
Medicaid Managed Care Policies Affecting Children With Disabilities: 1995 and 1996

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The authors present findings from a study of State Medicaid managed care enrollment and benefit policies in 1995 and 1996 for children with disabilities. During this time the number of States serving children through fully capitated plans grew by more than one-third, and enrollment of children receiving Supplemental Security Income (SSI) payments and children in subsidized foster care increased. Most States required plans to provide all mandatory and most optional Medicaid services. Although States have begun to make noticeable improvements in their contract language concerning medical necessity and the early and periodic screening, diagnosis, and treatment (EPSDT) benefit, overall State guidance in these areas remains weak.

INTRODUCTION

More than 4 million children in the United States have a chronic condition that results in some degree of limitation in their ability to participate in school or play or to engage independently in activities of daily living, such as eating or walking. These children are more likely than their healthier peers to obtain their health insurance coverage through Medicaid. In 1994 roughly 1.5 million children with limitation of activity were covered by Medicaid.

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Among poor children, 70 percent of those with an activity limitation had Medicaid coverage, compared with only 59 percent of those with no limitation. Among non-poor children, Medicaid covered 15 percent of those with a limitation, but only 6 percent of those without limitation (Newacheck, 1997).

The Medicaid program guarantees eligible children a comprehensive package of health insurance benefits, one that is far more extensive than those typically offered through commercial plans. Under the program children have access to benefits that include routine preventive visits, medically necessary diagnostic and evaluative services, and medically necessary treatment services that range from office-based medical services to various mental health and developmental therapies in non-traditional settings, to home health and other long-term care services.

Medicaid children's entitlement to these services was established early in 1990 when the Omnibus Budget Reconciliation Act of 1989's amendments to Medicaid's EPSDT provision took effect. Since that time States have been statutorily required to pay not only for comprehensive pediatric screening services, including those additional to the screens prescribed under the State's periodicity schedule, but also for all federally allowable health care, diagnostic, and treatment services determined as a result of a screen to be necessary to correct or ameliorate a defect or physical or mental condition. These services must be reimbursed for children regardless of whether

they are covered for other Medicaid beneficiaries. Although States retain some discretion in defining and authorizing EPSDT expanded benefits, the statutory language of EPSDT constitutes a fairly uniform standard of coverage for all Medicaid-eligible children—and one that is particularly important to those with disabling conditions.

At the same time that States have been struggling to structure EPSDT coverage policies, however, many have also been accelerating their use of capitated managed care, in effect shifting decisionmaking authority for children's services from Medicaid agencies to plans. The plans with which they are contracting often are commercial entities new to serving low-income children or furnishing a pediatric benefit package as comprehensive as Medicaid's. Unless otherwise directed these plans are likely to draw upon their commercial experiences, where definitive coverage limits usually apply and services are considered medically necessary only when they are needed to treat an accident or illness (Fox and McManus, 1996a).

Enrollment into capitated managed care arrangements marks a major shift in the way that Medicaid children with disabling conditions receive their care; it creates new provider relationships and establishes new rules for accessing services. Just as little has been known about the effectiveness of Medicaid's fee-for-service arrangements on children with disabilities, the evidence regarding managed care's impact is also limited. Research suggests, however, that these children are likely to confront difficulties in obtaining necessary specialty services in capitated arrangements. Findings from a survey of pediatricians revealed that a significant proportion had referral requests for pediatric subspecialists denied, and that one-third of these pediatricians believed their patients' care was compromised as a result (Cartland and Yudkowsky, 1992).

Similarly, a recent study of Medicaid demonstration waiver programs in four States found that prior authorization policies imposed at the plan level were often structured to prevent children from obtaining ancillary therapies, mental health services, durable medical equipment, and pediatric subspecialty services, particularly if those services were available only from out-of-network providers (Fox and McManus, 1996b).

