

# **CMS' Medicaid Regulations: Implications for Children with Special Health Care Needs**

Sara Rosenbaum J.D.<sup>1</sup>

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## **Introduction**

The Centers for Medicare and Medicaid Services (CMS) is currently engaged in a policy initiative that should serve as a reminder of the power of a single federal administrative agency to change the course of national health policy. Through a virtual deluge of regulations and policy issuances, CMS has sought to redirect the course of Medicaid; in a number of respects, the course that CMS has sought to chart for the program is not only poorly thought out and ill-considered, but would actually propel the program in a direction directly contrary to both longstanding federal statutory provisions and recent decisions by Congress to reject precisely the same direction when presented by CMS as a statutory proposal.

Recent estimates show that these proposals would result in quantifiable federal Medicaid funding losses amounting to billions of dollars over the 2008-2013 time period.<sup>2</sup> Paradoxically, these losses would begin to take effect at precisely the time that Congress is considering a series of investments to provide an economic stimulus for hard hit states and localities. Thus, from a purely financial perspective, the policies that the regulations seek to advance rest on shaky grounds.

But what is perhaps most striking about the proposals is their effect on Medicaid's ability to carry out one of its most enduring and fundamental roles – the provision of high quality care to children and adults with serious and chronic health conditions, and in particular, children with special health care needs. Better health care for these children has been at the statutory heart of federal Medicaid law since 1967. Not once does CMS, in its regulations, assess the impact of its policies on this statutory imperative, or even its power -- in light of these statutory provisions -- to promulgate certain of its proposed policies, at least where children are concerned.

This seemingly total disregard for the terms of the underlying statute on the part of CMS would appear to have the most profound impact on health care and rehabilitation services for special needs children and the use of public health nursing in home and community settings (including the schools) as a Medicaid administration strategy. As is the case with health care for special needs children, the use of public health nursing in community settings has been a core Medicaid statutory strategy for four decades. Congress has repeatedly reaffirmed this set of statutory priorities, and as recently as

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<sup>1</sup> Harold and Jane Hirsh Professor of Health Law and Policy and Chair, Department of Health Policy, The George Washington University School of Public Health and Health Care Services

<sup>2</sup> Orris, A. & Solomon, J. (2008). Administration's Medicaid regulations will weaken coverage, harm states, and strain health care system. Washington, DC: Center on Budget and Policy Priorities. <http://www.cbpp.org/2-13-08health.htm> (Accessed Feb. 19, 2008)

2006, it rejected alterations in Medicaid's child health component that had been sought by CMS.

Furthermore, while the regulations pose a direct threat to programs and services for children of any age, and whose special needs arise from any cause, the most endangered group of children may be those who were born prematurely and at very low birthweight, and who may require both immediate and ongoing services throughout their lives as a means of achieving maximum rehabilitation from birth injury.<sup>3</sup> It is these children for whom public health nursing –in homes, schools, and communities -- has played an especially strong role in the history of federal and state Medicaid administration. It is in this context that CMS' effort to redefine what constitutes federally permissible Medicaid health care and program administration expenditures not only draws no support from the statute itself, but directly contravenes federal law in numerous respects. For this reason it is perhaps not surprising that not once does CMS explain in its regulations and guidance how its actions are justified under the EPSDT provisions of federal Medicaid law.

This policy brief focuses on CMS' regulatory changes in the context of health care and patient and family supports for children with special health care needs. For purposes of longstanding Medicaid policy, special needs children are defined not by their nominal family income, but by their diminished health status and a level of health care need that is substantial enough to threaten the economic stability of all but the wealthiest families. The brief then describes and examines the implications of recent CMS regulations and directives.

## **Who Are Special Needs Children and What Is the Role of Comprehensive Health Insurance?**

Depending on how their surveys are designed and administered, leading researchers estimate that between 13 and 18 percent of all children experience one or more special health care needs. The lower bound estimate uses a definition of special need that is tied to specific types of activity limitations.<sup>4</sup> The upper bound estimate uses the broader definition found in the Title V Maternal and Child Health Services Block Grant program for children with special health care needs (so renamed in 1981 from its former name, the crippled children's program). This broader definition of children with special health care needs (CSHCN) focuses on having a chronic physical, developmental, behavioral or emotional condition, as well as a need for health and related services of a type and amount beyond that required by children generally.<sup>5</sup>

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<sup>3</sup> Wang, C.J. (2008). Population-based assessments of ophthalmologic and audiologic follow-up in children with low birth weight enrolled in Medicaid: A quality of care study. *Pediatrics* 2(121), e278-e285.

<sup>4</sup> Van Dyke P., et. al. (2004). Prevalence and characteristics of children with special health care needs. *Arch. Ped. & Adol. Medicine* 158 (9), 884-891.

<sup>5</sup> Newacheck, P. et. al. (2000). Access to health care for children with special health care needs. *Pediatrics* 105(4), 760-769.

Regardless of the definition used, special needs prevalence estimates hold across all income groups. That is, the proportion of special needs children does not appear to decline as family income rises.<sup>6</sup> Similarly, rising family income reduces, but by no means eliminates, the likelihood that families of special needs children will report unmet needs for their children and access barriers.

Health insurance is essential for all children, but particularly so in the case of children with special needs. Among children with special needs, an analysis from the 1994-1995 National Health Interview Survey showed that nearly 30 percent (29.1 percent) of special needs children at that time relied on public insurance only and that another 3.5 percent relied on a combination of public and private health insurance.<sup>7</sup> Not surprisingly, reliance on public insurance was far higher among special needs children living in low income families. Even at higher family income levels, as shown in **Table 1**, approximately one in 11 special needs children rely on public health insurance.

