

**OPTIONAL PURCHASING SPECIFICATIONS:  
MEDICAID MANAGED CARE FOR  
CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

**A TECHNICAL ASSISTANCE DOCUMENT  
(August, 2000)**

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*This document, "Optional Purchasing Specifications: Medicaid Managed Care for Children with Special Health Care Needs," was prepared by the George Washington University Center for Health Services Research and Policy (CHSRP) in consultation with officials from Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), Health Care Financing Administration (HCFA),<sup>1</sup> Office of the Assistant Secretary for Planning and Evaluation (ASPE), and the Department of Education (DOE). The March of Dimes Birth Defects Foundation also provided technical and financial assistance in the review of this document.*

*This technical assistance document should be viewed as a tool to assist state officials in purchasing services from managed care organizations (MCOs) on behalf of children with special health care needs under age 21 who are eligible for Medicaid.*

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<sup>1</sup> On October 5, 1998, HCFA transmitted a guidance to State Medicaid Directors entitled "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs," [www.hcfa.gov/medicaid/smd-snpf.htm](http://www.hcfa.gov/medicaid/smd-snpf.htm). This guidance has a number of potential uses for interested states. One is to "tailor purchasing specifications and delivery systems contracts to create value-based systems of care." These sample purchasing specifications are consistent with the purchasing approach articulated in the HCFA guidance.

In addition, HCFA is using "Draft Interim Review Criteria for Children with Special Needs," (June 4, 1999) for Medicaid programs that are applying for new or renewing existing §1915(b) managed care waivers. A recent GAO analysis of the Interim Criteria concluded that the criteria "were grouped into 11 categories of safeguards, including identification of children with special health care needs, provider capacity, access to specialists, and quality of care. However, there are no accompanying standards, guidelines, or definitions. For example, the capacity safeguard requires 'experienced' providers, but provides no guidance to identify a sufficient experience level. The criteria also do not address how best to apply safeguards in light of the multiple and divergent requirements of children with special needs. Moreover, the interim criteria do not refer states to any supporting documents, such as HCFA's previous efforts related to special needs populations. This situation suggests that review of the interim criteria alone may not be sufficient to guide in developing an adequate response." General Accounting Office, Medicaid Managed Care: Challenges In Implementing Safeguards for Children with Special Needs (March 2000) GAO/HEHS-00-37, p. 27, [www.gao.gov](http://www.gao.gov)

*While the document's primary focus is on Medicaid and its beneficiaries, much of the illustrative language may also be useful to other state purchasers as well as to large employers and other private purchasers of managed care products.*

***These sample purchasing specifications are optional, and do not necessarily reflect the views of HRSA, SAMHSA, HCFA, ASPE, or DOE.***

*There are a variety of perspectives on the enrollment of children with special health care needs (CSHCN) in managed care. Some states and MCOs believe that managed care is an appropriate, cost-effective vehicle for delivering services to this population. Some providers and some children's advocates have concerns about the ability of managed care models to deliver necessary services to children with special health care needs. This document is designed to be used by state purchasers, as well as MCOs, providers, and child advocates, to assist in the design of managed care contracting arrangements that offer accessible and quality services to this population.*

*There are two basic approaches that states may take in purchasing Medicaid services from MCOs on behalf of eligible children with special health care needs. They may enroll these children in MCOs that serve children and adults without disabilities as well as those with special needs, or they may enroll these children in MCOs that serve only children or adults with disabilities. Research by Fox and McManus<sup>2</sup> and Regenstein and Schroer<sup>3</sup> indicates that, in the states that enroll persons with disabilities (children or non-elderly adults) into managed care, most of these individuals are enrolling or being enrolled into MCOs (or PCCMs) that serve non-disabled populations as well. The most recent available data (from the summer of 1998) indicates that only 5 of the 36 state Medicaid agencies that enroll persons with disabilities in managed care operate programs exclusively for persons with disabilities (D.C., Indiana, Michigan, Ohio, and Wisconsin). Accordingly, these purchasing specifications are designed to be integrated into contracts, purchasing agreements, RFPs, and similar documents that cover populations with and without individuals with special health care needs*

### ***Process for Developing This Technical Assistance Document***

*Since 1995, CHSRP has conducted an intensive examination of contracts between state Medicaid agencies and MCOs. This analytic work has produced three editions of a comprehensive study of contract provisions. The most recent version is the five-volume document, Rosenbaum, et al., Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts (3<sup>rd</sup> Ed. 1999), [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp). The study breaks down the contracts into a series of analytic tables. While there is no table specific*

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<sup>2</sup> Harriette Fox and Margaret McManus, Maternal and Child Health Policy Research Center, Medicaid Managed Care for Children with Chronic or Disabling Conditions: Improved Strategies for States and Plans, July 1996.

<sup>3</sup> Marsha Regenstein and Christy Schroer, Economic and Social Research Institute, Medicaid Managed Care for Persons with Disabilities: State Profiles, Kaiser Commission on Medicaid and the Uninsured, December 1998, <http://www.kff.org/content/archive/2114/>.

to children with special health care needs, a number of the tables contain provisions that address issues specific to this population (see Tables 1.1, 1.4, 2.1, 2.4, 2.8, and 4.1).

*Negotiating the New Health System* is a part of a broader analytic studies and technical assistance project on managed care contracts financed by numerous funders, including HRSA, Centers for Disease Control and Prevention (CDC), SAMHSA, the David and Lucile Packard Foundation, and the Commonwealth Fund. Original funding for this project was supported by the Pew Charitable Trusts and the Annie E. Casey Foundation. The development of optional specifications for purchasing managed care products constitutes one component under this project.