Specialty care access problems have also been identified in the managed care literature for Medicaid children generally. Much of this literature, which refers only to children eligible for Medicaid because of their Aid to Families with Dependent Children (AFDC) status, is dated and does not reflect the utilization control methods employed by today's fully capitated plans. Nor does it always take sufficient account of selection bias in enrollment or the generosity of benefits available under comparative fee-for-service arrangements. Nevertheless the studies generally report a reduction in specialty physician (Freund et al., 1989; Hurley, Freund, and Gage, 1991) and emergency room use (Bonham and Barber, 1987; Hurley, Freund, and Paul, 1993; Hurley, Freund, and Taylor, 1989), but show little or no change in the rate of inpatient hospital stays (Hurley, Freund, and Paul, 1993; Bonham and Barber, 1987; Leibowitz, Buchanon, and Mann, 1992). With respect to primary care services, the findings suggest that utilization of preventive services by children may be the same or higher (Balaban, McCall, and Bauer, 1994; Hohlen et al., 1990; Mauldon et al., 1994), while acute care services may be the same or lower (Hurley, Freund, and Gage, 1991; Mauldon et al., 1994). Freund and Lewit (1993) conclude that children in Medicaid managed care arrangements appear to experience decreased access to

specialty care without a commensurate increase in primary care services.

In this article we present new information on State Medicaid managed care policies affecting children with disabilities for 1995 and 1996. We provide information on enrollment policies and on pediatric benefits, including EPSDT and medical-necessity guidance for health maintenance organizations (HMOs) and other fully capitated managed care arrangements. Although Medicaid managed care policies have been discussed by other authors (Horvath and Kaye, 1995, 1997; Johnson, 1997; Rawlings-Sekunda, 1997; Saucier and Mitchell, 1995), they have not included multiyear analyses focused on enrollment and benefit issues of particular relevance to children with special health care needs.¹

STUDY METHODS

This study is based on a combination of telephone interviews with State Medicaid agency staff and reviews of State managed care contracts in 1995 and 1996. In 1995, 29 States using HMOs and other fully capitated plans to serve children were studied; in 1996 the number of States rose to 39. We focused this analysis on State policies regarding general managed care plans and excluded policies related to specialized plans that serve disabled populations exclusively.

Our telephone interviews consisted of a series of detailed questions concerning enrollment and benefit policies under fully capitated plans. We asked about enrollment policies for categorical and special

child population groups and whether enrollment was voluntary or mandatory. We also asked about whether 13 Medicaid-allowable services relevant to children with disabilities were included in the capitated contract or separately reimbursed, whether plans were expected to provide all EPSDT expanded benefits, and what guidance was furnished to plans regarding medical necessity. In addition we gathered information on the reasons for these policy decisions. The interviews were conducted with the director of managed care in each State Medicaid office during the spring of 1995 and again, approximately 18 months later, during the late fall of 1996.

The telephone surveys were supplemented by reviews of State contracts for fully capitated plans that were in effect at the time of our survey. We examined those sections of the contract related to enrollment, service responsibilities, EPSDT, medical necessity, and definitions of terms. In cases where the contracts referenced other relevant documents, such as a provider manual or the administrative code, we obtained copies of these documents and incorporated them in our analysis.

We analyzed the contract language for EPSDT and medical necessity using objective criteria. EPSDT language was assessed according to whether it included core elements federally required under the EPSDT benefit. Medical-necessity language was assessed according to the extent to which it would permit coverage for habilitative and other therapeutic interventions for children with disabling chronic conditions.

To verify our enrollment and coverage policy findings, summary confirmation was sent back to each State Medicaid managed care office for review, along with State-specific questions we needed to have answered. Through this process we were able to clarify any discrepancies between

¹The National Academy for State Health Policy collected, through interviews with State Medicaid staff, information on the scope and operations of State managed care programs in 1994 and 1996. The George Washington University's Center for Health Policy Research prepared a detailed summary of State Medicaid managed care contracts in effect during 1995. The Center for Vulnerable Populations developed, based on State interview data, a directory of State Medicaid managed care programs serving persons who were elderly or disabled in 1995 and 1996.

what was reported to us and what appeared in the contract documents and to address any gaps in our information. In some instances we learned that State managed care policies actually differed from those specified in the contract because of delays in implementation. In other instances we determined that Medicaid managed care staff were not fully aware of all of the plan features, particularly with respect to Medicaid payments for public program services, and we made additional telephone calls to public program or other Medicaid staff to gain clarification.

It should be noted that in classifying a State's enrollment policy as voluntary or mandatory, we chose the policy applicable to the largest composite geographic area of the State, that is, the largest number of managed care counties. Geographic scope was selected as the best measurement because of the difficulties in obtaining estimates of the number of Medicaid child beneficiaries in specific counties or even the population size of specific counties. In addition we considered a State to have a voluntary enrollment policy with respect to fully capitated plans if the State required enrollment in either a primary care case management system or a fully capitated plan.