**Table 1 Health Insurance Coverage Among Children with Special Health Care Needs**

Children	Health Insurance Status (%)				
	Any insurance	Private only	Public only	Public and private	No insurance
All children	88.8	56.2	29.1	3.5	11.2
<100% FPL	83.3	10.2	68.5	4.5	16.7
100%-199% FPL	81.9	49.7	28.3	3.9	18.1
200% FPL +	96.9	87.6	5.8	2.6	4.1

Source: Newacheck et. al.

Special need children studies also show that higher nominal family income may mitigate, but by no means eliminates, the risk for unmet needs and health care barriers, as shown in **Table 2**. Indeed, government research studies published by senior officials in the United States Department of Health and Human Services offer evidence of the limited relief that moderate family income actually provides when a child is a special needs child.

<sup>6</sup> Prevalence and characteristics, op. cit. Table 1.

<sup>7</sup> Access to care, op. cit. Table 1.

**Table 2. Unmet Health Needs Among Special Needs Children by Family Income**

Children by family income	Any unmet need for specific care services	Any unmet need for family support services	Child had no usual source of care	Child had no personal physician or nurse	Difficulty receiving referrals or specialty care	Lacks one or more satisfaction measures associated with family centered care
0-99	31.6	8.2	8.2	17.9	33.3	50.4
100-199	26.8	6.8	8.0	13.1	25.6	38.1
200-399	14.6	5.2	7.1	8.2	19.0	29.8
400+	8.6	2.8	6.4	8.1	18.2	25.3

Source: Van Dyke et. al.

Health insurance coverage makes an enormous difference for special needs children. Parents of insured special needs children are significantly less likely to report that their children are without a usual source of care, lack a regular clinician or after-hours coverage, or that they are dissatisfied with one or more aspects of their care.<sup>8</sup> Whereas 79.2 percent of parents of uninsured children with special needs report having a regular source of care, that figure rises to 97.6 percent and 95.3 percent, respectively, in the case of privately insured and publicly insured children.<sup>9</sup> Nearly one in five parents of uninsured children with special needs report delaying health care because of cost, while reported delays decline to 4.3 percent in the case of privately insured children and 3.5 percent in the case of publicly insured children.<sup>10</sup> Families at all income levels report barriers related to the cost of coverage (more than 74 percent of respondents) and inability to obtain coverage because of health problems (slightly more than one percent of respondents).<sup>11</sup>

Since these special needs studies were conducted, there are reasons to assume that the proportion of special needs children with private health insurance coverage has declined, given the general erosion in private health insurance coverage shown in **Figure 1**.

<sup>8</sup> Id. Table 2.

<sup>9</sup> Id.

<sup>10</sup> Id. Table 4.

<sup>11</sup> Id. 764

**Figure 1. Changes in Job Based Health Insurance and Medicaid 2000-2006**

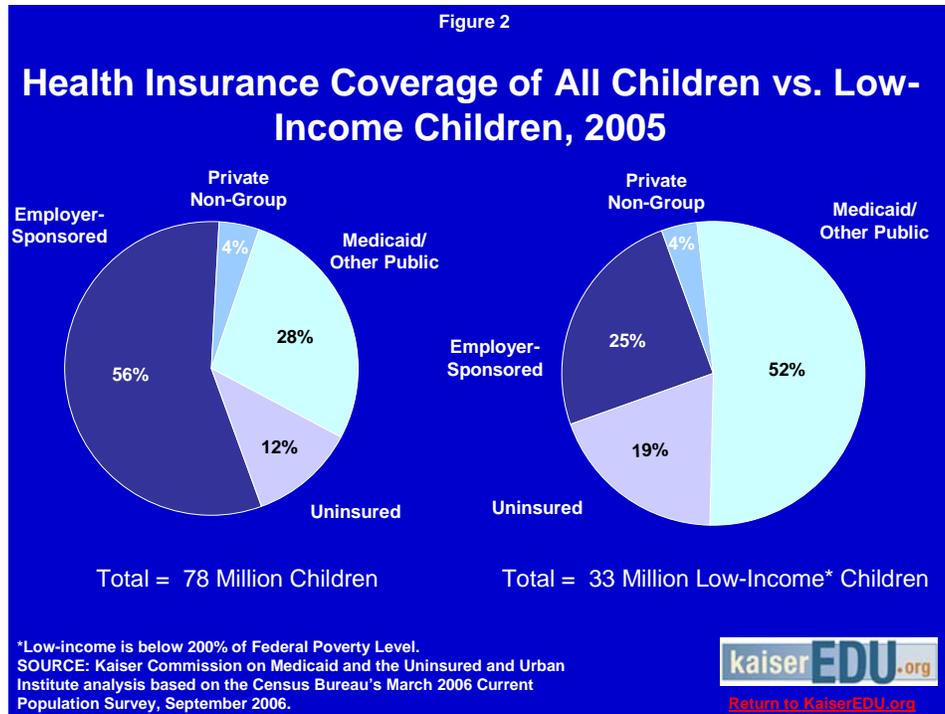
HEALTH INSURANCE COVERAGE

**Insurance Coverage**

	UNINSURED	MEDICAID	JOB BASED INSURANCE
2006	15.83%	12.90%	59.68%
2005	15.25%	12.97%	60.21%
2004	14.94%	13.04%	60.53%
2003	15.60%	12.37%	60.36%
2002	15.24%	11.63%	61.31%
2001	14.61%	11.20%	62.59%
2000	13.99%	10.35%	64.11%

Source: U.S. Census Bureau, Current Population Survey, 2006, 2005, 2004, 2003, 2002, 2001, 2000 Annual Social and Economic Supplements.

