandatory or voluntary program. Nineteen of the 36 states enroll five to six BBA categories in capitated plans, while 10 states typically enroll two or three BBA categories. Although many states do not offer the optional Medicaid coverage for Katie Beckett children, 11 states enroll these children in capitated managed care. Seventeen states prohibit the enrollment of children in certain BBA categories in capitated managed care. For example, seven states prohibit title IV-E foster children from enrolling in capitated health plans. Table 3 summarizes BBA categories by enrollment policies, and appendix III presents detailed state enrollment policies by BBA category, including the categories excluded from enrollment.

Table 3: BBA Categories of Children With Special Needs by Enrollment Type as of October 31, 1999 (36 states)

BBA categories	Mandatory	Voluntary	Mandatory and voluntary	Total
SSI children	14	12	5	31
Katie Beckett children ^a	2	7	2	11
Title V CSHCN children	13	10	4	27
Children receiving adoption assistance under title IV-E	12	7	3	22
Children receiving foster care under title IV-E	13	11	3	27

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BBA categories	Mandatory	Voluntary	Mandatory and voluntary	Total
Other children in foster care or otherwise in an out-of-home placement	14	8	3	25

^aAccording to HCFA, 14 of the 36 states use a 1902(e)(c) state option to enroll Katie Beckett children in Medicaid. However, of the 11 states that reported enrolling Katie Beckett children in capitated health plans, only 5 states were reported as using the 1902(e)(c) state option: Delaware, Massachusetts, Mississippi, New Hampshire, and South Carolina. The other states enroll children similar to those covered by the Katie Beckett state option through other types of waivers (Colorado, New York, and Ohio) or generally identify similar children in their regular Medicaid program (Montana, New Mexico, and Washington).

Source: GAO survey of state Medicaid directors.

Program Characteristics of States With Mandated Enrollment

Almost all of the 25 states that mandate enrollment in at least part of the state or for some populations include many children with special needs in health plans with other populations. For example, children with special needs in mandatory arrangements are included with the rest of the population on a statewide basis in Maryland and Oregon, and in the general managed care program in Michigan. In addition, Michigan and the District of Columbia enroll some of these children in a separate, specialized, voluntary program and enroll others mandatorily in health plans with other populations, while Texas operates a separate program with mandatory and voluntary enrollment for some children with special needs.

Limited Enrollment Data

Many states were not able to readily report an unduplicated count of the children in the BBA-defined categories who are enrolled in capitated Medicaid managed care. Only 19 of the 36 states we surveyed provided enrollment data for at least one BBA category of children with special needs in capitated Medicaid programs, so we could not determine the total number of children enrolled (see app. IV). Moreover, some of the state-reported enrollment figures are from different points in time, are combinations of enrollment in two or more BBA categories, or both. On the basis of our analysis of available federal program data, we estimate that the total number of children in the BBA categories ranges from 1.5 million to 2.4 million.¹¹

¹¹The lower end of this range excludes title V children because some are not eligible for Medicaid. The higher end includes title V children who are not Medicaid-eligible and represents some double counting of children who are eligible for both title V and SSI. See GAO/HEHS-00-37, Mar. 3, 2000, pp. 38-41.

Enrollment Exclusions and Exemptions

Most of the 36 states reported that they exclude certain categories of children with disabilities that are not in the BBA-defined categories from capitated Medicaid managed care. Thirty-two of the 36 states exclude children in nursing facilities, intermediate care facilities for the mentally retarded, and institutions for those with mental diseases from enrollment in capitated Medicaid managed care. Twenty-three of these 32 states also exclude children receiving home- and community-based waiver services, and 9 states exclude other children with special needs.¹² Two states do not allow children with special needs to be excluded from enrollment in capitated Medicaid managed care (the remaining two states did not respond to this question).

Eleven of the 25 states with mandatory enrollment allow exemptions from enrollment in capitated Medicaid health plans for one or more of the following reasons:

- the child is undergoing a plan of treatment (6 states),
- the child's provider is not in the capitated health plan (3 states),
- enrollment would disturb long-standing care arrangements (3 states), or
- the parent prefers the child not to be enrolled (3 states).

Five of these 11 states allow exemptions on a case-by-case basis. Another 11 states with mandatory enrollment have no policy regarding exemptions (3 states did not respond).

Adoption and Effectiveness of Safeguards Vary Among States

States vary in the safeguards they adopt and implement for children with special needs. Moreover, some states believe the BBA categories do not include all children with special needs, such as children who are severely emotionally disturbed or those aged 19 to 21, and have therefore expanded

¹²Home- and community-based waiver services participants are those receiving long-term care services in the community under section 1915(c) of the Social Security Act. Children receiving services under this waiver must be eligible for Medicaid if institutionalized and must require the level of care furnished in an institution. Other children with special needs excluded from enrollment in capitated Medicaid health plans include those eligible for both Medicare and Medicaid; children with acquired immunodeficiency syndrome (AIDS); medically needy children (also referred to as spend-down children—that is, children whose family income, minus incurred medical expenses, falls below the state's medically needy income and resource standards [see GAO/HEHS-00-37, Mar. 3, 2000, p. 11]); and children covered by both private health insurance and Medicaid.

the population protected by their safeguards.¹³ All the states we surveyed addressed safeguards in one or more of the areas that we identified as being important for children with special needs: (1) program development, (2) enrollment procedures, (3) provider capacity and accessibility, (4) comprehensive care coordination, (5) appropriate reimbursement to health plans, and (6) targeted quality monitoring. Some types of safeguards have been more widely adopted by states than others. For example, 31 of the 36 states we surveyed have at least one measure that addresses adequate pediatric provider capacity. On the other hand, 18 states do not inform health plans of the presence of special needs when enrolling children, and 18 do not require health plans to conduct a needs assessment soon after enrollment. Additionally, other safeguards may be less effective for children with special needs because states have made them optional rather than mandatory, have not adopted more rigorous approaches for their design and use, or do not target them specifically to these children.

Program Development Offers Opportunities to Build in Safeguards for Children With Special Needs

During the development of their capitated managed care programs, states may incorporate various safeguards for children with special needs, such as a public input process and an appropriate medical necessity definition. Our interviews with HCFA and state officials indicate that states often use public input processes that involve relevant advocacy groups and families in the planning and operation of their managed care programs to ease the transition of children with special needs into Medicaid managed care programs. However, in one critical area—developing their managed care program’s definition of medical necessity (a standard used to determine whether a service will be covered for a specific individual)—14 states did not include the concept of maintaining function to justify coverage. This omission is significant given that many children may have conditions that will not improve, yet they need services to maintain functioning or prevent further deterioration.

According to a HCFA official, states responding to the interim criteria often used public input processes to coordinate with other agencies and advocacy groups in designing their managed care programs. Furthermore, all four states we visited involved advocates and families to some degree in planning their managed care programs, and at least three of the states (Florida, Maryland, and Michigan) involve advocates on a continuous basis

¹³For more discussion of children who are not covered by the BBA definition but who may have special needs, see GAO/HEHS-00-37, Mar. 3, 2000, pp. 16-18.

through standing advisory committees.¹⁴ For example, in Maryland, seven work groups composed of advocates, providers, and legislators met on a weekly basis throughout the planning process to focus on populations such as children with special needs, the developmentally disabled, and the physically disabled.¹⁵ Currently, Maryland has three advisory committees, including one focused on children with special needs whose membership includes two parents as well as an advocate for disabled children. In addition, Florida and Michigan require their specialized health plans for children with special needs to have a family representative on staff, while Maryland requires health plans' advisory boards to include a family representative.

Only 19 of 34 states that include a definition of medical necessity in their contracts with capitated plans include the concept of maintenance of function in that definition. In contrast, 14 states base their medical necessity definition on the concept of cure or rehabilitation (one state did not respond). Of the two states we visited that enroll children with special needs in their general managed care programs, only Maryland includes the concept of maintenance of function as a qualifying criterion for coverage of health services in state regulations. Florida and Michigan, the two states we visited that have separate programs for a portion of their children with special needs, include maintaining function in their specialized programs' medical necessity standard. However, neither includes maintaining function in its general Medicaid capitated programs, even though children with special needs may enroll in these plans.

States' Use of Enrollment Procedures to Protect Children With Special Needs Varies

Although many states have adopted various enrollment procedure safeguards, a significant number have not. Enrollment procedure protections include identifying children with special needs, providing their families adequate information about managed care during the health plan selection process, and allowing children to disenroll from a plan or managed care if their needs are not being met.

¹⁴As we reported in 1996, state officials involved in tailoring managed care programs for people with disabilities stressed the need to involve beneficiaries and advocates both in the planning process and in overseeing program implementation. See *Medicaid Managed Care: Serving the Disabled Challenges State Programs* (GAO/HEHS-96-136, July 31, 1996).

¹⁵Other work groups focused on the homeless, individuals with human immunodeficiency virus (HIV)/AIDS, pregnant and postpartum women, and substance abusers.

While many states surveyed have some procedures in place for identifying children with special needs, about one-third do not. Eighteen states do not inform health plans of the presence of special needs when enrolling children, and 18 do not require health plans to conduct a needs assessment soon after enrollment. Moreover, 10 states, many of which have mandatory enrollment in capitated health plans, do not have either procedure in place to identify children with special needs during or soon after enrollment, which means plans may not know about the children with special needs who are enrolled. Maryland provides an example of how multiple steps may improve the odds that health plans know when special needs children enroll and receive information about their needs. To begin with, Maryland health plans know the Medicaid eligibility status (such as SSI or foster care) and the risk status (which is based on the receipt of a higher payment for individuals with higher expected costs) of all new beneficiaries. In addition to this information, Maryland health plans also receive a copy of each beneficiary's health risk assessment form. This form, which is completed by most beneficiaries during Medicaid enrollment, allows beneficiaries to indicate whether a child has special needs, a developmental or physical disability, certain health problems (such as asthma or cerebral palsy), or the need for pharmaceutical or medical equipment. Within 15 days of receiving a beneficiary's health risk assessment, health plans are required to conduct an initial health visit for individuals who identify themselves as having a high-risk condition.¹⁶

In responding to our survey, 26 states reported that they assist at least some of their families of children with special needs in selecting a health plan, though the type or level of assistance provided varied among our site visit states. In the four states we visited, help in selecting a plan often is limited to the general assistance afforded to all Medicaid beneficiaries through phone conversations with states' enrollment brokers and Medicaid informational brochures.¹⁷ In contrast, Michigan's enrollment broker has counselors specially trained to assist families of children with special

¹⁶Maryland considers the following seven groups of people to be high-risk: pregnant and postpartum women, substance abusers, the physically disabled, individuals with HIV/AIDS, children with special needs, the developmentally disabled, and the homeless. These seven groups were the focus of the previously mentioned work group meetings involving advocates, providers, and legislators.