RESULTS

At the end of 1996, more than three-quarters of States were serving Medicaid children through fully capitated plans, either on a statewide basis or in limited geographic areas. State policies regarding the enrollment of different categorical groups of children, the extent of pediatric benefits included in capitation contracts, and the guidance given to plans regarding EPSDT expanded benefits and medical-necessity standards are discussed in the next section. The discussion includes information for 1995 as well as 1996.

Table 1
Trends in State Enrollment
of Children in Fully
Capitated Plans: 1995 and 1996

Categorical Groups Enrolled on Voluntary or Mandatory Basis	Percent of States Using Fully Capitated Plans	
	1995 (n=29)	1996 (n=39)
AFDC	100	100
Mandatory	38	44
Voluntary	62	56
AFDC-Related	90	100
Mandatory	34	44
Voluntary	55	56
SSI	45	54
Mandatory	10	18
Voluntary	38	36
Foster Care	41	64
Mandatory	7	21
Voluntary	34	44

NOTES: AFDC is Aid to Families with Dependent Children.
SSI is Supplemental Security Income.

SOURCE: Information was obtained by Fox Health Policy Consultants through telephone interviews conducted with State Medicaid agency staff in the spring of 1995 and fall of 1996 and through an analysis of State general managed care contracts in effect.

Managed Care Enrollment Policies Affecting Children

States' enrollment of children in fully capitated plans has focused primarily on those eligible for Medicaid by virtue of their AFDC or AFDC-related status, as shown in Table 1. Among the 39 States that were using fully capitated plans to serve children in 1996, all States enrolled children for whom AFDC payments are made and children in AFDC-related categories, including those who qualified for Medicaid because of their poverty-level status and, where Section 1115 demonstration waivers were in effect, those who qualified by meet-

ing higher income criteria. In about one-half of the States, enrollment for these children was mandatory.

By contrast States were more reluctant to enroll Medicaid children who are receiving SSI disability benefits or are in subsidized foster care, citing concerns that they did not have the requisite information to set capitation rates or monitor quality and that the plans themselves might not be structured to deliver the range and intensity of services that these children require. Just under two-thirds of the States enrolled foster care children, only slightly more than one-half enrolled SSI children, and only slightly more than one-third enrolled both populations. States were also significantly less likely to require mandatory enrollment of these children. Less than one-third of the States that enrolled the SSI or foster care populations in fully capitated plans mandated their enrollment.

Not only did nearly two-thirds of States exclude either SSI or foster care children or both from participation in fully capitated managed care arrangements in 1996, but more than one-third also had policies to exempt certain other groups of children with special needs, many of whom may be eligible for Medicaid because of their AFDC or AFDC-related status. Such policies have been established for children served by the Federal Title V program for children with special health care needs (two States), children with serious emotional disturbances (three States), children served by the early intervention program (one State), and children with developmental delay (one State). Other States allowed for exemptions on an individual basis, with evidence of a disability or severe medical problem that could not be served adequately by participating plans. In fact, six States, most with mandatory enrollment, excluded one or more of these groups and also excluded SSI children. Only two man-

datory enrollment States had no exemptions at all.

A comparison to State policies in 1995 reveals rapid growth in Medicaid managed care enrollment. In just 18 months (from the time of our first round of interviews in the spring of 1995 to our second in the fall of 1996), the number of States using fully capitated plans to serve children grew by just over one-third, from 29 States in 1995 to 39 States in 1996. During the same period, the proportion enrolling the SSI population in fully capitated plans grew from 45 to 54 percent, while the proportion of States enrolling children in subsidized foster care grew from 41 to 64 percent.

Yet the increase in mandatory enrollment of the SSI and foster care populations between 1995 and 1996 was even more striking. For SSI children the portion of States mandating their enrollment almost doubled, up from only 10 percent in 1995 to 18 percent in 1996. For children in foster care, it tripled, growing from 7 percent in 1995 to 21 percent in 1996. Although States showed no overall tendency to increase their use of child-enrollment exemptions based on public program eligibility or individual criteria, they did allow for more individual exemptions where plan enrollment of SSI children was mandatory.