Indeed, as shown in **Figure 2**, as of 2005, 52 percent of all children with family incomes at or below twice the federal poverty level were enrolled in public health insurance, and only 25 percent had employer-sponsored coverage.



Taken together, these statistics underscore the high reliance among special needs children on public health insurance, either as a primary source of coverage or as a means of supplementing limited private health insurance benefits. The evidence also shows that even children from families with moderate incomes report cost-related barriers to private coverage as well as exclusion from the commercial health insurance market for health related reasons.

## How Medicaid and SCHIP Work to Promote Health Care for Special Needs Children

Medicaid and SCHIP work in three powerful ways to assist children with special needs. First, the programs make health insurance available to special needs children who, because of family income or health conditions, are either completely uninsured, or (in the case of Medicaid, which by law can “wrap around” or supplement private coverage) seriously under-insured in relation to their health care needs. Second, Medicaid and SCHIP – and particularly Medicaid – provide comprehensive health care coverage for potentially disabling conditions. Third, federal Medicaid law contains specific requirements whose purpose is to ensure that state Medicaid agencies not only pay for care, but provide administrative care management in concert with other public agencies (particularly state Title V maternal and child health agencies and schools), that will ensure that children actually get the care they need.

## Eligibility for Assistance

### *In general*

Much of what makes Medicaid and SCHIP such powerful funders of health care for special needs children is the result of their eligibility features that avoid many of the limitations found in commercial insurance plans. Unlike commercial insurance, Medicaid contains no waiting period for coverage (however, in the case of SCHIP, the anti-crowdout provision effectively can operate as a waiting period). Both Medicaid and SCHIP prohibit the imposition of preexisting condition exclusions once coverage begins. Furthermore, Medicaid regulations explicitly prohibit state agencies from discriminating on the basis of condition in the provision of required coverage. This non-discrimination clause effectively acts as a parity requirement, assuring that any limits on coverage will be based on need, not on arbitrary limitations tied to the nature of the child's condition.<sup>12</sup>

### *Financial eligibility*

In key ways, Medicaid and SCHIP allow states to finance health care for special needs children, regardless of whether such children live in low or moderate income families.

- The Family Opportunity Act, a bipartisan measure that was added to Medicaid as part of the Deficit Reduction Act of 2005, permits states to furnish coverage to children with serious disabilities who live in families with incomes up to 300 percent of the federal poverty level.<sup>13</sup>
- Both Medicaid and SCHIP permit states to structure the methods they will use to evaluate financial eligibility.<sup>14</sup> This statutory flexibility means that in evaluating family income, a state has the ability to create income deductions and disregards that take into account the considerably higher costs associated with caring for a child with special needs in the community. For example, a state might develop a budgeting methodology that takes into account the extra shelter costs that parents may incur when they must add special safety features to their homes; similarly, food costs may be much higher because of specific dietary requirements of their children and child care costs can be considerably higher. Thus, families whose nominal incomes may place them above a state's income eligibility threshold for Medicaid nonetheless may qualify for coverage once their incomes are adjusted to take these extraordinary needs into account. This adjustment is comparable to the special taxable income adjustments available under the Internal Revenue Code to families with high health related costs.

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<sup>12</sup> Rosenbaum, S. & Wise P. (2007). Crossing the Medicaid and private health insurance divide: the case of EPSDT. *Health Affairs* 26(2), 382-394.

<sup>13</sup> CMS, Roadmap for Medicaid Reform.

<http://www.cms.hhs.gov/NewFreedomInitiative/downloads/LTC%20Roadmap%20to%20Reform.pdf>  
(Accessed February 9, 2008).

<sup>14</sup> 42 U.S.C. §§1396a(r)(2) (Medicaid) and 1397 (SCHIP)

## Coverage and the Management of Children's Access to and Use of Health Care

Medicaid and SCHIP offer an approach to coverage that is unlike the level of coverage found under virtually any commercial health insurance plan. Indeed, it is this unique approach to what health care and support services will be considered covered and payable that makes Medicaid and SCHIP so singularly capable of assuring that special needs children have access to a broad range of treatments in community settings.<sup>15</sup> In the case of SCHIP, this breadth of coverage is a state option. In the case of Medicaid, however, broad pediatric coverage, as well as the management supports to assure health care access, are statutory requirements. This special set of laws is known as early and periodic screening diagnostic and treatment (EPSDT).<sup>16</sup>

### *The Special Coverage and Care Management Requirements of EPSDT*

EPSDT was added to both Medicaid and Title V in 1967. Eligible children were entitled to Medicaid from its original enactment in 1965, but the terms of coverage originally paralleled those used for adults. The 1967 amendments resulted in a new statutory vision of health care for children.