¹⁷Enrollment brokers, private companies under contract with the state, generally offer Medicaid enrollees assistance by making sure they understand what managed care is and what options are available to them.

needs as well as a disability services worker who is available to make home visits.

While 13 of the 25 states that have a mandatory program have at least one special disenrollment provision for children with special needs, children in the remaining 11 states have no special options (one state did not answer this question). Nine of the 13 states allow children with special needs to switch among capitated health plans at any time without cause. In addition, children with special needs can opt out of capitated health plans without cause in five states. None of these five states have only mandatory enrollment for children with special needs; that is, all of these states enroll at least one category of BBA children in managed care on a voluntary basis. In Michigan, for example, because the specialty health plan program is voluntary, each month enrolled children have the option to switch to fee-for-service care.

Making Some Provider Access Safeguards Optional May Limit Effectiveness

Most of the states we surveyed take some action to ensure that Medicaid capitated health plans have a sufficient number of pediatric providers and specialists in their networks to serve children with special needs. However, while they attempt to make providers available, states are less likely to impose consistent requirements to ensure that these providers and specialists are readily accessible. Instead, many leave to health plans the decision about whether to adopt such measures as using pediatric specialists as primary care providers or granting standing referrals to specialists.

Ensuring Adequate Provider Networks

Almost all of the 36 states we surveyed (31 states) impose at least one requirement intended to ensure that the capacity of pediatric providers in their health plans is adequate to serve children with special needs. States can require, for example, (1) access to pediatric specialty centers; (2) specific contract conditions regarding participation by pediatric providers; (3) the incorporation of providers experienced in serving children with special needs into health plan networks; and (4) provisions to address a lack of available providers, such as allowing children to use providers outside the health plan network. Several of the state officials we interviewed said that plans' pediatric provider capacity was evaluated prior to contracting for services through an initial provider panel approval process. However, Maryland officials noted that states face difficulties in prospectively setting requirements for pediatric specialists: No general criteria or standards exist—in fee-for-service or managed care—for the

number and mix of specialists needed to serve a population or for when and how often referrals to specialists should be made.

Specialty centers. Just over half of the 31 states that impose at least one requirement require health plans to demonstrate access to pediatric specialty centers or children's hospitals. For example, in Oregon health plans are required to have contracts with centers of excellence such as the Child Development and Rehabilitation Center, a statewide agency that offers specialty clinics and serves children with special needs. Florida's contract with Medicaid capitated health plans requires them to assure beneficiaries of access to one or more of the state's regional perinatal intensive care centers, which are specialized units within hospitals with a full range of newborn intensive care services.¹⁸

Contract requirements. Fourteen of 31 states have specific requirements in their contracts with managed care plans regarding the number and type of providers with pediatric expertise that must participate in the health plan network or be available through other arrangements.

Experienced providers. Fourteen states require plans to demonstrate that primary care providers in their network have experience in serving children with special needs.¹⁹ For example, Maryland requires health plans to "flag" physicians with experience in providing care for children with special needs to be able to refer children to the most appropriate provider. In shifting to a capitated arrangement, Florida's specialized program is requiring interested health plans to detail the availability of board-certified specialists and pediatric providers.

Unanticipated need. Fourteen states require plans to have policies in place that address the unanticipated need for, or limitations in the availability of, providers with pediatric specialty expertise. Of the states we visited, Florida, Maryland, and Oregon required plans to have arrangements for

¹⁸Plans may request a waiver of this provision if unable to reach an agreement with centers that are within a reasonable travel time. Florida told us that effective July 1, 2000, after the date of our site visit, Florida's Medicaid contract changed to provide health plans the option to ensure access to either a regional perinatal intensive care center or a hospital licensed for neonatal intensive care unit level III beds.

¹⁹There is some evidence that the use of experienced health care providers and institutions can result in better health outcomes. For children with special needs, relevant experience may include expertise in pediatric care as well as an understanding of special risk factors that affect health, such as the risk of abuse among foster children.

children to see out-of-network providers should the need arise. In addition, in Oregon children may use out-of-network providers even if they are outside the state, and health plans must pay the travel expenses for such out-of-state care.

Ensuring Access to Providers

Many of the states we surveyed have limited requirements for specialty or out-of-network provider access for children with special needs. Instead, they often let health plans decide whether to adopt these measures, as shown in table 4. Leaving implementation of access safeguards to health plans may have the effect of limiting the safeguards' use, both across states and among different health plans within states, if plans decide not to voluntarily incorporate these safeguards. The scarcity of specialists in rural areas, or their reluctance to serve as primary care physicians for children with special needs, further complicates attempts to ensure access to pediatric specialists.

Table 4: Numbers of States Using Various Requirements to Ensure Provider Access for Children With Special Needs

Requirements	States in which requirement applies to some or all children with special needs	States in which plans have option to adopt requirement or not	States that have no requirement
Pediatric specialists must be allowed to be primary care providers	17	15	4
Standing referrals to specialists are allowed ^a	10	13	13
Children have access to pediatric rather than adult specialists ^b	12	16	5
Newly enrolled children may be cared for by nonnetwork providers	22	8	6

^aStanding referrals allow enrollees to obtain ongoing care for specific medical conditions from a specialist without seeking repeated referrals from a primary care provider.

^bThirty-four of the 36 states polled responded to this question. Additionally, one state responded that it did not know or was not sure of the answer to this question.

Source: GAO survey of state Medicaid directors.

Of the four states we visited, Florida, Michigan, and Oregon generally permit health plans to decide whether to allow specialists to serve as primary care providers, and Maryland, Michigan, and Oregon permit plans to decide whether to authorize standing referrals.²⁰ In contrast, while provider access safeguards generally are not left to the discretion of health plans in Michigan's Children's Special Health Care Services (CSHCS) specialty program and Florida's planned capitated Children's Medical Services (CMS) program, only title V children are enrolled in these programs.

Michigan and Oregon officials said the use of pediatric specialists as primary care providers in their general Medicaid programs varies by health plan. Neither of the two health plans whose representatives we interviewed in Oregon generally uses pediatric specialists as primary care providers, though one plan noted limited exceptions for oncologists. Each of the total of four health plans we visited in Oregon and Maryland has different rules for addressing standing referrals. One Oregon health plan specifies that the primary care physician may authorize up to six visits within a 3-month period if the plan verifies the referral. The second health plan also allows a specific number of visits for a standing referral but said that the length of the referral is flexible. In Maryland, one health plan usually allows at least two specialist visits within a certain time frame, depending on the duration of the treatment needed, while the other allows individual providers to determine the need for standing referrals.

Even when states require some access to pediatric specialists, health plans may face difficulties when attempting to meet those requirements. For example, there are generally a small number of pediatric providers in a given area. Additionally, health plans and advocates in several of the states said pediatric specialists might not be located in more rural areas, requiring families either to travel to urban areas or to substitute other providers. Some states and health plans found that specialists who are qualified to serve children's intensive needs may not want to act as primary care physicians because of their responsibilities to provide for coordinated general health care and to act as "gatekeepers" in determining referrals for specialty services. For example, Maryland requires primary care physicians to become certified as providers of Medicaid Early and Periodic Screening,

²⁰Michigan requires health plans to designate a specialist as a primary care provider when appropriate for an enrollee's health condition. The determination is made on a case-by-case basis by the health plan and must be requested by the child's family.

Diagnostic, and Treatment (EPSDT) program services;²¹ state officials said some specialists might not want to be accountable for immunizations and well-child care and therefore might decline to act as primary care physicians.

Availability of Care Coordination Services Differs Among States

Children with special needs tend to be eligible for care coordination services in most states; however, states often provide health plans the discretion to decide who actually receives these services. Therefore, in many states being eligible for care coordination services does not guarantee access to these services. Care coordination can include conducting a comprehensive assessment of needs; developing a plan of care; facilitating access to the medical and nonmedical services identified in the care plan; and providing assistance in planning for transitions in care, such as hospital discharge.

In 20 of the states surveyed, all children with special needs are eligible for care coordination services. In the remaining 16 states, a child's eligibility for care coordination is determined on the basis of factors such as the severity of illness, the existence of multiple or co-occurring conditions, or membership in a certain categorical group (such as SSI or foster care). Of the 34 states that provided information regarding the receipt of care coordination, only 3 states retain sole authority to determine which children with special needs should actually receive these services (1 state did not answer the question and another state did not know the answer to the question). In 14 states, health plans are allowed to make this decision, and in the remaining 17 states, the health plans and the state share the responsibility for determining which children with special needs should receive care coordination. For example, Oregon makes SSI and foster children eligible for special care coordination services; however, the service must be requested from the health plan, since it is not automatically provided. A 1997 parent satisfaction survey found that the majority of Oregon parents surveyed were not aware of the availability of this service.

Because decisions regarding the receipt of care coordination are most often either shared with or left to capitated health plans, the majority of

²¹EPSDT provides comprehensive health screening (for example, physical examinations, health and developmental history, laboratory tests, blood lead level testing, and 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.

states were unable to say what percentage of children with special needs actually receive care coordination services. Only four states were able to provide figures on the percentage of children with special needs who receive care coordination. For example, Michigan and Florida said that all of the children in their specialized programs receive care coordination services, but they did not know how many children with special needs in their general Medicaid program receive such services.

In addition, it is unclear what level of care coordination is provided in most states—that is, the extent to which services include the child’s social needs, such as education and housing, in addition to medical service needs. The specialized programs in two of the four states we visited, Florida and Michigan, require the coordination of both the child’s medical and social needs. However, both states’ special programs are limited to title V children. If they receive any care coordination, children with special needs enrolled in Florida’s and Michigan’s regular capitated managed care programs receive only coordination of their medical needs. Medicaid health plans in Maryland and Oregon have employees who are responsible for coordinating care for some children with special needs; however, the types of service provided vary by plan. Appendix V provides a description of the care coordination systems in the four states visited.

In addition to providing care coordination services, most states require health plans to coordinate with at least one of the agencies that frequently serve children with special needs. For example, 28 states require health plans to coordinate with mental health programs, and 26 states require coordination with early intervention programs, which provide developmental services for children under age 3 with developmental delays.²² In states such as Maryland, where many services, including mental health and therapy services, are carved out of managed care and provided separately under other plans, it is essential that health plans have ongoing coordination with these other providers in order to provide seamless care. However, representatives of both Maryland health plans we interviewed

²²Twenty-three states require health plans to coordinate with special education programs, and 24 require coordination with other developmental disability programs. Coordination is required with child protective or social services in 23 states and with title V programs in 22 states. Although there are no statutory requirements for Medicaid agencies to coordinate services and activities with educational entities, the Individuals With Disabilities Education Act does require that educational entities bear the responsibility for coordinating services with other agencies, such as Medicaid. See *Medicaid and Special Education: Coordination of Services for Children With Disabilities Is Evolving* (GAO/HEHS-00-20, Dec. 10, 1999), p. 9.

are concerned that carving out these services makes providing coordinated care more difficult.