Pediatric Services In Managed Care Plans

Children enrolled in fully capitated arrangements in 1996 received most Medicaid services from their plan, as shown in Table 2. State contracts with plans typically required the provision of all mandatory Medicaid services, including inpatient and outpatient hospital services, physician services, and laboratory and X-ray services. Most State contracts also required plans to furnish the majority of the optional Medicaid services covered by the State, including most of the treatment services required under EPSDT.

Table 2
Trends in Pediatric Services Excluded from State Contracts
with Fully Capitated Plans: 1995 and 1996

Service Excluded from Contract	Percent of States Using Fully Capitated Plans	
	1995 (n=29)	1996 (n=39)
Mental Health (All or Some)	76	74
All	31	44
Beyond Specified Limits	17	13
Services Primarily or Exclusively for Children with Serious Emotional Disturbances	34	26
Dental	69	67
Health-Related Special Education	55	67
Personal Care	55	49
Vision (All or Some)	34	23
Early Intervention (All or Some)	31	46
Prescription Drugs	24	26
Durable Medical Equipment (All or Some)	17	10
Expanded EPSDT Benefits	14	0
Private Duty Nursing	14	15
Specialized Services for Children in Foster Care (All or Some)	10	13
Ancillary Therapies (Certain or Intensive)	10	13
Title V Services for Children with Special Health Needs	7	8
Average Number of Services Carved Out of the 13 Services Listed Above	4.2	4.1

NOTE: EPSDT is early and periodic screening, diagnosis, and treatment.

SOURCE: Information was obtained by Fox Health Policy Consultants through telephone interviews conducted with State Medicaid agency staff in the spring of 1995 and fall of 1996 and through an analysis of State general managed care contracts in effect.

However, all but 2 of the 39 States² that used fully capitated plans to serve children elected to exclude at least some Medicaid services for children from their capitated contract and reimburse these services separately.³ Many States excluded certain pediatric services so that the Medicaid benefit package provided by the plan would resemble the type and amount of services offered to commercial enrollees, presuming that plans did not have the capacity or inclination to furnish these services. In some instances services were excluded only above specified coverage limits or under certain

situations. Services that were carved out from State contracts for these reasons included: dental services (in 26 States), personal care services (in 19 States), prescription drugs (in 10 States), vision services (in 9 States),⁴ ancillary therapies (in 5 States)⁵, and durable medical equipment (in 4 States). States sometimes used a separate capitated arrangement to pay for excluded services: four States capitated dental services under another contract, for example. In some instances, plans were given the option of furnishing certain otherwise excluded services if they had the capacity and desire to furnish them.

²Minnesota was counted as not excluding any services, even though it carves out case management services for children with serious emotional disturbances (SED). Very few children with SED are enrolled in Minnesota's managed care plans because the State excludes these children from enrollment if they are determined to have SED at the time of enrollment.

³Services that are capitated only at a plan's option were considered to be excluded from the contract.

⁴This number includes States that carved out eyeglasses only as well as States that carved out all vision services.

⁵This number refers to States that carved out ancillary therapies beyond specified limits or excluded one or more types of therapy from their contracts.

Equally often, however, States excluded services from their contracts to protect certain populations and to ensure continuity of their care, or to preserve Medicaid financing for service providers that have historically relied on public funds and provided the State's share of the Medicaid service cost. The carve-out of mental health services is the best example of this. About three-quarters of the States (29) excluded some or all mental health services from their contract for these reasons. Of these, 17 excluded all mental health services, sometimes paying for these services under a separate capitated contract. The other States limited plans' responsibilities for mental health services in essentially one of two ways: Either the States created a separate payment arrangement for services provided primarily or exclusively to children with serious emotional disturbances (10 States),⁶ or they paid on a fee-for-service basis for services beyond an established benefit limit (5 States). Three States did both. Regardless of the specific policy, the carve-out of mental health services usually was intended to ensure that community mental health centers and other providers within the children's mental health system would continue to receive Medicaid reimbursement for services provided to Medicaid-eligible children.

Other types of public program providers were also frequently protected by contract exclusions of the services they provide. Two-thirds of States (26) carved out health-related special education services provided by schools to children with disabilities, just over 45 percent (18) carved out services furnished under the early intervention program to developmentally de-

layed children under age three, and nearly 40 percent carved out both services. Five States excluded special assessment, counseling, and court-ordered services for foster care children (although, as previously mentioned, a larger number of States elected to exclude the children themselves from enrollment). Finally, three States omitted the medical and other specialty services provided by the Title V program for children with special health care needs. Specialty services furnished by Title V program providers reportedly were less likely to be excluded from managed care contracting, because, unlike the other public program services, Title V services have historically been included in the State Medicaid budget and would presumably be perceived by plans as medically necessary.