EPSDT was added by Congress and at the request of President Johnson in response to extensive evidence showing a high level of preventable physical, dental, and mental health conditions among low income children and adolescents, including both preschool children in early Head Start programs, young children served in the nation's first community health centers, and young military draftees.<sup>17</sup> The intent of the EPSDT amendments was to both assure access to health care and establish comprehensive coverage for all categorically needy children under age 21 (that is, children whose family incomes and assets make them eligible for Medicaid). The result is the broadest vision of pediatric health care ever articulated in health insurance, public or private.<sup>18</sup>

Congress amended the Social Security Act in 1972 and again in 1981 and 1989 to further expand and strengthen EPSDT.<sup>19</sup> Although the Deficit Reduction Act of 2005 gave states new authority to limit the scope of coverage, both Congress and the Administration reiterated that none of the amendments was intended to alter the provisions of EPSDT.<sup>20</sup>

### *EPSDT's benefit and coverage standards*

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<sup>15</sup> Crossing the Medicaid private insurance divide, op.,cit.

<sup>16</sup> Id.

<sup>17</sup> 42 U.S.C. §§1396d(a)(4)(B) and (r)

<sup>18</sup> Foltz, A. (1982). An ounce of prevention: Child health politics under Medicaid. Chicago: AAAS Press; Children's Defense Fund (1977). EPSDT: Does it Spell Health Care for Poor Children? Washington, D.C.: Children's Defense Fund; Rosenbaum, S., Mauery D.R., Shin, P., & Hidalgo, J. (2006). National Security and U.S. Child Health Policy: The Origins and Continuing Role of Medicaid and EPSDT. Washington, DC: GWU SPHHS. [http://www.gwumc.edu/sphhs/healthpolicy/new\\_publications.html](http://www.gwumc.edu/sphhs/healthpolicy/new_publications.html).

<sup>19</sup> Crossing the Medicaid private insurance divide, op. cit.

<sup>20</sup> Crossing the Medicaid private insurance divide, op. cit.

EPSDT is a required service for all categorically needy children enrolled in Medicaid from birth to age 21.<sup>21</sup> EPSDT benefits are preventive in the broadest possible sense. Thus, the emphasis in EPSDT is on the term “early,” which modifies each of the title’s other terms; in other words, the term “early” modifies “screening,” “diagnosis,” and “treatment.”<sup>22</sup> Not only must screens (i.e., health examinations) start early in life (beginning with the newborn exam) but diagnostic and treatment interventions also must be furnished “early.”

In order to assure that the goal of “early” is satisfied, EPSDT requires states to cover the broadest possible array of benefits, as shown in **Figure 3**. Furthermore, the legislation specifies a statutory *standard of medical necessity*, a feature of Medicaid that has no parallels in the case of adult coverage. This standard specifies that coverage must not only be early, but must be sufficient to “correct or ameliorate physical and mental illnesses and conditions discovered by the screening services.” The common sense definition of “ameliorate” is to “lessen the effects of,” meaning that even when conditions (whether beginning at birth or otherwise) cannot be cured, health care to lessen their effects must still be furnished. This unique coverage standard places Medicaid apart from commercial insurance, which typically limits not only the classes of benefits but also the extent to which payment for covered classes will be approved even in the absence of the potential for total correction.<sup>23</sup>

A relatively simple example serves to illustrate Medicaid’s power where special needs children are concerned. Most commercial insurance plans would reject speech therapy for a child born with hearing loss or physical therapy for a child born with cerebral palsy, because the therapy is necessary to *attain* the ability to speak or walk, not to *restore* previous speech or mobility. Medicaid, on the other hand, would cover both in accordance with a standard that assures intervention at the earliest sign of developmental delay and that continues throughout the child’s developmental years.

The EPSDT benefit contains none of the payment exclusions found in commercial insurance coverage, which routinely excludes otherwise covered services when they are furnished in child care, educational, or other settings that combine health care and educational and social services. Indeed, the statute expressly prohibits the Secretary from refusing to pay for any medical assistance service on the ground that it is specified in a child’s individual educational plan or individual family services plan under the Individuals with Disabilities Education Act (IDEA).<sup>24</sup> The reason for this prohibition against payment exclusion is obvious: if special needs children are to both receive the

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<sup>21</sup> The Deficit Reduction Act permits states that elect certain coverage flexibility options to end EPSDT coverage at age 19. However, the DRA does not alter any other aspect of EPSDT. See letter from Mark McClellan to Congressional Staff, December 19, 2005, and discussion in Crossing the Medicaid private insurance divide.

<sup>22</sup> Crossing the Medicaid private insurance divide, op. cit.

<sup>23</sup> Rosenbaum S. et. al.(2004). Public health insurance design for children: The evolution from Medicaid to SCHIP. *Journal of Health and Biomedical Law* 1, 1-46.

<sup>24</sup> 42 U.S.C. §1396b(c)

Medicaid services to which they are entitled and benefit from the educational mainstreaming required under the IDEA, then such a payment exclusion would directly undermine both the Medicaid and IDEA statutes.