Payment Mechanisms in 17 of 36 States Include Risk Adjustment Based on Beneficiaries' Health Needs

Research suggests that using health-related factors such as clinical diagnoses or prior utilization of medical services helps predict future care costs. State managed care payment mechanisms that adjust rates states pay to health plans for the variation in costs associated with different types of disabling conditions help mitigate plans' financial risks associated with providing services to children with special needs. At the same time, researchers have identified significant variation in medical costs among people who fall into the same subcategories of conditions.²³ However, disabled individuals, including children with special needs, generally have a larger proportion of costs for chronic needs, which are by definition more consistent over time. Therefore, health-related factors may better predict the costs for children with special needs than they would for all children. Aligning rates paid to health plans with expected costs helps reduce incentives for health plans to attempt to limit enrollment of or services for high-cost children. To varying degrees states are using (1) risk adjustment to more closely match payments with the expected costs of the enrolled population of beneficiaries or (2) risk corridors to share profits and losses between states and health plans.²⁴

Most of the states we surveyed (31 states) are using some form of risk adjustment to align capitation rates with expected beneficiary care costs. Many of the states using risk adjustment attempt to account for beneficiary differences by segmenting populations into broad subgroups, or cells, of individuals with similar characteristics. Twenty-eight states pay rates on the basis of demographic variables, such as age or sex; 26 states use category of Medicaid eligibility, such as SSI eligibility; and 22 states vary

²³For more detail regarding this research, see GAO/HEHS-00-37, Mar. 3, 2000, p. 19, and GAO/HEHS-96-136, July 31, 1996, p. 49.

²⁴Risk corridors, a part of funding agreements between states and health plans, reimburse plans for a portion of losses but also require plans to return part of the profits exceeding a specified level. See GAO/HEHS-96-136, July 31, 1996, p. 48. Another mechanism often used by health plans is reinsurance. Twenty-eight states said health plans use reinsurance, also called stop-loss protection, to contain financial risk. Reinsurance provides retrospective adjustments to reimburse plans for losses resulting from very high-cost individuals or disproportionate numbers of enrollees with above-average costs. However, while reinsurance relieves some of the financial pressure on health plans, it does not remove the negative incentives to avoid enrolling high-cost beneficiaries or to underserve them.

rates by geographic area, such as county or region. For example, Florida uses four eligibility categories, eight age groups, 10 geographic areas, and gender to develop different payment levels for all beneficiaries.²⁵

Only 17 of the states we surveyed use measures based on the actual health needs of beneficiaries, including children with special needs, to risk-adjust capitation rates. Fourteen states use either clinical diagnosis or prior utilization to develop their risk-adjusted rates, while three states use both factors. For example, for some beneficiaries, Maryland’s risk adjustment uses prior medical claims to assign beneficiaries to risk categories, while Oregon’s and Michigan’s risk-adjustment methods identify high-cost diagnoses (see app. VI).

Risk adjustment can result in large differences in payments to plans for particular enrollees. For example, in reviewing the records of Medicaid children with high medical costs enrolled in Michigan’s general Medicaid managed care program, one health plan identified 31 children who later were found eligible for the separate program for children with special needs. Michigan’s health-based capitation payments for these children are significantly higher than its capitation payments in the regular program, as shown in table 5. For example, one child’s capitation rate increased from \$612 per year to \$19,140 per year (capitation payments are paid monthly).

Table 5: Comparison of Annual Capitation Payments for 31 Selected Children Moved From Michigan’s General Medicaid Program to Its Specialty Health Plan

Program	Lowest annual capitation payment	Highest annual capitation payment	Average annual capitation payment
General Medicaid program	\$372	\$4,296	\$969
Specialty program	2,376	19,140	9,386

Problems with health data reliability and completeness can serve as obstacles to states in developing and implementing risk-adjusted capitation rates. Some state and health plan officials we interviewed said that, as more Medicaid beneficiaries with special needs are enrolled in managed

²⁵Florida told us that as of July 1, 2000, their risk-adjustment methodology changed, increasing from six to eight age groups and adding gender as a factor.

care, collecting reliable encounter data from health plans is becoming an important component in developing appropriate risk-adjusted rates.²⁶ For example, before Michigan began collecting encounter data from health plans in mid-1999, health plans were not required to submit specific diagnosis and treatment data as a condition for receiving capitated payments, which led to problems in obtaining this information, state officials said.

Eight states have developed risk corridor arrangements that share the risk of profits or losses between the state and health plan. Such arrangements can protect both sides from potentially large losses that may result from inadequate adjustment of capitation rates. We reported in 1996 that risk corridors appeared to have the greatest potential for reducing plans' incentives to underserve or to attempt to avoid enrollment of beneficiaries with greater health care needs.²⁷

Quality-Monitoring Efforts Are Seldom Specifically Targeted to Children With Special Needs

Most of the quality-monitoring efforts employed by the states that responded to our survey are used for all populations in Medicaid managed care, or for all populations with special needs (see app. VII).²⁸ Only five states surveyed indicated that they specifically developed quality-monitoring activities for some children with special needs: Delaware, the District of Columbia, Maryland, Michigan, and Oregon (see table 6). Quality-monitoring activities afford an opportunity to hold health plans accountable for providing the more specialized and coordinated care required by children with special needs. Researchers suggest that three

²⁶As more states move beneficiaries into managed care, fee-for-service claims data become less available and less suitable for use in rate-setting for capitation payments and for risk-adjusting capitation. See GAO/HEHS-96-136, July 31, 1996, p. 57.

²⁷See GAO/HEHS-96-136, July 31, 1996, p. 48.

²⁸Populations with special needs are defined in various ways. For example, Maryland's definition of populations with special needs includes children with special health care needs, individuals with a physical disability, individuals with a developmental disability, pregnant and postpartum women, individuals who are homeless, individuals with HIV/AIDS, and individuals in need of substance abuse treatment. HCFA's draft report to the Congress, intended to identify safeguards needed by populations with special needs in Medicaid managed care, includes as Medicaid managed care beneficiaries with special health care needs individuals with serious and persistent mental illness, substance abuse, or both; homeless individuals; older adults with disabilities; and nonelderly adults who are disabled or chronically ill with physical or mental disabilities, in addition to children with special health care needs.

characteristics of the care for children with special needs have implications for effective monitoring: (1) few children experience any of the many health conditions affecting children, making monitoring for individual conditions of limited use; (2) childhood chronic conditions need to be monitored in relation to children's various developmental stages; and (3) children's care must be monitored in the context of their family situation.²⁹ Therefore, general monitoring may not capture enough information about these children to provide the specificity needed for assessing their care.

Table 6: State-Reported Quality Assurance Measures Specific to Children With Special Needs

State	Conducts satisfaction survey	Reports on specific quality indicators	Establishes separate quality oversight entities	Monitors grievance resolution procedures
Delaware	X			
District of Columbia	X	X	X	
Maryland		X ^a	X	X ^a
Michigan ^b	X	X	X	X
Oregon	X			

^aMaryland reports on specific quality indicators only for children with asthma and has conducted focused studies of children with a diagnosis of cerebral palsy and with sickle cell disease. Regarding grievance procedures, the state tracks and monitors the complaints of eight categories of children who either have a specific diagnosis, such as cerebral palsy, or are part of a specific group, such as state-supervised children.

^bMichigan's specialty children's program, rather than the general Medicaid managed care program, incorporates these monitoring activities. The specialty program also uses several other quality assurance measures specific to children with special needs.

Source: GAO survey of state Medicaid directors and follow-up telephone interviews.

The five states with targeted quality monitoring generally conducted satisfaction surveys focused on the experience of families whose children have special needs, reported on specific quality indicators, or established separate quality oversight bodies. The value of this focused approach is illustrated by Oregon's experience. Oregon's 1997 satisfaction survey of parents of children with special needs informed the state that while these

²⁹Karen Kuhlthau and others, "Assessing Managed Care For Children With Chronic Conditions," *Health Affairs*, Vol. 17, No. 4 (1998), p. 43.

parents were basically satisfied with care coordination, few parents were aware of a specific care coordination program for SSI recipients and foster children. Oregon is collaborating with the Foundation for Accountability³⁰ to jointly conduct a second survey that will focus on access to care, satisfaction, and quality of services. Maryland, which has a separate quality oversight committee, told us that it is also working with the Foundation to pilot a tool to identify children with special needs that will be used to develop a survey with a focus on this population. Maryland officials noted that they have been hampered by the lack of identification tools and techniques needed to develop satisfaction surveys and specific quality indicators related to children with special needs.

Florida's planned capitated specialty CMS program will include various monitoring activities specifically for children with special needs. Michigan and Florida have no targeted activities for children with special needs in their general Medicaid managed care programs. However, both states have developed a wide variety of quality-monitoring activities that are either currently implemented or planned for their separate children's programs, such as collecting and analyzing encounter data specifically for children with special needs and performing focused clinical studies. These targeted quality assurance mechanisms are specific to children who qualify for title V services, and therefore they do not cover all of the BBA-defined children with special needs.³¹

Observations

While the number of states enrolling children with special needs in capitated Medicaid health plans has grown significantly since the mid-1990s, diversity exists among states' approaches. States vary considerably in terms of both enrollment characteristics and requirements adopted to ensure that health plans address these children's expected additional needs for health care and services.

States recognize the need to adopt some additional health plan requirements to ensure adequate care for children with special needs, but the scope of their requirements varies, and sometimes the requirements are

³⁰The Foundation for Accountability is a nonprofit institution that develops consumer-focused quality measures and supports public education about health care quality.

³¹Michigan officials said that title V children may also qualify for SSI or Katie Beckett.

optional. The usefulness of some safeguards may be lessened when states choose to delegate to health plans decisions on whether and how to provide various measures. Additionally, difficulties in implementing some of these safeguards likely influence their effectiveness—for example, there are fewer pediatric specialty providers, especially in rural areas, and the development of health-based, risk-adjusted capitation rates is affected by considerable administrative and data requirements.

Because the interim criteria are applied only to mandatory capitated programs that are new or up for renewal, not all states' programs are subject to the criteria, and those that are may not undergo review for some time. Additionally, because they are required only for the BBA-defined children with special needs, the interim criteria may inherently fail to protect all children with special needs, because some states have identified other children outside the BBA categories whom they acknowledge as having special needs.