Considering the extent to which children with disabilities require speciality services, many of which are non-traditional, and the difficulties of establishing reasonable capitation rates for them, it was perhaps surprising that the enrollment of SSI children in fully capitated plans did not appear to have any significant overall effect on States' carve-out policies for services particularly important to this population. On average States that enrolled SSI children were only slightly more likely to exclude public program services and other specialized services such as personal care, prescription drugs, durable medical equipment, private duty nursing, and ancillary therapies, from their contracts as were States that exempted these children from enrollment.

When States that mandatorily enrolled SSI children in fully capitated plans were compared with States in which these children were exempt or allowed to enroll on a voluntary basis, carve-out policies for public program and other specialized services still were not dramatically different. If anything, States with mandatory SSI enroll-

⁶Some States explicitly excluded services provided to children with serious emotional disturbances. Other States excluded certain types of mental health services but explained that these services were targeted primarily to children with serious emotional disturbances. We have grouped both policies as "services primarily or exclusively provided to children with serious emotional disturbances."

ment established somewhat fewer service carve-out protections than the other States. This was most notably the case for carve-out policies regarding mental health services primarily or exclusively for children with serious emotional disturbances and private duty nursing.

Overall States did not make substantial changes between 1995 and 1996 in the number of services excluded from their contracts. In both years States excluded an average of 4 of the 13 pediatric services we examined. States did, however, make some significant changes in the types of services they excluded. For example, States moved away from carving out expanded EPSDT benefits from their contracts; by 1996 no State carved out this set of services, whereas in 1995 four States did.

Looking specifically at State contract policies regarding public program services for special-needs children in 1995 and 1996, we found a slight increase in the average number of services that States carved out. The portion of States that excluded early intervention services grew fairly significantly. The proportion that excluded health-related special education services increased somewhat, and the proportion that excluded services furnished through the children's mental health program decreased.

Looking at other specialized services of particular importance to children with disabling conditions in 1995 and 1996, the average number of service carve-outs remained about the same. However, States became less likely to exclude durable medical equipment and somewhat more likely to exclude ancillary therapies.

State shifts in mental health service carve-out policies over the 18-month period of our study deserve special notice. Although the proportion of States with mental health carve-outs remained at three-quarters, there were notable changes in

State policy. States showed a greater tendency to carve out all mental health services from their general managed care contract and were less inclined to exclude services for children with serious emotional disturbances or mental health services beyond certain limits.

State Guidance on EPSDT and Medical-Necessity Decisions

Except for specifically excluded services, children in fully capitated plans depend on their plan for all of the diagnostic and treatment services to which they are entitled under Medicaid's EPSDT provision. Yet our review of 1996 contracts shows substantial variation in the extent of guidance States gave plans about EPSDT coverage and how it differs from children's private health insurance coverage⁷ and Medicaid coverage for adults, as shown in Table 3. Among the 38 States that included EPSDT in their capitated contracts (Oregon has a waiver to eliminate the EPSDT benefit), all communicated the preventive focus of EPSDT and described the screening component of the benefit,⁸ and about 85 percent referenced Federal regulations pertaining to EPSDT or, at a minimum, indicated that the benefit is federally mandated. However, just under 40 percent (15) of the States used contract language regarding the diagnosis and treatment components of the benefit that is substantially similar to Federal law, stipulating (1) the requirement to provide services to correct or ameliorate a problem detected by a screen, (2) the requirement to provide services for both physical and mental

⁷The Bureau of Labor Statistics (1993) surveys employer-based coverage for services such as mental health, dental and vision care, home health and hospice care, and found that in each instance benefits were available but limited.

⁸However, 24 percent of the 38 States failed to identify specific statutory requirements regarding the types of screens to be furnished, the periodicity schedules, or the responsibilities for anticipatory guidance and followup referrals.