### Figure 3. EPSDT Benefit Classes and Coverage Standard

<p><i>EPSDT coverage classes</i></p> <p>Periodic screening services that meet reasonable standards of medical practice</p> <p>Interperiodic (as needed) screening services</p> <p>Screens that consist of</p> <ul style="list-style-type: none"><li>• A comprehensive health and developmental history (including assessment of both physical and mental health development)</li><li>• A comprehensive unclothed physical exam</li><li>• Appropriate immunizations in accordance with standards of the CDC Advisory Committee on Immunization Practice (ACIP)</li><li>• Laboratory tests (including blood lead level assessment appropriate for age and risk factors)</li><li>• Health education, including anticipatory guidance</li></ul> <p>Periodic and interperiodic vision care, including professionally recommended exams, eyeglasses and diagnosis and treatment for defects in vision</p> <p>Periodic and interperiodic hearing care, including professionally recommended exams and diagnosis and treatment for defects in hearing, including hearing aids</p> <p>Periodic and interperiodic dental care to relieve pain and infection, restore teeth, and maintain dental health</p> <p>All classes of items and services that fall within the federal definition of medical assistance, regardless of whether the class of service or benefit is covered for adults</p> <p><i>The EPSDT Coverage standard</i></p> <p>Coverage must be early and must be sufficient to correct or ameliorate physical and mental conditions disclosed through a screen</p>
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Source: 42 U.S.C. §1396d(r)

#### *Assuring Access to Health Care and Coordination with Public Agencies*

Where EPSDT is concerned, the statute represents a particularly dramatic departure from treatment standards for adults because it requires that state Medicaid programs not merely pay for care *but assure that children actually receive care*. In carrying out this singular obligation, state Medicaid agencies must “inform eligible persons” about EPSDT, “provide or arrange for the provision of” screening services, and “arrang[e] for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment”<sup>25</sup> In other words, state Medicaid agencies must make sure that children receive care and that their care is *managed*.

<sup>25</sup> 42 U.S.C. §1396a(a)(43)

In order to carry out this management requirement, the statute specifically contemplates a strong program of public health nursing in community settings – homes, child care centers, schools, and neighborhoods -- as part of state Medicaid administration. Because Medicaid agencies operate much like health insurers rather than managers of care, federal law also requires that state agencies carry out their child treatment responsibilities through public agencies, including schools and other agencies, with particularly close ties specified in the case of state health agencies. Indeed, this link between state health and Title V agencies relates to the 1965 statute and the 1967 EPSDT amendments.<sup>26</sup> Specifically, the Medicaid statute provides that state Medicaid plans must

(A) Provide for entering into cooperative agreements with the state agencies responsible for or administering or supervising the administration of health services, (B) to the extent prescribed by the Secretary, provide for entering into agreements with any agency, institution, or organization receiving payments under (or through an allotment under) Title V (i) providing for utilizing such agency, institution or organization in furnishing care and services which are available under such title . . . and which are included in the State plan approved under this section; [and] (ii) making such provision as may be appropriate for reimbursing such agency, institution, or organization . . . for the cost of any such care and services furnished any individual for which payment would otherwise be made to the State with respect to such individual under section 1903.

In other words, the law specifies the use of Title V maternal and child health agencies in the provision of care and services covered under the state plan and for paying Title V agencies that furnish services to the extent that such payments are recognized as federally payable under federal Medicaid law. This obligation to use and pay state health agencies for care and services is not limited to care and services that fall within medical assistance classifications, but encompasses *any* care and services payable under section 1903. Thus, services that involve administrative management activities that further the child health obligations of Medicaid agencies would be payable under section 1903, either as medical assistance or administrative services.

The administration and coverage duties of Medicaid agencies can be summarized as follows:

- State agencies must pay for comprehensive assessments and early diagnosis and treatment for children beginning at birth and continuing to their 21<sup>st</sup> birthdays.
- States must make medical assistance payments in accordance with a coverage standard that emphasizes “early” care that will “ameliorate” (i.e., lessen) the effects of physical and mental health conditions disclosed through periodic or interperiodic assessments.

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<sup>26</sup> An ounce of prevention, op. cit.

- State agencies must assure that care is actually furnished, not merely financed, through the application of administrative procedures that inform families, provide and arrange for preventive care, and provide and arrange for diagnosis and treatment. Access activities include the cost of transporting children to services, whether those services are at clinics, in schools, or in other community settings. Indeed, the EPSDT access and transportation obligations entail access not only to medical assistance service providers but also to other services of importance to the health of children.<sup>27</sup>
- State agencies must use state health agencies and Title V agencies to carry out those responsibilities linked to providing or arranging for care and followup for children and must pay these agencies the reasonable cost of any care and services and activities for which federal financial assistance is available under federal law, which covers both administration and medical assistance activities.

Implementing federal regulations build on and reflect these statutory provisions and requirements:

- Interagency coordination rules reissued in 1979 specify that state Medicaid agencies must “describe cooperative arrangements with state health and Title V agencies that administer, or supervise, the administration of health services” and . . . “provide for arrangements with Title V agencies, under which the state Medicaid agency will utilize the grantee to furnish services that are included in the state plan” and “provide, if requested by the Title V grantee . . . that the Medicaid agency reimburse the grantee or the provider for the cost of services furnished recipients by or through the grantee.” The agreement must specify, among other matters, “methods for early identification of individuals under 21 in need of medical or remedial services,” “reciprocal referrals,” and “coordination plans for health services provided or arranged for recipients”<sup>28</sup>
- EPSDT regulations specify that state Medicaid agencies must “make appropriate use of state health agencies . . . and Title V grantees.”<sup>29</sup> Furthermore, the rules specify that “the agency should make use of other public health, mental health, and educational programs and related programs...”<sup>30</sup>
- In accordance with the interagency coordination requirements, state Medicaid agencies would be required to pay Title V agencies for the reasonable cost of EPSDT medical assistance and administration services furnished under the plan.