HCFA's planned revisions to the interim criteria provide an opportunity to add additional safeguards and to address the lack of specificity in some safeguards in the initial version. While the interim criteria are fairly general, HCFA intends to revise the requirements to provide increased specificity and to reflect recent research and proposed federal regulations for Medicaid managed care. In light of the increase in the number of states enrolling children with special needs in capitated managed care and states' limited implementation of some safeguards, HCFA's efforts to develop more comprehensive waiver review criteria for programs enrolling these children are important for ensuring that they receive necessary care and services.

Agency Comments

We provided HHS and officials from the four states we visited an opportunity to review a draft of this report. HHS and the states generally concurred with our findings. HHS' comments are included as appendix VIII. HHS indicated it was concerned about the report's finding that more rigorous work needs to be conducted to ensure that adequate health care is delivered to children with special needs in mandatory and voluntary Medicaid managed care plans. The Department commented that it has implemented safeguards contained in the draft interim review criteria, which are applied when states seek to renew existing waiver and demonstration programs that mandatorily enroll children with special needs. HHS said that the interim criteria are undergoing revisions intended

to improve their focus, as we suggested in a previous report, and to address many of the issues discussed in this report.

HHS noted that the report points to good practices already in place in states to ensure that children with special needs receive appropriate care, but that the report also suggests that some states may leave significant discretion to health plans on which safeguard protections are implemented and how they are implemented. The Department said that it believes it is not sufficient for such safeguards to be optional or discretionary and added that the interim criteria require mandatory implementation of safeguards in areas such as enrollment, care coordination, and specialist access when BBA-defined categories of children with special needs are enrolled in capitated managed care. Currently, not all states with capitated managed care programs have responded to the criteria.

HHS highlighted the following issues or related initiatives in progress:

- The Department agreed with our finding that adequate reimbursement of managed care organizations and providers is a key concern and noted that it will research issues related to adequate payment methodologies—specifically, the development and implementation of risk-adjustment methodologies appropriate for children.
- It also agreed with us that the absence of a uniform definition of children with special needs hinders data collection efforts intended to determine the number of children enrolled in managed care systems and to evaluate the services these children receive in Medicaid managed care. In December 2000, the Department said it will review existing tools and strategies for identifying and monitoring children with special needs and determine what additional resources are needed by states and managed care organizations.
- The National Center for Health Statistics will conduct a telephone survey, to be tested in the autumn of 2000, that is intended to provide states with national data on health and insurance status for children with special needs.
- HHS said that it is collaborating with other researchers to develop sample purchasing specifications to guide and assist state Medicaid agencies and managed care organizations on approaches for providing quality care to children with special needs.

Finally, HHS commented, and we agree, that although our report focused on Medicaid managed care, these same issues apply to children with

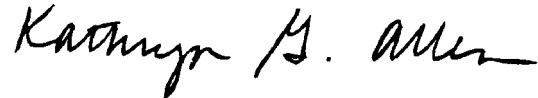
special needs who are enrolling in the State Children's Health Insurance Program.

Michigan commented that it had concerns regarding establishment of a national definition of children with special needs and concurrent national safeguard standards because states differ in how they define and identify these children and in the Medicaid-covered services that are offered. Therefore, Michigan said that states may be in a better position to establish standards for children with special needs and that state participation with HHS in addressing these issues is important. We agree that states can offer valuable assistance to HHS in defining children with special needs and developing safeguards for them; however, we believe that national minimum standards like those HHS is formulating are needed to set a floor. States, of course, may always choose to provide more protections to more children than the minimum required by HHS.

Maryland's comments focused on quality-monitoring efforts, with the state noting that it defined children with special needs more broadly to include children who may have a health or functional impairment, regardless of whether they qualify for a specific program category included in the BBA definition. State officials said that this broader definition is more difficult to administer when attempting to survey children with special needs for quality monitoring because the few assessment tools that exist are in the design and development stage. Responses from Florida and Oregon were limited to technical comments and clarifications. We incorporated technical comments from HHS and the four states where 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 DeParle, Administrator of HCFA; the Honorable Claude Earl Fox, Administrator of the Health Resources and Services Administration; state officials in the four states we visited; appropriate congressional committees; and other interested parties. We will also make copies available to others upon request.

If you or your staff have any questions about this report, please call me at (202) 512-7118 or Walter Ochinko at (202) 512-7157. See appendix IX for other GAO contacts and staff acknowledgments.

A handwritten signature in black ink that reads "Kathryn G. Allen". The signature is written in a cursive style with a large initial 'K' and a distinct 'G'.

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

Scope and Methodology

We surveyed 36 selected state Medicaid directors concerning safeguards in place for children with special needs in capitated Medicaid managed care.¹ The states were chosen on the basis of data from the Health Care Financing Administration (HCFA) indicating states that, as of July 1, 1999, enrolled children receiving Supplemental Security Income (SSI) benefits and children in foster care (two of the five categories of children with special needs cited in the Balanced Budget Act [BBA] of 1997) in capitated Medicaid managed care plans.² States not sampled may enroll children in other BBA-cited categories in their capitated programs, but data indicating enrollment by the other categories were not readily available. The survey focused on state policies for the identification of children with special needs, enrollment and disenrollment options, access to pediatric primary and specialty care providers, care coordination, risk adjustment/rate setting, and quality assurance mechanisms.³

Our survey was based on programmatic safeguards cited as important mechanisms to protect children with special needs in capitated Medicaid managed care plans. We identified the safeguards through a review of the research literature and our previous work. Experts in the field provided comments on draft versions of the surveys.

In addition to the surveys, we conducted site visits to four states that enroll children with special needs in capitated managed care health plans: Florida, Maryland, Michigan, and Oregon. These states were selected after consulting with a number of experts from HCFA, the Health Resources and Services Administration, advocacy groups, and research organizations. The four states provide a cross section of approaches to serving children with special needs in capitated Medicaid managed care. Maryland and Oregon have demonstration waivers authorized by section 1115 of the Social Security Act, and Florida and Michigan have program waivers authorized

¹The District of Columbia is included within state totals.

²Fifteen states were not surveyed because as of July 1, 1999, they did not enroll SSI or foster children in capitated managed care programs. Alabama, Arkansas, Idaho, Louisiana, and South Dakota had primary care case management (PCCM) programs but not capitated plans. Illinois, Iowa, Kansas, Nevada, North Dakota, Oklahoma, and Rhode Island had managed care organizations but, according to HCFA data, SSI and foster children were not eligible for enrollment. Alaska and Wyoming do not have managed care programs, and New Jersey does not have a waiver to enroll children with special health care needs.

³The survey was mailed to 32 states. The four states we visited (Florida, Maryland, Michigan, and Oregon) answered the survey questions during our in-person interviews. In some cases, we contacted selected states by phone to clarify their responses.

by section 1915(b) of the Social Security Act. Appendix II provides more information on waivers used in states' managed care programs. In addition, Maryland and Oregon enroll children with special needs in mainstream managed care, while Florida and Michigan have separate managed care programs for some children with special needs (see table 7). During our site visits, we used a structured interview protocol to obtain information on the care of children with special needs. We interviewed various people involved in the care of these children, including officials with the state Medicaid and title V programs, health care plan administrators and providers, advocates for children with special needs, and family members of children with special needs.

In the course of this study, we analyzed numerous documents, such as federal law, state regulations, policy statements, and quality guidance. In addition, we reviewed journal articles and other publications on children with special health care needs and managed care. For the four states, we reviewed waiver applications and renewals, requests for proposals to contract for capitated Medicaid managed care plans, program evaluations, enrollment and disenrollment reports, and risk-adjustment methodology reports.

In addition, we interviewed officials from HCFA headquarters and its regional offices that are responsible for the states we studied. We discussed HCFA's interpretation of the BBA, general waiver review, and the interim criteria developed by HCFA for children with special needs in capitated Medicaid managed care plans.

**Appendix I
Scope and Methodology**

Table 7: Overview of Medicaid Managed Care Programs in Florida, Maryland, Michigan, and Oregon That Enroll Children With Special Needs

	Florida	Maryland	Michigan	Oregon		
	Children's Medical Services	HMO option^a	HealthChoice^b	CSHCS Special Health Plan^c	Comprehensive Health Plan	Oregon Health Plan
Date implemented	1998	1991	1997	1998	1997	1994–Phase I 1995–Phase II ^d
Waiver type	1915(b)	1915(b)	1115	No waiver	1915(b)	1115
General or separate program	Separate	General	General	Separate	General	General
Program area	Statewide	Statewide	Statewide	Seven counties in southeast portion of state	Statewide	Statewide
Enrollment policy	Voluntary	Voluntary	Mandatory	Voluntary	Mandatory	Mandatory
Children with special needs enrolled	Title V	SSI, foster care, adoption assistance	SSI, title V, foster care, adoption assistance	Title V	SSI	SSI, title V, foster care, adoption assistance
Children with special needs excluded	^e	Title V, Katie Beckett	Katie Beckett	^e	Title V, foster care, Katie Beckett	^e
Enrollment of children with special needs	17,425 as of Sept. 1, 1999	25,908 as of Aug. 1999	24,910 as of June 1999	821 as of Aug. 1, 1999	Not available	Not available

^aIn Florida, Medicaid beneficiaries are mandatorily enrolled in managed care. Once enrolled, beneficiaries choose between a health maintenance organization (HMO) and a PCCM option. However, if no choice is made, an SSI child could be assigned to either option, while foster, adoption assistance, and other out-of-home placement children would only be assigned to the PCCM option.

^bIn Maryland, children with chronic, complex medical conditions may be eligible to enroll in the Rare and Expensive Case Management fee-for-service program, instead of in HealthChoice.

^cUnder the Children's Special Health Care Services (CSHCS) program, title V children may choose between a fee-for-service program and a capitated health plan, referred to as a CSHCS Special Health Plan.

^dIn 1994, Oregon began enrolling its Medicaid population, except for the disabled and elderly, in capitated health plans. The state refers to this as phase I. Approximately a year later, the state began phase II, in which the aged, blind, and disabled (SSI) and foster children were enrolled in capitated health plans.

^eThese programs did not note any specific exclusions of BBA categories of children.

Source: GAO analysis.