Table 3
Trends in Specification of EPSDT Language Regarding
Diagnosis and Treatment in State Medicaid Managed Care Contracts: 1995 and 1996

EPSDT Diagnostic and Treatment Language	Percent of States Using Fully Capitated Plans	
	1995 (n=28) ¹	1996 (n=38) ¹
Specifies and Explains the EPSDT Benefit	96	100
Requires Services to Correct or Ameliorate	54	68
Requires Services for Physical and Mental Health Problems	46	76
Requires all Federally Allowable Diagnostic, Treatment, and Other Health Care Services	43	53
Incorporates Federal Law by Reference	64	84

¹ One State (Oregon) has been excluded from the analysis because it has a waiver to eliminate the EPSDT benefit.

NOTE: EPSDT is early and periodic screening, diagnosis, and treatment.

SOURCE: Information is based on an analysis of State general managed care contracts in effect in the spring of 1995 and the fall of 1996, performed by Fox Health Policy Consultants. Provider manuals, administrative rules, and other documents referenced in the contracts were included in the analysis.

health problems, and (3) the requirement to provide all federally allowable diagnostic, treatment, and other health care services for a problem identified by an EPSDT screen.

Of the remaining 23 States, 6 did not include in their contract any of the core elements of the EPSDT expanded benefit requirement, and 2 did not even make reference to Federal (or State) law pertaining to EPSDT. Thirteen of the States failed to specify that EPSDT allows for coverage "to correct or ameliorate" an identified problem. Nine did not specify that EPSDT encompasses coverage of mental as well as physical health problems, although five of these were States that carved out all mental health services. Further, 18 States failed to describe children's entitlement to all federally allowable Medicaid services, although 5 had very extensive carve-out policies for children's public program and other specialized services.⁹

Although EPSDT guidance can affect access to care by children with chronic or disabling conditions, a State's medical-necessity policy can have even more significance, because it establishes the circum-

stances under which a service is presumed to be covered. In 1996 about 80 percent (31) of the 39 States enrolling children in fully capitated plans included a medical-necessity definition in their contract, as shown in Table 4. Of these, 20 States required plans to follow a medical-necessity standard that included preventive, diagnostic, and treatment services for a condition or disability as well as an illness or injury. (The medical-necessity standard in three of these States was child-specific.) In three instances, however, the preventive focus was limited to cases in which the problem is significant, severe, or life-threatening. Also in four instances, qualifying criteria were included that could restrict coverage by directing plans either to use the least costly alternative treatment (three States) or to provide only services with evidence of effectiveness or proven medical value (three States).

Among the remaining 11 States with a medical-necessity definition that did not incorporate the prevention and treatment of conditions and disabilities, only 1 State offered a definition equivalent to a commercial standard, defining as medically necessary only those services that are required

⁹States were considered to have extensive carve-out policies if 6 or more of the 13 pediatric services we examined were excluded from their contract.

Table 4
Trends in Scope of Medical-Necessity Definitions in State
Medicaid Managed Care Contracts: 1995 and 1996

Medical-Necessity Definitions in Contracts	Percent of States Using Fully Capitated Plans	
	1995	1996
Presence of Medical-Necessity Definition	(n = 29)	(n = 39)
Yes	59	79
General	55	72
Child-Specific	3	8
No	41	21
Criteria Used in Definition	(n = 17)	(n = 31)
Includes Services for Preventive Purposes as Well as Diagnostic and Treatment Purpose	65	71
Includes Treatments for a "Condition," or "Disability" in Addition to an "Illness or Injury"	71	90
Qualifies Terms Such as "Disability," "Handicap," or "Pain" with "Severe" or "Significant"	24	13
Requires Conformance with Standards of Good Medical Practice	71	61
Requires the Most Appropriate Level of Services That Can Be Safely Provided	29	32
Requires the Least Costly Alternative Treatment Without Stipulating Equal or Reasonably Equal Effectiveness	29	19
Requires Evidence of Effectiveness or Proven Medical Value	12	16

SOURCE: Information is based on an analysis of State general managed care contracts in effect in the spring and the fall of 1996, performed by Fox Health Policy Consultants. Provider manuals, administrative rules, and other documents referenced in the contracts were included in the analysis.

to diagnose or treat an illness or injury.¹⁰ Three States, however, included qualifying criteria that restricted medically necessary services to those that were the least costly (three States), of proven effectiveness (two States), or required only for conditions that were severe or significant (one State).