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<sup>27</sup> 42 C.F.R. §441.56(c) and 441.62

<sup>28</sup> 42 C.F.R. §431.615(c) and (d)

<sup>29</sup> Renamed children with special health care needs in 1981

<sup>30</sup> 42 C.F.R. §441.61(c)

## **How CMS' Regulatory Actions Undermine Federal Medicaid and SCHIP Laws That Provide for Health Care and Public Health Nursing for Children with Special Health Care Needs**

With this background it is now possible to consider several of CMS' recent regulatory actions and policy directives and their implications for special needs children.

### The August 17<sup>th</sup> SCHIP Directive and its Subsequent Application to State Medicaid Programs

On August 17, 2007, CMS issued a policy directive that establishes certain "anti-crowdout" policies applicable to state SCHIP programs.<sup>31</sup> These anti-crowdout policies, which appear to be applicable to both separately administered SCHIP programs and SCHIP plans administered as Medicaid expansions,<sup>32</sup> effectively prohibit states from using the income flexibility provisions of both statutes to recognize certain income disregards and adjustments for special needs children when evaluating family income. The policies prohibit coverage above an "effective level" (undefined) of 250 percent of the federal poverty level, unless states take certain steps to avoid health insurance crowdout, including proving that 95 percent of the poorest children are covered, establishing 12 month waiting periods, and assuring no loss in employer coverage levels. The directive is estimated to have a widespread impact on coverage.<sup>33</sup>

The August 17 guidance appears to establish obligations wholly unrelated to Medicaid and SCHIP, with particularly serious implications for special needs children:

- The Family Opportunity Act sets eligibility standards for children with severe disabilities at 300 percent of the federal poverty level. Furthermore, the Act makes no changes in states' discretion to adjust family incomes to take into account the extraordinary expenses incurred by families of special needs children
- Both the Medicaid and SCHIP statutes give states the broad flexibility to adjust family income to take into account the higher expenses of families with special needs children, even if their special needs do not rise to a full disability level. The directive, and its subsequent application to Medicaid expansion states, contains no explanation of how its terms square with this statutory income flexibility.

The Medicaid statute contains no anti-crowdout provisions at all; indeed, Medicaid allows children with private insurance to receive supplemental Medicaid wraparound coverage through its special third party recovery rules. Thus, in any Medicaid expansion SCHIP state, imposing a 12-month waiting period would be absolutely prohibited, and, in effect, would likely pose a clear and present danger for children with special needs. ;

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<sup>31</sup> <http://www.cms.hhs.gov/smdl/downloads/SHO081707.pdf> (August 17, 2007)

<sup>32</sup> See letter from Dennis Smith to State of Ohio, December 21, 2007.

<sup>33</sup> Mann, C. & Odeh, M. (2007). Moving backward: Status report on the impact of the August 17<sup>th</sup> SCHIP directive to impose new limits on states ability to cover uninsured children. Washington, DC: Georgetown Center on Children and Families. <http://ccf.georgetown.edu/pdfs/movingbackward1212.pdf>

- The data presented at the outset underscore the health care risks that flow from imposing coverage barriers of the type crafted by CMS in the case of special needs children: the lower likelihood of a regular source of health care; the greater likelihood that children will lack a regular clinician or after-hours coverage; the increased level of parental concern about one or more aspects of their children's care; and the greater likelihood that parents will be forced to delay health care because of cost or be unable to obtain private coverage because of cost or health problems.
- Under the provisions of the Employee Retirement Income Security Act of 1974 (ERISA) states do not have the legal power to mandate that employers offer health plans that contain dependent coverage. Thus, to deny federal Medicaid and SCHIP funding in states with declining employer coverage, unless states can demonstrate that levels of employer sponsored insurance for children are not declining, is not only a violation of ERISA but is wholly irrational as a matter of law. Nothing in either Medicaid or SCHIP gives states powers that are denied to them under ERISA. Ironically, the ability of small employers to continue to offer affordable group health plans may be affected by the extent to which the special needs children of workers can receive supplemental coverage for their special needs children.

### The "school" regulation

On December 28, 2007, CMS issued final regulations related to the use of schools by state Medicaid agencies.<sup>34</sup> Citing the need for "efficient" administration,<sup>35</sup> the regulations prohibit the use of schools to administer Medicaid:

Federal financial participation under Medicaid is not available for expenditures for administrative activities by school employee, school contractors, or anyone under the control of a public or private educational institution.<sup>36</sup>

The rule directly contravenes the statute in several respects:

- The regulation limits the power of state Medicaid agencies to administer their programs in recipients' best interests,<sup>37</sup> because it curtails the use of federal funds to involve schools in EPSDT administration, including informing and care management. In light of the relationship between children and schools, nothing is more "efficient" where Medicaid is concerned than closely aligning their EPSDT administration duties toward children with special needs with school operations. These children overwhelmingly receive special education and child care services in schools, are present in schools on a daily basis, and thus are in a position to be

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<sup>34</sup> 72 Fed. Reg. 73635

<sup>35</sup> 72 Fed. Reg. 73636

<sup>36</sup> 42 C.F.R. §433.20

<sup>37</sup> 42 U.S.C. §1396a(a)(19)

reached most efficiently in school settings. The final regulation dismisses the obvious on the grounds that assuring that children receive health care services is not an educational function. This is not the case. Under the Individuals with Disabilities Education Act (IDEA), it is the responsibility of schools to assure that all children receive a free and appropriate public education. It is the duty of Medicaid agencies to assure that these children receive the health care to which they are entitled.

- To the extent that schools contract with health agencies, including agencies and programs receiving Title V funding, to provide administration services in schools, the regulation directly contravenes federal laws requiring the use of health agencies and Title V agencies and grantees, as well as state agency payment, for all services furnished by such agencies, whether medical assistance or administrative in nature.