Medicaid Managed Care for Children With Special Needs

Medicaid expenditures for children who qualify because of a disability represent a disproportionate share of program costs. HCFA identified 1 million children with disabilities in the Medicaid program, which may not include all BBA categories of children with special needs. These children constituted 7 percent of beneficiaries under age 21, but they accounted for 27 percent of the \$26 billion of payments for children.¹

States commonly enroll beneficiaries in two types of Medicaid managed care: capitation and primary care case management (PCCM). Under capitation, a health plan receives a fixed monthly fee per enrollee (the capitation fee) in exchange for providing all needed covered services. The PCCM model is 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. About five times as many beneficiaries are enrolled in capitated health plans as in PCCM enrollment arrangements. Capitated plans typically emphasize primary care and cost containment efforts and thus may place limitations on access to the highly specialized and costly medical services that populations with special needs often require. Thus, the greatest concern for children with special needs in managed care has focused on capitated programs.

States must comply with certain federal statutory requirements for the development and oversight of their managed care programs. The BBA allowed states to establish mandatory capitated programs for most Medicaid beneficiaries through a state plan amendment that states submit to HCFA, the federal agency responsible for Medicaid. However, this provision does not apply to children with special needs, Indians who are members of federally recognized tribes, and beneficiaries eligible for both Medicare and Medicaid. For mandatory enrollment of these beneficiaries, states must obtain HCFA approval in the form of a waiver of certain statutory provisions, such as beneficiaries' freedom to choose their providers. Waivers are of two types: program and demonstration. The program waiver, known as the 1915(b) freedom-of-choice waiver, allows states to require that each beneficiary enroll in a capitated managed care or a PCCM plan. Demonstration waivers authorized by section 1115 of the Social Security Act allow states to have most Medicaid requirements waived in order to test concepts likely to assist in promoting program objectives. The nature of HCFA's requirements for and oversight of waiver

¹Our figures for payments for children and the percentage of payments for disabled children are based on 1997 data because separate 1998 data for these populations were not available.

programs depends on the type of waiver that is authorized—generally, section 1115 demonstration waivers are subject to more terms and conditions and undergo more oversight than 1915(b) waivers.

While states have sought to include children with special needs in Medicaid managed care programs, there is some debate regarding the appropriateness of managed care for children with special needs. Because of their need for highly specialized and costly medical services, and the likelihood that these children have established relationships with providers, children with special needs may face difficulties in managed care plans, which have incentives to limit the choice of or access to providers and to emphasize primary care and cost containment efforts. As a result, in June 1999, HCFA instituted the “Interim Review Criteria for Children with Special Needs”—the first set of requirements for states mandating the enrollment of children with special needs in capitated managed care programs.

HCFA’s interim criteria, summarized in table 8, cover 11 areas, such as provider capacity, access to specialists, and plan payment methodology. These 11 areas can be grouped into the 6 areas of safeguards discussed in this report. HCFA plans to issue a revision of the interim criteria in the fall of 2000 to reflect states’ best practices and findings from a BBA-required report on appropriate safeguards for special needs populations.² Additionally, the revised criteria will draw on regulations implementing BBA Medicaid managed care standards, which are expected to be published in the fall of 2000.³

²The BBA mandated a 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. HCFA completed a draft report of the study in the summer of 1999; however, a final version had not been issued by July 2000. HCFA did not have an estimated issuance date.

³In 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 officials said the final regulations will include provisions for populations with special needs in such areas as medical necessity, reimbursement, and quality assurance.

**Appendix II
Medicaid Managed Care for Children With
Special Needs**

Table 8: Summary of HCFA's Interim Review Criteria for Children With Special Needs

General safeguard area	HCFA's interim criteria safeguard area	HCFA requirements for state managed care programs^a
Program development	• Public process	• Stakeholders such as advocates, providers, and consumer groups are included during waiver development.
	• Definition of children with special needs	• Definition includes at least the BBA categories of children with special needs.
Enrollment procedures	• Identification	• Children with special needs are identified, and specific data are collected on these children.
	• Enrollment/disenrollment	• Enrollment includes outreach activities and assistance from specially trained personnel, and children with special needs can disenroll or reenroll in another plan for good cause. The auto-assignment process assigns these children to an existing or otherwise capable provider. ^b
Provider networks	• Provider capacity	• Health plans should have sufficient experienced providers to serve children with special needs, and the state will monitor provider capacity.
	• Specialists	• Health plans should have sufficient 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.
Care coordination	• 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.
Reimbursement	• Payment methodology	• The payment methodology accounts for children with special needs enrolled in capitated managed care.
Targeted quality monitoring	• Quality of care	• Specific performance measures and performance improvement projects addressing children with special needs must be developed.
	• Plan monitoring	<ul style="list-style-type: none"> • Access to specialists and to services, quality of care, coordination of care, and enrollee satisfaction is monitored. • Americans With Disabilities Act access standards are monitored. • Medical necessity is defined for health plans, and its application is monitored.

^aThe interim criteria also include a requirement that the state adequately address HCFA guidance regarding BBA provisions relevant to Medicaid managed care.

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

Source: HCFA's "Interim Review Criteria for Children with Special Needs."

State Managed Care Enrollment Policies for Children With Special Needs

Enrollment of the categories of children with special needs identified in the BBA in capitated managed care programs varies among states (see fig. 1). Some states did not provide data on all categories of children with special needs.

**Appendix III
State Managed Care Enrollment Policies for
Children With Special Needs**

Figure 1: Managed Care Enrollment Policies as of October 31, 1999

State	(Title IV-E)						State	(Title IV-E)					
	SSI	Title V	Katie Beckett Children	Foster Care	Adoption Assistance	Other ^a		SSI	Title V	Katie Beckett Children	Foster Care	Adoption Assistance	Other ^a
Arizona	<input type="checkbox"/>	<input type="checkbox"/>	b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Montana ^c	▲	▲	▲	▲	⊖	▲
California	▲	▲	b	▲	▲	▲	Nebraska	<input type="checkbox"/>	⊖	⊖	<input type="checkbox"/>	⊖	<input type="checkbox"/>
Colorado ^c	▲	▲	▲	▲	▲	▲	New Hampshire	▲	▲	▲	▲	▲	d
Connecticut	<input type="checkbox"/>	<input type="checkbox"/>	b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	New Mexico	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Delaware	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	New York ^c	▲	d	▲	▲	⊖	⊖
District of Columbia	▲	<input type="checkbox"/>	b	⊖	⊖	⊖	North Carolina	<input type="checkbox"/>	<input type="checkbox"/>	b	▲	▲	▲
Florida^c	▲	⊖	⊖	▲	▲	▲	Ohio	▲	▲	▲	⊖	⊖	⊖
Georgia	▲	▲	⊖	⊖	⊖	⊖	Oregon	<input type="checkbox"/>	<input type="checkbox"/>	b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hawaii	⊖	d	b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pennsylvania	▲	▲	b	▲	▲	▲
Indiana	<input type="checkbox"/>	<input type="checkbox"/>	⊖	▲	▲	▲	South Carolina	▲	▲	▲	▲	▲	▲
Kentucky	<input type="checkbox"/>	<input type="checkbox"/>	b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Tennessee ^e	<input type="checkbox"/>	<input type="checkbox"/>	b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maine	⊖	⊖	⊖	▲	⊖	⊖	Texas	▲	d	d	d	d	d
Maryland	<input type="checkbox"/>	<input type="checkbox"/>	⊖	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Utah ^e	<input type="checkbox"/>	d	d	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Massachusetts ^c	▲	▲	▲	▲	▲	▲	Vermont	d	d	⊖	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Michigan	<input type="checkbox"/>	▲	⊖	⊖	d	⊖	Virginia	<input type="checkbox"/>	d	⊖	⊖	⊖	⊖
Minnesota	⊖	▲	d	▲	⊖	▲	Washington ^c	▲	▲	▲	d	d	<input type="checkbox"/>
Mississippi ^c	▲	▲	▲	▲	▲	▲	West Virginia ^f	d	<input type="checkbox"/>	d	d	d	d
Missouri	▲	<input type="checkbox"/>	⊖	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Wisconsin ^c	▲	▲	⊖	⊖	⊖	⊖

- Mandatory Enrollment
- ▲ Voluntary Enrollment
- ▲ Both Mandatory and Voluntary Enrollment
- ⊖ Mandatory Exclusion

Note: The states we visited are in bold lettering.

^aOther children in foster care or otherwise in an out-of-home placement.

^bThis state has no state option/waiver for Katie Beckett.

Appendix III
State Managed Care Enrollment Policies for
Children With Special Needs

^cColorado, Florida, Massachusetts, Mississippi, Montana, New York, Washington, and Wisconsin allow voluntary enrollment in capitated managed care plans of children with special needs who do not fall into a BBA category.

^dThis state did not provide data for this category.

^eTennessee and Utah have mandatory enrollment in capitated managed care plans of children with special needs who do not fall into a BBA category.

^fAccording to HCFA, as of July 1, 1999, West Virginia was enrolling SSI and foster children through a 1915(b) waiver and, therefore, was selected for our survey. As of October 31, 1999, West Virginia was no longer enrolling these children in capitated managed care programs.

Source: GAO survey of state Medicaid directors.

State-Reported Numbers of Children in BBA Categories Enrolled in Capitated Health Care Plans

Table 9 shows data from 20 states on the number of children with special needs enrolled in capitated Medicaid managed care plans. Nineteen states provided data through our survey; Florida provided its data to HCFA during the recent review of the state's 1915(b) waiver renewal application, and we obtained the data from HCFA. States' enrollment figures are from different points in time, are combinations of enrollment in two or more BBA categories, or both.

Table 9: Number of Enrolled Children

State	SSI	Title V	Katie Beckett	Foster care (title IV-E)	Adoption (title IV-E)	Other children in foster care or otherwise in an out-of-home placement
Colorado	3,091 ^a	54 ^a	b	610	25	c
Connecticut	3,451 ^d	b	e	5,500 ^f	2,000 ^f	2,500 ^f
Delaware	3,600	b	b	b	b	b
District of Columbia	2,036	b	e	g	g	g
Florida	21,900	g	g	1,447	1,254	430
Maryland	12,000	b	g	10,910	h	2,000
Massachusetts	2,002 ^j	b	b	539	j	j
Minnesota	g	86	b	1,491	g	805
Mississippi	566	b	4	10	k	b
Missouri	l	b	g	3,466	3,595	4,204
Montana	6 ^m	0	0	1 ^m	g	7 ^m
Nebraska	b	g	g	4,780	g	n
New Hampshire	o	b	28	42	37	b
New Mexico	6,637	b	p	2,331	q	q
New York	11,676 ^r	b	b	b	g	g
Utah	1,013	b	b	804	914	1,404 ^s
Vermont	b	b	g	481	249	405
Virginia	8,509 ^t	b	g	g	g	g
West Virginia	b	529	b	b	b	b
Wisconsin	189	b	g	g	g	g

Notes: Data are as of June 1, 1999, unless otherwise specified. The data for the states we visited are in bold lettering.