Notwithstanding the many problems we identified in State guidance concerning EPSDT and medical necessity, a comparison to contracts in effect in the spring of 1995 shows that States have begun to make noticeable improvements in this area in just 18 months. By the fall of 1996, all States included in their contract a description of the EPSDT diagnostic and treatment benefit, whereas one State in 1995 had failed to explain EPSDT service requirements at all. Moreover by 1996 the number of States that provided contract language on EPSDT that is substantially similar to Federal law increased

from 32 to 39 percent. In particular, States became more likely to include language on mental health treatment in their descriptions of EPSDT.

Similarly States in 1996 were more likely to include a definition of medical necessity in their contracts in 1996. In 1995 almost 40 percent of State contracts were silent on the issue of medical necessity, but by 1996 the proportion dropped by one-half. Also in 1996 two additional States moved to establish a child-specific definition of medical necessity tailored specifically to the health, mental health, and developmental needs of children. Beyond this, however, trends in medical-necessity guidance were mixed. States were less likely to restrict treatment for a handicap or disability to situations where the condition is severe or significant. On the other hand, they were more likely to require that interventions show evidence of medical effectiveness or proven medical value in order to be considered medically necessary and also somewhat less likely to reference standards of good medical practice.

¹⁰Insurance companies and health plans have sought to keep their medical-necessity definitions vague and focused on services required for the treatment of an illness or injury (Bergthold, 1995).

DISCUSSION

States are proceeding cautiously with the enrollment of SSI and foster care children into fully capitated managed care plans, in contrast to the enrollment of children in AFDC and AFDC-related categories. Still, by the fall of 1996 more than one-third of the States using fully capitated plans did enroll SSI and foster care children, and nearly one-third of these States enrolled these children on a mandatory basis. Indeed, notwithstanding certain exemptions based on program eligibility or individual criteria, most children with disabling chronic conditions were included in States' fully capitated arrangements. Between the spring of 1995 and the fall of 1996, more categories of children were enrolled into fully capitated plans and more often on a mandatory basis.

Where Medicaid children are enrolled in fully capitated plans, they receive most of their preventive, primary, and chronic care services from the plan. In 1996 responsibility for many of the services of particular importance to children with disabilities—EPSDT expanded benefits, ancillary therapies, durable medical equipment, foster care services, private duty nursing, prescription drugs, and Title V services for children with special health needs—was left to the plans in about three-quarters of States. In fact personal care, early intervention, and health-related special education were the only specialized services for this population that were omitted from contracts and reimbursed separately in about one-half the States. Overall, between 1995 and 1996, States became more likely to exclude certain public program services and less likely to exclude other specialized services. On average States carved out about four Medicaid benefits for children in 1995 and 1996, irrespective of SSI and foster care enrollment policies.

Given the extent of pediatric services included in States' fully capitated contracts, the specification of the EPSDT benefit and the content of medical-necessity guidance in State contracts is of critical concern for children with disabilities. Our study found that all States provide managed care plans with at least some information about EPSDT and are particularly expansive regarding the preventive component of the benefit. Yet about 60 percent of States failed to specify EPSDT diagnostic and treatment services required in a manner that is consistent with Federal Medicaid law. Our study also found that medical necessity was defined in about 80 percent of States' contracts and usually in a somewhat more liberal manner than in the commercial sector. However, 35 percent of these States used a standard that did not require preventive, diagnostic, and treatment services for conditions and disabilities as well as accidents or injuries. In addition almost one-half as many States required evidence of medical effectiveness. Significant improvements occurred in 1996 with respect to EPSDT language, but there was more variability in the direction States were taking with respect to medical-necessity guidance.

Our results indicate that although States are proceeding cautiously with managed care enrollment of foster care children and SSI children, they are rapidly enrolling AFDC and AFDC-related children with little attention to the special service requirements of those with disabilities. Only a few States have exempted broad categories of children in these eligibility categories. One reason for this appears to be the common presumption that AFDC and AFDC-related children are generally healthy. Recent national data, however, suggest otherwise. An Urban Institute study found that between 11 and 16 percent of AFDC children have a disability

(Loprest and Acs, 1996). Another reason may be the difficulties that States face in identifying children with chronic or disabling conditions within the broader AFDC population. Unfortunately there is no widely accepted approach for defining or identifying children with disabilities in managed care organizations, leaving States without practical guidance or strategies about whether to use public program eligibility, diagnostic criteria, functional criteria, or some combination (Division of Services for Children with Special Health Care Needs, 1996).