#### The rehabilitative services regulation

On August 13, 2007, CMS proposed to redefine the class of medical assistance known as “rehabilitative services”<sup>38</sup> to exclude services that are “intrinsic elements” of programs other than Medicaid, such as “foster care,” “child welfare,” or “education.”<sup>39</sup> This regulation raises numerous legal issues:

- In contravention of the Medicaid statute specifying payment of services identified in children’s educational or family development plans, the rule imposes a payment exclusion that is directly prohibited under federal law.
- Where the rehabilitation service is furnished by a Title V agency or grantee, the rule is directly contravened by the federal statute, which requires Medicaid agencies to pay Title V agencies and grantees for the reasonable cost of all covered care and services furnished.
- The regulation attempts to introduce precisely the type of “setting” exclusion that is common to commercial insurers and exists nowhere in Medicaid. The absence of such an exclusion is part of the broad fabric of the EPSDT statute, whose purposes is to assure access to the type of health care, at the earliest point in a child’s diagnosis, that is essential to the amelioration of physical and mental conditions.

The regulation violates the EPSDT statute in other ways:

- The regulation excludes “habilitation” from the meaning of rehabilitation. In excluding “habilitation” services from the meaning of rehabilitation services, the

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<sup>38</sup> 72 Fed. Reg. 45201. See generally Crowley, J. & O’ Malley M. 2007. Medicaid’s rehabilitation services option: Overview and current issues. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. <http://www.kff.org/medicaid/upload/7682.pdf> .

<sup>39</sup> 42 C.F.R. §441.45 (proposed)

regulation directly contravenes the EPSDT “amelioration” statute, which requires the provision of any class of service when needed to “ameliorate” a physical or mental condition, that is, limit its effects. *Where children with special needs are concerned, the statute does not distinguish between the rehabilitation of children whose health conditions developed subsequent to birth and those found to have health conditions at the time of birth. Indeed, experts in perinatal health use the term “rehabilitation” to describe the care and services furnished to infants born prematurely and at low birthweight.*<sup>40</sup> In either case, the duty imposed on states is to ameliorate those conditions through the provision of every class of service that falls within the statutory definition of medical assistance, including rehabilitative services.

### The targeted case management regulation

On December 4, 2007, CMS issued an interim final rule curtailing federal financial participation for “targeted case management.” The regulation was aimed at implementing the Deficit Reduction Act, which narrowed the definition of targeted case management under §1915(g) of the Social Security Act. The regulation prohibits states from claiming federal financial participation for administrative case management services.<sup>41</sup> The regulation also prohibit billing for case management services that are “integral to the administration of [a] non-medial program such as . . . child welfare or . . . special education.”<sup>42</sup>

- The regulation directly contravenes federal law, specifically the EPSDT statute, which requires the provision of administrative services to assure access to care.
- When furnished as a type of health care, targeted case management services are a recognized class of medical assistance to which children are entitled under EPSDT if their screens demonstrate a medical need for case management. Examples of such children might be a child with severe emotional disorders, a child with HIV or a child with cancer, who has a need for specially trained health professionals who can closely monitor their receipt of care and adjust their care plans as needed.
- The DRA made no changes whatsoever in states’ administrative obligations to manage the care of children receiving care financed through EPSDT. Access to care is an administrative obligation of all Medicaid programs under the statutory EPSDT access requirements. The EPSDT access statute mandates that state Medicaid agencies *manage health care of all children, special need or otherwise, as part of their EPSDT administration obligations*. Administrative case management, unlike medical assistance case management, is a general directive to help children -- special need or otherwise -- gain access to care. Administrative case managers obviously must be knowledgeable about child

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<sup>40</sup> Population Based Assessments, op. cit.

<sup>41</sup> 42 C F R §441.18 (b)(5)

<sup>42</sup> 42 C.F.R. §441.18 (b)(4)

health care and how to secure access to care, but need not be a specially trained health professional with subject area expertise in a particular health condition or set of conditions. Furthermore, EPSDT administration also includes transportation to covered services, and to the extent that covered services are available in schools as a companion to educational mainstreaming activities, these costs would also be permissible.

- For the same reason that the rehabilitation rule’s “intrinsic element” test violates federal Medicaid law, so does the exclusion of federal payment for covered case management services when they are an “integral part” of another public program. Child welfare case management is intended to assure the provision of child welfare services. Education case management services are intended to assure access to education service. Medicaid administrative case management, in contrast, is intended to assure access to covered EPSDT benefits, and payment for such benefits cannot be denied because they are part of IDEA services. Payment for EPSDT medical assistance and administrative services is required regardless of whether the child is *also* receiving child welfare or special education services. Indeed, EPSDT offers the means for financing medical care and access services for special needs children, regardless of whether they also are receiving additional supportive services in the areas of education and child welfare.

#### Regulations to restrict the definition of hospital outpatient services

On October 29, 2007, CMS proposed a new hospital outpatient rule that would redefine hospital outpatient services to parallel the Medicare definition:

- Medicare covers no children other than children with end stage renal disease (ESRD). The Medicare benefit package does not include EPSDT. To the extent that states have defined outpatient hospital services to include the special services offered by hospital outpatient departments to children (such as developmental therapies and interventions for children with physical or mental health conditions), the regulation directly contravenes the EPSDT statute in excluding federal financial participation in hospital outpatient care programs that furnish EPSDT diagnostic and treatment services that may have no counterpart in federal Medicare law.