^aSSI data are as of October 1, 1999, and title V data are as of June 30, 1999.

^bThis state did not provide data for this category.

^cThe figure for foster care (title IV-E) includes other children in foster care or otherwise in an out-of-home placement as of August 20, 1999.

Appendix IV
State-Reported Numbers of Children in BBA
Categories Enrolled in Capitated Health
Care Plans

^dSSI data are as of November 1, 1999.

^eThis state has no state option/waiver for Katie Beckett.

^fData for foster care (title IV-E), adoption assistance (title IV-E), and other children in foster care or otherwise in an out-of-home placement are as of September 1, 1999.

^gThis state excludes this BBA category from enrollment.

^hThe figure for foster care includes adoption assistance.

ⁱSSI data are as of September 28, 1999.

^jThe figure for foster care includes adoption assistance and other children in foster care or otherwise in an out-of-home placement as of September 28, 1999.

^kThe figure for foster care includes adoption assistance.

^lMissouri does not use its SSI eligibility criteria to determine Medicaid eligibility: it is one of several states allowed to use 1972 state assistance eligibility rules to determine Medicaid eligibility for disabled recipients. These states are often called "209(b)" states because the origin of this requirement was sec. 209(b) of the Social Security Amendments of 1972. Missouri is therefore unable to determine the number of SSI children who are enrolled in its capitated Medicaid program.

^mThe data for SSI, foster care, and other children in foster care or otherwise in an out-of-home placement are as of October 1999.

ⁿThe figure for foster care includes other children in foster care or otherwise in an out-of-home placement.

^oNew Hampshire is also a 209(b) state and is therefore unable to determine the number of SSI children who are enrolled in its capitated Medicaid program.

^pThe figure for SSI includes Katie Beckett children as of October 1999.

^qThe figure for foster care includes adoption assistance and other children in foster care or otherwise in an out-of-state placement as of October 1999.

^rThe figure for SSI includes children through age 20.

^sThe figure for other children in foster care or otherwise in an out-of-home placement includes other categories of children considered by Utah to have special needs.

^tSSI data are as of May 27, 1999.

Source: GAO survey of state Medicaid directors, unless otherwise specified.

Care Coordination for Children With Special Needs in Four States

While each of the four states we visited has a care coordination system to assist children with special needs in accessing needed services, the systems are all different. For example, in Florida children are assigned to different types of care coordinators on the basis of their level of need, while in Michigan families can access the services of three different types of care coordinators. Furthermore, in both Maryland and Oregon, health plans are required to have a designated contact person for individuals with special needs, although the health plans are given discretion in deciding the role of this individual. Finally, state-employed nurses or social workers serve as care coordinators in Florida, while Michigan's specialty program uses both health plan and community-based care coordinators. In both Maryland and Oregon, care coordinators are hired by the health plans. The care coordination systems in each of the four states are summarized in table 10.

Florida's Children's Medical Services (CMS)

All children enrolled in the state's CMS program (for title V children) receive care coordination services. Upon enrolling in CMS, the family works with one of the state's nurses to complete a Child and Family Database Form, a three-page form that details the child's and the family's medical history, the child's physiological information, and a family support assessment.¹ On the basis of the complexity of their case, children in CMS are generally assigned to one of two types of case managers. Children with more severe and complex cases are assigned to a nurse specialist, while senior community health nurses handle individuals with less complicated cases.² The main difference between these two types of case managers is that nurse specialists are required to make home visits for each child every 6 months, while community health nurses do not visit beneficiaries' homes. In addition, nurse specialists tend to have much smaller caseloads because the children they assist have more complicated needs. According to the nursing director of the CMS Tampa regional office, the average caseload is

¹Possible physiological concerns are tracked for ten basic areas: vision, hearing, language, respiration, circulation, integument (pertaining to the skin), neuro-musculo-skeletal function, digestion/hydration, bowel function, and genitourinary function. The family support assessment asks parents to list environmental (food, shelter, work); psychosocial (schooling, child care); health-related (child development, medications, therapies); and physiological (medical equipment, emergency contacts) concerns they have regarding their child's condition or the family's situation.

²In addition to nurse specialists and community health nurses, some case managers coordinate care for children with specific diagnoses, such as HIV/AIDS and brain and spinal cord injuries, or who obtain services from other programs, such as early intervention.

50 children for nurse specialists and 150 children for community health nurses.

CMS case managers, who are either nurses or social workers employed by the state, undergo a preservice training in which they learn about family support services and how to access community resources outside the medical field. Furthermore, CMS has a contract with a university-affiliated center for child development to provide additional training for its case managers. At the time of our visit, CMS was also in the process of revamping its case manager training with the hope of providing clinical updates through distance learning in the future.

In addition to coordinating beneficiaries' medical services, CMS case managers are expected to coordinate with other entities from which the child receives services, including schools, day care and respite care agencies, and other community agencies. Case managers also attend court on the CMS enrollee's behalf, as well as foster care and school meetings. For example, CMS case managers have worked with parents and the schools to transfer children from schools without a full-time nurse to those that have a nurse on staff and are therefore better prepared to serve the child. However, according to families we interviewed, some case managers take a more active role in a child's care than others. CMS officials agreed that some case managers, regardless of training, are simply better than others at addressing all of the child's needs.

When the CMS program moves to a risk-based, capitated program, children's medical care will be provided by an integrated care system, as opposed to by independent providers. Although the integrated care system will be responsible for authorizing and paying for services and for routine utilization management, the CMS state agency will continue to be responsible for care coordination.³ Therefore, the care coordination system will remain unchanged.

³According to the American Association of Health Plans' Web site, utilization review or management comprises a set of procedures used by purchasers of health benefits to contain health care costs through assessment of the appropriateness of care, usually before the care is provided. (www.aahp.org/services/consumer_information/definitions/definit.html).

Maryland's Healthchoice

In Maryland, all children with special needs are eligible for care coordination services, but according to state officials, not all these children receive such services since many families do not request or want the assistance. However, all Medicaid health plans in the state make the services of a special needs coordinator (SNC) available to all individuals with special needs, including children with special needs, who request the service.⁴ In addition to SNCs, health plans have other case managers on staff or under contract. SNCs, who are usually nurses or social workers, serve as liaisons among Medicaid, the health plan, populations with special needs, and other case managers. In some health plans, SNCs have responsibility for coordinating beneficiaries' care, while in other plans they serve more as patient advocates and leave the coordination services to case managers. However, training from the state regarding populations with special needs is targeted to the SNCs who are responsible for informing other case managers.

Maryland leaves much of the organization of the care coordination system for populations with special needs—which includes the type of services provided, staff qualifications, and caseload—to the discretion of the health plan. State regulation provides that health plans be responsible for “assessing, planning, coordinating, monitoring and arranging the delivery of medically necessary and appropriate health-related services.” Within these general guidelines, health plans have considerable leeway to set up programs. We spoke with representatives of one health plan that requires its SNC to be either a registered nurse or a social worker and to have at least 3 years of experience with a health or human services organization. This plan's SNC acts as a patient advocate and a case manager, while SNCs in other plans may not serve as case managers but may have the responsibility of managing high-cost cases.

Generally, case managers conduct an initial assessment of beneficiaries referred for care coordination and tend to be mobile, allowing them to visit beneficiaries' homes for an environmental assessment if necessary. From this assessment and input from the primary care physician, a care plan is developed that includes an evolving set of short- and long-term goals and may address medical, social, and educational needs. If a case manager

⁴Maryland defines seven populations as having special needs: children with special needs, individuals with developmental disabilities, individuals with physical disabilities, pregnant and postpartum women, the homeless, individuals with HIV/AIDS, and substance abusers.

elects to involve the SNC in a case, then the case manager may be responsible for the medical aspects of the individual's care, while the SNC may deal with some of the social aspects, such as ensuring the family home has working electricity. To keep abreast of the beneficiary's progress, the case manager remains in touch with the family and the primary care physician. Case managers in one plan have an active caseload of about 30 beneficiaries, while there is no limit on the SNC's caseload. However, other plans may have vastly different systems.

Michigan's Children's Special Health Care Services (CSHCS) Special Health Plans

The CSHCS Special Health Plans are a Medicaid managed care option available to title V children. The special health plans provide care coordination services to all enrollees.⁵ Three different types of care coordinators, each with distinct responsibilities, are available to plan enrollees. Upon enrollment, each family is contacted by the plan level care coordinator (PLCC), an individual who works for the health plan as a reviewer and authorizer of services and is available to answer enrollees' questions. The PLCC works with new enrollees to help them find an appropriate local care coordinator, the second type of coordinator involved with enrollees. Local care coordinators, often nurses who work in a community agency, such as the local title V program, the local health department, or a home health agency, are paid by the special health plan to assist families in developing an individualized health care plan (IHCP)—the centerpiece of the system's care coordination program. One health plan pays each local care coordinator a flat fee to cover the preparation of the IHCP and any ongoing care coordination provided, while a second plan pays the coordinator a smaller fee for the completion of the IHCP and preauthorizes payment for two other contacts per year. Additional contacts beyond these two must be authorized in order for the local care coordinator to be reimbursed. Finally, each plan has a parent of a child with special needs on staff to serve as the plan's family-centered care coordinator. The family-centered care coordinator's primary responsibility is to provide guidance and assistance to enrolled families and to provide a family perspective to the plan. According to enrolled families, having a parent of a child with special needs on staff who can empathize with their situation is essential to the program's success.

⁵CSHCS Special Health Plans also enroll title V children who are not Medicaid-eligible.

The IHCP contains a comprehensive record of the child's medical, social, and educational needs. Information detailed on an IHCP includes demographic information; a list of the child's providers; all of the child's medical, equipment, and supply needs (for example, durable medical equipment, home health services, and medications); and therapy, transportation, and educational needs. Once it is compiled, the family, the PLCC, and the child's principal coordinating doctor must approve the IHCP before it can take effect.⁶ In addition to communicating the overall plan of care to the various providers, the IHCP also serves as a referral and prior authorization for care. IHCPs are supposed to be completed for each new enrollee within 60 days of enrollment and must be updated annually. In addition, the IHCP may be amended as new care needs arise.

Although advocates believe that the special health plans' care coordination programs cover the necessary services, there have been implementation problems. An advocate has reported that the health plans are not being given enough funding from the state to build the infrastructure necessary to provide coordinated medical and social services, making it difficult for the plans to build their care coordination systems. In fact, at least one special health plan reported difficulty in finding individuals who are capable and willing to serve as local care coordinators and to develop IHCPs. In addition, some physicians in one of the special health plans are unwilling to serve as principal coordinating doctors or to agree on the IHCPs written by the local care coordinators. As a result, the plan is unable to complete many IHCPs in a timely fashion.