Relying solely on SSI and foster care eligibility status as indicators for childhood disability is not only problematic for enrollment purposes but also for determining pediatric capitation rates that avoid adverse risk selection. A large number of SSI children, for example, are relatively inexpensive and mostly require basic preventive and primary care services. Yet, States have established SSI capitation rates that are in many instances at least twice the AFDC rate, with stop-loss protections typically set only for extreme outliers. Recent research based on Colorado's Medicaid claims data shows, however, that AFDC and SSI children had virtually the same distribution of expenditures (Kronick et al., 1996). Considering the prevalence of disability and the diversity of service needs among all Medicaid-eligible groups, States probably need to consider a broader strategy for identifying children with disabilities, obtaining reliable actuarial data, and setting appropriate risk-adjusted capitation rates.

State Medicaid agencies have been struggling with how to structure managed care contracts with respect to service and population carve-outs. Most States favor carving out specific services and not children, given that their long-term strategy is to enroll as many eligible children as possible into fully capitated managed care ar-

rangements. Service carve-outs, though relatively few in number, are common and have been designed in large part to protect public program services. States appear to be considering several factors—including the capacity of plans, continuity of care, pressure from public programs and their constituents, as well as existing agreements regarding Medicaid revenues (Fox et al., 1996). By maintaining certain service carve-outs, States are purchasing from general managed care plans the benefit package that they are best able to deliver, while at the same time ensuring that children have access to services that are not likely to be available or perceived as medically necessary in the commercial sector. Mental health, health-related special education, and early intervention services are the most common examples of this. In each case States recognize the difficulties in transferring the broad service responsibilities performed by these programs and in ensuring that their public program providers continue to obtain Medicaid reimbursement for their services. Still, by retaining these carve-outs—particularly for mental health services—the ability of plans and pediatric providers to integrate physical health, mental health, and developmental services for children may be compromised.

Considering the nature and extent of the health care problems presented by Medicaid-eligible children and the array of Medicaid benefits for which managed care plans are now responsible, contractual requirements concerning Medicaid services, particularly in the area of developmental, habilitative, and mental health interventions, have become critically important. Equally important is State guidance on how coverage decisions are made. Our survey findings reveal that States have made some improvements in defining Medicaid's EPSDT provision. This may be the result of increased awareness on the part of States

resulting from Health Care Financing Administration (HCFA) guidance on this subject (Office of Managed Care and Medicaid Bureau, 1996). Among those States that have not yet defined the EPSDT expanded benefit requirement, however, there is a significant potential for plans that have served privately insured children to reduce diagnostic and treatment services critical to children with disabilities.

Although more States are including medical-necessity definitions in their managed care contracts, some have begun to impose requirements for services to meet medical effectiveness criteria. Moreover, where States have been silent on the medical-necessity issue—there are eight such States—plans themselves are free to require that services be of proven effectiveness in order to be considered medically necessary. For children this requirement to prove effectiveness is particularly problematic, because little has been published about the effectiveness of many of the interventions required by children, particularly those with disabilities.

If States omit from their contract a particular benefit category, such as personal care services, the State's responsibility is clear. However, if States transfer to plans responsibility for a particular benefit, then families, providers, plans, and even the State presume that decisionmaking responsibility for that benefit rests with the plan. A State's residual responsibility for types or amounts of services denied may not become clear in the absence of legal procedures.

It appears inevitable that many Medicaid children with disabilities will continue to be enrolled in some form of capitated managed care in the next 5 to 10 years. How effectively this move takes place will depend on many factors, including how well States are able to identify and count Medicaid children with chronic or disabling condi-

tions, the specification of the EPSDT benefit and a medical-necessity standard for children, and the partnerships that can be formed between plans and the various public program providers that have historically served this population. This is a critical period for Medicaid children with disabilities, and a great deal is at stake in the transition to managed care. Unfortunately no comprehensive evaluation studies have been conducted on the effects of current managed care arrangements for this population. In addition few examples of special pediatric managed care arrangements exist. A much greater level of investment is urgently needed by both the public and private sectors in program design and implementation, quality performance measurement, Federal and State oversight, and evaluation.

ACKNOWLEDGMENT

The authors wish to thank Paul Newacheck of the Institute for Health Policy Studies, University of California, San Francisco, for providing helpful comments and suggestions on the manuscript and for preparing tabulations from the National Health Interview Survey.

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