#### Regulations that would shield CMS from challenges to the unlawful refusal to make federal payments that are legally required under the statute.

CMS’ regulatory efforts to curtail lawful state expenditures for children do not end with regulations that redefine benefit and service classes or place new restrictions on federal funding for statutory program administration options and mandates. On December 28, 2007, the Secretary and CMS jointly proposed regulations that, if implemented, would effectively render meaningless state appeals of denials of federal

financial participation by CMS.<sup>43</sup> Prior to seeking judicial review, the states appeal to the Departmental Appeals Board, the special administrative agency within HHS that, among other matters, reviews state appeals from CMS denials of federal financial participation. It is here that the administrative record, on which a subsequent judicial review will be based, is finalized.

One might wonder why, if judicial review is permitted, the Secretary would focus on the appeals process before the DAB. The answer is that under principles of administrative law, courts review rulings by the Secretary “on the record,” upholding, modifying, or overturning the Secretary’s decision on the record. To the extent that changes in the DAB standards and procedures allow the Secretary to alter the record presented for review, convincing a court to overturn the decision can become far more difficult unless the appellant can show an arbitrary or capricious disregard for facts or a legal misreading of the statute and regulations.

Given the breathtaking sweep of the regulations proposed by CMS, as well as a high volume of audit disallowances, it can be expected that many states would appeal these denials of what appear to be lawful claims for federal financial participation. Because state health care expenditures for special needs children raise issues related to coverage definitions, coverage exclusions, and recognition of legitimate administrative expenditures, persons concerned with special needs children should be exceedingly concerned about the proposed rules:

- The proposed rule would permit the Secretary – for the first time—to overturn or remand board decisions. On remand, the Secretary could “instruct the [Board] in the proper application of statutes, regulations, or interpretive policy,” In other words, the Secretary could unilaterally, and outside of the normal review process, tell the board what the law means, thereby depriving the Board of its independent authority to interpret statutes, regulations, and policies.
- The proposed rule would require the Board to follow HHS guidance and policy (including potentially unpublished and even unwritten “policy”) “to the extent not consistent with statute or regulation.”<sup>44</sup> Furthermore, the Secretary’s interpretation would be “binding” on the Board.<sup>45</sup> In the unlikely event that the Board nonetheless continued to depart from the Secretary’s interpretation, the Secretary presumably could continue to reverse or remand the Board’s decision (no limits are placed on the Secretary’s intervention in Board decisions) until the Board got it right, so to speak.
- The Secretary’s power to review and reverse Board decisions would not be bounded by any timelines or procedures, nor would this review be part of the administrative record so that a court could review the propriety of the Secretary’s intervention.

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<sup>43</sup> 72 Fed. Reg. 73716

<sup>44</sup> 42 C.F.R. §423.1085(c)

<sup>45</sup> Id.

It is hard to conclude that the proposed rule represents anything other than an intention on the part of the Department and CMS to shield the Department against state agency challenges to the potentially unlawful denial of federal financial participation in Medicaid. Indeed, the issuing agencies for this rule were *both* the Secretary and CMS, suggesting insulation of CMS against reversal of Medicaid disallowances by the DAB played a major role in the timing and nature of the DAB rule.

It is difficult to overstate the chilling effects of the DAB rule when read in combination with the substantive Medicaid changes outlined in this policy brief, as well as equally controversial CMS regulations that revise standards for federal payments toward expenditures by public health care providers and for graduate medical education. These two sets of changes can be expected to significantly affect the operation of public health agencies and public hospitals, as well as teaching programs, including the teaching programs of public and children's hospitals that treat large numbers of special need children.<sup>46</sup>

## Conclusion

Despite decades of commitment to children with special health care needs and a federal statute that specifies the provision of comprehensive medical care and administrative supports, while prohibiting the type of payment exclusions typically found in commercial insurance policies, the Centers for Medicare and Medicaid Services has engaged in a wholesale rewrite of the law. Its directives on eligibility would seriously impair the ability of states to assure that special need children in moderate income families can receive Medicaid or SCHIP. Its efforts to reinvent the meaning of statutory definitions would result in the unlawful denial of payment for covered services. Its exclusion of schools as a source of administrative support for children receiving health care would deprive Medicaid agencies of one of the most *efficient* methods for carrying out their health care access duties. The agency's case management rule would cut off all federal funds for the conduct of administrative duties related to health care access for Medicaid enrolled children. And the Department's DAB rule is no less than a blatant attempt to control the appeals process and shield CMS from challenges.

Because special needs children are particularly dependent on Medicaid, they stand to be hurt the most by these rulings. It is also clear that the rulings are meant to be interactive and cumulative. For example, the school regulation effectively eliminates schools as a means of achieving EPSDT administration, while the rehabilitation and case management "intrinsic" exclusions serve to exclude payment for medical assistance services furnished in schools to special education students, even though CMS claims that its school regulations, considered separately, would not affect the direct provision of medical care. Thus, although Congress has placed a moratorium on the implementation of the school regulation, it is evident that the only effective means of protecting the most

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<sup>46</sup> For a discussion of these regulations see Rudowitz, R. (2008). Medicaid: overview and impact of new regulations. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. <http://www.kff.org/medicaid/upload/7739.pdf>

vulnerable children and adults is a broader moratorium that effectively preserves pre-regulation Medicaid policies while allowing time for a more considered approach to encouraging payment and administrative efficiencies in Medicaid.