The Oregon Health Plan

Oregon's care coordination program is targeted to individuals who meet the state's own definition of special needs individuals, since beneficiaries in the state's phase II population—including SSI and foster care children—can access the services of an exceptional needs care coordinator (ENCC). The ENCC serves as the health plan's point of contact for members, medical providers, and others with an interest in the health care of elderly or disabled beneficiaries. Although the state did specify that the ENCC service should include a specialized case management function housed in managed care plans to assist the phase II population in obtaining services and coordinating care, it provided health plans with broad discretion in implementing the program. As a result, the roles, responsibilities, and

⁶A principal coordinating doctor—a pediatrician, specialist, or subspecialist—is selected by the family to ensure that providers of care are working together.

backgrounds of ENCCs vary across plans. For example, one health plan uses the ENCC to conduct utilization review for high-cost cases, while in another plan the ENCC serves solely as a patient advocate. Generally, however, the ENCC assists beneficiaries in accessing needed medical services and may also advocate on their behalf and refer them to appropriate agencies that are able to meet their social needs. Since ENCCs' functions differ among plans, their active caseload may range from as few as 25 cases to as many as 100. Finally, some health plans seek trained social workers to fill their ENCC position, while others prefer nurses with knowledge of community agencies or utilization review.

Although all phase II beneficiaries are eligible to receive the services of an ENCC, not all of the population actually receives the service. In most health plans, ENCCs do not initiate contact with a beneficiary; rather, either the beneficiary must request the service or the beneficiary's case must be referred to an ENCC. At the time of health plan enrollment, individuals may be referred to the ENCC for services through the use of the state's Continuity of Care Referral Form (CCR). The CCR, which may be filled out by the enrollment caseworker, contains information about the beneficiary's living arrangements, health status, medical needs, and any special concerns. Although the CCR provides enrollment caseworkers with a tool to convey a beneficiary's needs to an ENCC, there is no requirement that the CCR be completed for each enrollee or at any specific time. Therefore, it is unclear how many eligible individuals are actually referred to an ENCC using this mechanism. Parents may also request the services of an ENCC for their eligible child with special needs. However, a 1997 satisfaction survey of parents of children with special needs found that 86 percent of phase II parents were not aware of the availability of the ENCC service. Thus, many children who may have benefited from the assistance of an ENCC have not received the service.

**Appendix V
Care Coordination for Children With Special
Needs in Four States**

Table 10: Care Coordination Activities for Children With Special Needs in Four States

Program	BBA children enrolled	Medical services only^a	Medical services plus others^b	Location of care coordinator	Primary features
Florida's Medicaid HMO option	SSI, title IV-E foster care and adoption assistance, out-of-home placement	X		Health plan	Medicaid HMOs are required to provide care coordination services to only two populations: individuals with developmental disabilities and children with mental health needs. For individuals with a chronic disease, health plans are required to develop a follow-up program to ensure appropriate treatment to minimize deterioration.
Florida's CMS ^c	Title V		X	State	Each child enrolled in CMS is assigned to one of two different types of case managers on the basis of the complexity of the child's needs and an assessment of available family support. ^d
Maryland's HealthChoice	SSI, title V, title IV-E foster care and adoption assistance, out-of-home placement	X ^e		Health plan	All Medicaid health plans are required to designate an SNC to serve as the point of contact for individuals belonging to one of the state's seven populations with special needs, which includes children with special needs. The care coordination structure and service provision differ by plan.
Michigan's Comprehensive Health Plan	SSI	f	f	f	f
Michigan's CSHCS Special Health Plan	Title V		X	Health plan, community	All enrolled children receive the services of two different care coordinators: a PLCC, whose role is to review and authorize services, and a local care coordinator, who helps develop a detailed health care plan for each child.
Oregon Health Plan	SSI, title V, title IV-E foster care and adoption assistance, out-of home placement	X ^g		Health plan	Oregon's SSI and foster children can request the services of an ENCC, a designated advocate to assist in organizing their care needs. However, ENCCs do not initiate contact with beneficiaries; unless their assistance is requested, no services are provided.

Appendix V
Care Coordination for Children With Special
Needs in Four States

^aThe care coordinator assists the child only in coordinating medical services, such as doctors' appointments and referrals to specialists.

^bIn addition to coordinating medical services, the state requires care coordinators to assist children in coordinating other social, behavioral, or educational services, such as special education and family support services.

^cCMS is not currently a capitated system, but its case management services will remain unchanged when the system becomes capitated. Although children will soon be served by integrated care systems, the responsibility for care coordination will remain with the state agency.

^dChildren with HIV/AIDS or brain and spinal cord injuries, or those in early intervention programs, are assigned to special case managers.

^eIn Maryland, there is no requirement that children's social needs be coordinated, although some SNCs do assist beneficiaries in obtaining needed social services.

^fMichigan's Comprehensive Health Plan does not require health plans to provide care coordination to their beneficiaries.

^gAlthough some ENCCs may refer beneficiaries to community agencies that can serve their social needs, ENCCs' efforts are concentrated on beneficiaries' medical needs.

Health-Based Risk-Adjustment Systems Used by Maryland, Michigan, and Oregon

Three of the four states we visited use health-based risk-adjustment systems for at least some of their beneficiaries enrolled in managed care programs (see table 11). Since 1997, Maryland has adjusted capitation rates using a variation of the Adjusted Clinical Groups (ACG) system, which assesses beneficiaries' prior use of health services to assign them to various risk categories.¹ Maryland estimates that about two-thirds of beneficiaries who qualify for SSI are in ACG-adjusted categories, while only about 50 percent of generally healthy families and children have the necessary prior health data to be included in ACG-adjusted categories. When the state begins using encounter data from health plans in 2001, replacing its reliance on older and increasingly limited fee-for-service information, it expects to increase the number of beneficiaries with ACG-adjusted capitation payments to health plans.² Since 1998, Oregon has used a form of the Disability Payment System (DPS), a risk-adjustment system developed specifically for Medicaid programs.³ Oregon applies risk adjustment to the capitation rates paid primarily for SSI beneficiaries.⁴ Michigan uses a specially designed system to address the higher expected costs of treating children with special needs in its Children's Special Health Care Services Special Health Plans.⁵ In the fall of 2000, Michigan plans to implement the DPS system of risk adjustment for people with disabilities

¹For those beneficiaries without sufficient diagnostic data, Maryland relies on adjustment by two eligibility categories (families and children, or the disabled); age; sex; and region (city or county).

²Encounter data are individual-level data from managed care plans for each service provided to each enrollee. The data allow states to identify the care received by individuals and the provision of any procedure.

³For more information regarding the DPS, see Richard Kronick, Tony Dreyfus, Lora Lee, and Zhiyuan Zhou, "Diagnostic Risk Adjustment for Medicaid: The Disability Payment System," *Health Care Financing Review*, Vol. 17, No. 3 (spring 1996).

⁴Oregon's risk-adjustment system is applied to two additional groups: those Medicaid beneficiaries receiving state-provided assistance until they receive approval for SSI benefits and a category of newly eligible beneficiaries, most of whom are single adults and childless couples older than 19 years of age.

⁵In part because of concerns that program enrollment was so small that appropriate capitation rates could not be developed (593 children had enrolled as of Aug. 18, 1999), Michigan amended its health plan contracts soon after the program began in 1998 to add additional protections from financial losses. The state agreed to conduct a study at the end of the contract period comparing actual costs with those that might be expected for similar children in a fee-for-service system, and to reimburse health plans for higher-than-expected costs if necessary.

**Appendix VI
Health-Based Risk-Adjustment Systems Used
by Maryland, Michigan, and Oregon**

enrolled in its general Medicaid program, which include children eligible for SSI.

Table 11: Health-Based Risk-Adjustment Systems Used by Maryland, Michigan, and Oregon

State	Description
Maryland	Risk adjustment is conducted for two groups: families and children, and the disabled population. Within these two separate categories, the ACG classification is used to assign Medicaid beneficiaries to 1 of 52 unique groups on the basis of their age, sex, and inpatient and ambulatory diagnoses identified in prior medical claims. The state then uses these ACG data to define nine risk-adjustment categories that reflect relatively similar uses of resources. Each beneficiary is then assigned to one of the nine risk-adjustment categories according to the original ACG classification. Maryland also includes other adjustments: children under 1 year, pregnant women, and people with AIDS are in separate categories, and various other programs are “carved out” of the state’s risk-adjusted payments, including costs for the Rare and Expensive Case Management program, specialty mental health services, various HIV/AIDS services, services for infants, and long-term care services.
Michigan CSHCS Special Health Plans	The risk-adjustment system includes five variables: (1) four diagnostic categories that incorporate the 2,700 diagnoses identified by the state title V program, (2) the age of the child with special needs, (3) the county of residence, (4) whether the child also has private insurance, and (5) Medicaid eligibility. ^a
Oregon	The state uses a form of the DPS system developed specifically for Medicaid programs that employs past fee-for-service claims data to identify high-cost diagnoses. Specifically, the DPS uses claims data to count diagnoses and estimate the cost in a given year for a person with a specific disability in a previous year. The system uses 18 groupings corresponding to a body system, type of illness, or disability. These groupings are further distributed to 43 subcategories according to relative costs. The state also adjusts capitation rates according to maternity and newborn prevalence within each plan, and several adult eligibility categories for methadone treatment rates within each plan and region. In the fall of 2000, Oregon will move to a revision of the DPS—the Chronic Disease and Disability Payment System. This system is designed specifically for Medicaid populations and will use fee-for-service data from seven states to identify high-cost diagnoses, which will then be categorized into 19 major categories and 58 subcategories.

^aBecause the Michigan special health plans are a component of the state’s CSHCS program, which also enrolls non-Medicaid-eligible children, a fifth variable addresses whether the child is Medicaid-eligible.

Source: State interviews and reports.

Selected Quality-Monitoring Activities That Can Be Targeted to Children With Special Needs

Many of the quality-monitoring requirements for managed care programs are specified in Medicaid law and regulations, which were amended in 1997 by the BBA.¹ However, most of this monitoring activity is not specifically targeted to any eligibility group. Each state must develop and implement a quality assessment and performance improvement strategy that includes procedures for monitoring and evaluating the quality and appropriateness of care and services to beneficiaries. Additionally, managed care organizations are required to have an internal quality assessment and performance improvement program whereby the health plan must achieve minimum performance levels on standardized quality measures and undertake performance improvement projects in various clinical and nonclinical areas. State agencies also must provide for an annual independent, external review of the quality of services furnished under each state agency contract with a managed care organization.²

Quality monitoring can be carried out using various measures or processes, including clinical studies, beneficiary satisfaction surveys, and medical record audits (see table 12). These quality-monitoring activities can be modified to include a specific focus on children with special needs within a current Medicaid-wide program, or can be developed specifically for these children. States can focus activities by increasing sample sizes for children with special needs, holding focus groups, or conducting enrollee interviews. For example, because the number of children with special

¹For more information on the major federal requirements for monitoring Medicaid managed care programs, see GAO/HEHS-00-37, Mar. 3, 2000, app. II, p. 42. Federal requirements pertaining to monitoring are specified in sec.1903(m) of the Social Security Act and 42 C.F.R. 434.

²HCFA has collaborated with various public and private agencies to develop a range of technical assistance tools and guidance to provide resources for states in implementing quality assurance and improvement programs in Medicaid. Among them is "A Health Care Quality Improvement System for Medicaid Managed Care—A Guide for States," the product of the agency's Quality Assurance Reform Initiative in 1993. This guide includes a framework for quality improvement systems for managed care programs, guidelines for internal quality assurance programs for health plans, guidelines for clinical and health services focus areas and use of quality indicators and clinical practice guidelines, and guidelines for the conduct of external quality reviews. HCFA updated the guide in 1998 with the "Quality Improvement System for Managed Care," which contains a new set of approaches, tools, and techniques for performance improvement. HCFA also collaborated with other entities to produce a Medicaid version of the Health Plan Employer Data and Information Set, a standardized quality performance measurement system. Additionally, the Agency for Healthcare Research and Quality produced the Consumer Assessment of Health Plans survey instrument, which includes measures and tools specifically designed for use by state agencies.

**Appendix VII
Selected Quality-Monitoring Activities That
Can Be Targeted to Children With Special
Needs**

needs is small relative to the overall Medicaid population, it is unlikely that a large enough number would be included in a randomly chosen sample of beneficiaries for a systemwide satisfaction survey. To target children with special needs, a state or health plan can stratify the sample of those interviewed to intentionally include a large enough number of families with children with special needs for significant conclusions to be drawn about their experiences. Alternatively, a state may administer a special beneficiary survey only among families of children with special needs.

**Appendix VII
Selected Quality-Monitoring Activities That
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Needs**

Table 12: Measures or Processes States and Health Plans Can Use to Monitor the Quality of Care for Children With Special Needs

Monitoring measure or process	Description
Beneficiary surveys	Periodic satisfaction surveys—administered statewide or within individual health plans—can help measure the degree to which Medicaid beneficiaries are happy with the providers and services offered in their managed care plan. Some states have used analyses of such data to help identify problems that Medicaid beneficiaries have with managed care, such as difficulty in accessing specialists. Statewide surveys allow states to compare results across plans for various access and quality measures, such as use of specialty services and beneficiary perception of the quality of care provided. Indicators of beneficiary satisfaction can complement other analyses of provider network capacity and provided services.
Analysis of encounter data	Encounter data are individual-level data on all services provided to all patients. Analyses of encounter data allow states to examine patterns of care across plans, such as differences in service delivery by selected types of services, beneficiary groups, and providers.
Random audits of medical records	Medical record audits document problems with patient medical records, such as incomplete patient histories, lack of indication of follow-up care, and illegibility and unavailability of records. Audits have the potential to assess the appropriateness of the care provided as well as to determine whether patients' medical records properly document the health care and services that they received.
Grievance/disenrollment studies	Health plans must operate an internal grievance process through which beneficiaries can report their dissatisfaction with plan providers, services, and benefits. States can assess individual beneficiary grievances to identify specific and localized problems or can monitor the volume of grievances filed—particularly across plans—to reveal problems. Moreover, beneficiaries who disenroll from managed care plans may do so because of dissatisfaction with the care received. Therefore, collecting and analyzing data on disenrollments can provide insights into plan performance.
Focused clinical studies	A clinical study focuses on certain aspects of health care services, such as preventive care or care of chronic and acute conditions, to answer questions about the quality and appropriateness of care that has been provided.
Use of quality indicators	An indicator is a variable reflecting either a discrete event, such as whether an older adult has received a flu shot in the last 12 months, or a status, such as whether a person's hypertension is under control. An organization's performance on selected topics can be measured using one or more quality indicators. States and health plans can adopt standard indicators, such as those available in instruments like the Health Plan Employer Data and Information Set, which has a Medicaid version, or develop their own indicators.
Separate quality oversight entities	States can operate specific managed care quality divisions responsible for monitoring health plans. In order to target activities specifically for children with special needs, states can develop separate oversight entities, or subdivisions, within existing programs. For example, Florida's specialty children's program has a quality management unit that operates separately from the state's general Medicaid quality agency.

Comments From the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

SEP 11 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: States' Safeguards for Children With Special Needs Vary Significantly." 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: States' Safeguards for Children
With Special Needs Vary Significantly"**

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.

The Department is concerned with the findings of the report that more rigorous work needs to be done to assure that adequate health care is delivered to children with special needs in mandatory and voluntary Medicaid managed care plans. 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.

The Department recognizes that children with special health care needs (CSHCN) are by definition a vulnerable population and that certain safeguards are necessary to ensure that they receive the health care services to which they are entitled. In Medicaid, a program jointly administered and funded by the Federal Government and State governments, the Health Care Financing Administration (HCFA) has demonstrated their commitment to this population's well-being through the implementation of safeguards contained in the Draft Interim Review Criteria (DIRC). The DIRC are applied to waiver and demonstration programs that mandatorily enroll CSHCN. The CSHCN in question are children as defined by the Balanced Budget Act of 1997 (BBA) as having a special health care need.

The GAO report points to good practices already in place in States to ensure that CSHCN receive the appropriate care. However, GAO's report also suggests that States currently leave significant discretion to participating health plans on which CSHCN's protections are implemented, and on how they are implemented. Given the financial incentives of capitated managed care programs, the Department believes that it is not sufficient for such protections to be optional or discretionary. The DIRC make protections of this sort (in the areas of enrollment, care coordination, primary care physicians and specialist access, and others) mandatory when a State chooses to enroll BBA-defined CSHCN in capitated managed care.

As noted in GAO's report, managed care plans can both serve as a cost-saving mechanism and as a vehicle to preventive and primary care for populations that have perhaps been ill-served by other forms of health care delivery. However, as the report notes, some of those cost-saving mechanisms, such as limited access to specialists and constraints on services, may not be

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Comments From the Department of Health
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appropriate for children with life-threatening or chronic and debilitating conditions. It is for this reason that the Department's HCFA requires States that mandatorily enroll special needs children into managed care plans to implement a set of safeguards designed to ensure these children receive all the services to which they are entitled.

The report emphasizes the importance of identifying CSHCN and gathering accurate enrollment, service utilization and quality data for this specific population. The Department agrees that the absence of a uniform definition of children with special health care needs continues to hinder data collection efforts, and certainly poses a challenge to obtaining national data on the prevalence of CSHCN in managed care systems and evaluating how CSHCN are served through Medicaid managed care.

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

- The Department's Health Resources and Services Administration (HRSA) will fund a national State and Local Area Integrated Telephone Survey which will be tested beginning in Autumn 2000 by the National Center for Health Statistics to provide data on health and insurance status of CSHCN. This survey should provide valuable information for States as they refine and improve their Medicaid programs for CSHCN.
- Over the last few months, the Department's HCFA has been working with HRSA to revise DIRC to be more focused and address many of the issues discussed in the GAO report. Once the criteria are revised, the document may be reviewed by a group of stakeholders including providers, managed care organizations (MCOs), State Medicaid agencies, State Title V agencies and consumers.
- In December, the Department's HRSA is planning to review existing tools and strategies for identifying and monitoring CSHCN and determine additional resources needed by States and managed care organizations.
- The Department, with assistance from the George Washington University Center for Health Service Policy Research, is developing sample purchasing specifications for CSHCN in Medicaid managed care. These purchasing specifications provide guidance and technical assistance to State Medicaid agencies and managed care organizations on approaches for providing quality care to CSHCN. The specifications contain illustrative language relating to 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 Department's HRSA funds a number of organizations to research and evaluate the issues of CSHCN receiving care in managed care. These grants provide a wealth of information and resources on many of the issues cited in

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GAO's report. For example, the report notes that few States focus their managed care plan monitoring activities on the experience of CSHCN. The HRSA report entitled "Measurements of Quality of Care for Children with Special Health Care Needs" by the National Policy Center for Children with Special Health Care Needs is an excellent resource on monitoring quality for CSHCN.

The report notes that one key issue in assuring special needs children receive quality services is that both managed care organizations and providers are adequately reimbursed. As the report notes, some States have developed payment methodologies that account for special needs populations enrolled in capitated managed care. The HCFA must provide for adequate reimbursement of managed care organizations and providers to ensure special needs children receive quality services. The DIRC require States to develop a payment methodology that accounts for special needs populations enrolled in capitated managed care. The Department's HCFA and HRSA will collaborate on researching the issues related to the development and implementation of risk adjustment for children.

The report notes the collaboration of Oregon with the Foundation for Accountability (FACCT) in the assessment of quality monitoring for CSHCN. The HRSA, HCFA, and the Department's Agency for Health Care Research and Quality participate in the Child and Adolescent Health Measurement Initiative (CAHMI) which is coordinated by FACCT. The members of CAHMI have provided guidance on the development of FACCT's "Living with Illness" measure. This FACCT survey is specifically designed to assess the care rendered to children with chronic health conditions. This assessment survey should be a valuable addition to the tools that States use to evaluate the quality of care for CSHCN.

Finally, although GAO's report focused on Medicaid managed care, it is important to highlight that these same issues apply to CSHCN 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 CSHCN.

GAO Contacts and Staff Acknowledgments

GAO Contacts

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Staff Acknowledgments

In addition to those named above, Deborah Miller, Mike Piskai, Michelle Rosenberg, and Behn Miller made key contributions to this report.

Related GAO Products

Medicaid Managed Care: Challenges in Implementing Safeguards for Children With Special Needs (GAO/HEHS-00-37, Mar. 3, 2000).

Medicaid and Special Education: Coordination of Services for Children With Disabilities Is Evolving (GAO/HEHS-00-20, Dec. 10, 1999).

Medicaid Managed Care: Four States' Experiences With Mental Health Carveout Programs (GAO/HEHS-99-118, Sept. 17, 1999).

Medicaid Managed Care: Challenge of Holding Plans Accountable Requires Greater State Effort (GAO/HEHS-97-86, May 16, 1997).

Medicaid Managed Care: Serving the Disabled Challenges State Programs (GAO/HEHS-96-136, July 31, 1996).

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