CHSRP has developed sample purchasing specifications for the purchase of Medicaid services from MCOs on behalf of all eligible children. The Medicaid Pediatric Purchasing Specifications are divided into an Overview of Contractor's Duties and 14 accompanying Parts, which elaborate on issues that are generic to all children, ranging from benefits to provider network to data collection and reporting. The format of the CSHCN purchasing specifications parallels that of the Medicaid pediatric purchasing specifications. This parallel structure is intended to enable reviewers to focus on the issues specific to children with special health care needs in the context of the Medicaid specifications. Specific cross-references to the Medicaid specifications are cited as "MEDICAIDSPECS."

The process for developing the CSHCN purchasing specifications began with guidance from a Federal Working Group made up of representatives from HRSA and MCHB, SAMHSA, ASPE, HCFA, and the Department of Education. The draft specifications were reviewed by the working group and through a series of vetting meetings involving state Medicaid and public health officials, providers, MCO representatives, consumers, and experts and advocates in the service delivery of health care for children with special health care needs. The changes suggested at these vetting meetings have been incorporated into the specifications and have been reviewed by representatives from these meetings. The specifications are also available at [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).

### **Organization and Structure of This Technical Assistance Document**

This document is divided into two Parts. Part 1 sets forth the covered services for children with special health care needs. The benefit package from the Medicaid specifications is the main benefit package for this population. Part 1 also includes suggested language relating to care coordination services, including the development and implementation of a care plan and the services furnished by a care coordinator. Finally, Part 1 includes specifications regarding coverage determination standards and procedures as they affect children with special health care needs.

Part 2 of this document contains illustrative language relating to the delivery of services to children with special health care needs. This includes specifications on enrollment, provider selection, provider network, access standards, data, and enrolled

*child safeguards. Part 2 also contains illustrative language regarding memoranda of understanding between contractor and public agencies with specific programmatic responsibilities toward children with special health care needs in §206. In some cases, such as the state MCH agencies, §206 simply cross-references the applicable language in the Medicaid purchasing specifications. In other cases, such as the state education or Part C lead agency, §206 sets forth suggested language.*

*In addition to the sample purchasing specifications, this document, like the Medicaid Pediatric Purchasing Specifications, contains sample contract compliance measures. CHSRP's reviews of state Medicaid contracts with MCOs "have consistently observed an absence of clear and articulated measures for reviewing the extent to which contractors are in compliance with performance specifications, as well as a failure to specify the data that contractors will be expected to submit to demonstrate their compliance." Rosenbaum et al., Negotiating the New Health System, Special Report: Mental Illness and Addiction Disorder Treatment and Prevention, GW Center for Health Policy Research, March 1998, p.56. The compliance measures in these purchasing specifications have been drafted to assist interested purchasers in specifying data and articulating measures for reviewing the extent of compliance by contractors with their duties under the purchasing agreement.*

### ***How to Use This Technical Assistance Document***

*The illustrative language in this document is drafted to minimize ambiguity and maximize clarity. In its summary of a June, 1999 symposium on Medicaid managed care and children with special health care needs, the National Academy for State Health Policy reports that "MCO representatives caution states that they must be absolutely clear in the contract as to what the MCO's responsibilities are and that they cannot hold MCOs accountable for what is not in the contract."<sup>4</sup> The more clearly an MCO understands what is expected of it by the purchaser, and the more clearly a purchaser understands what the MCO is obligating itself to provide, the more likely it is that any agreement between the two parties will be carried out to the mutual satisfaction of each and to the benefit of the enrolled children with special health care needs.*

*The drafting format used in these sample specifications is as follows:*

- *Each Part is divided into sections, identified by "§".*
- *Each section, in turn, is divided into one or more subsections: "(a)", "(b)", etc.*
- *A subsection may be divided into one or more paragraphs: "(1)", "(2)",*

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<sup>4</sup> D. Curtis, N. Kaye, and T. Riley, *Transitioning to Medicaid Managed Care: Children with Special Health Care Needs* (October 1999), National Academy for State Health Policy, [www.nashp.org](http://www.nashp.org).

*etc.*

- *A paragraph may be divided into one or more subparagraphs: “(A)”, “(B)”, etc.*
- *A subparagraph may be divided into one or more clauses: “(i)”, “(ii)”, etc.*

*Every state purchaser has its own drafting format. The particular format used in these sample specifications is NOT intended as a substitute for each state’s own format. Instead, it is intended simply to divide each suggested provision into the smallest practicable policy elements. This division and subdivision format is designed to enable a user to identify quickly the policy choices contained in each provision and to identify which, if any, of the elements the user wishes to adopt. This format also serves as a detailed checklist for those users who wish to compare portions of their current purchasing documents with the relevant portions of these sample specifications.*

*For example, assume a state purchaser uses the following contract language relating to reporting of complaints and grievances:*

**“8.01** The HEALTH PLAN shall provide the STATE upon the STATE’s request in the format determined by the STATE and for the time frame indicated by the STATE, the following information...  
i.) Summaries of all written complaints received by the HEALTH PLAN under this contract...”

*Assume further that this purchaser is interested in expanding Medicaid managed care enrollment to include children with special health care needs. If this purchaser were to find that potential contractors are seeking greater specificity regarding reporting requirements in order to better evaluate the administrative burden that they would be undertaking if they enrolled such children, the purchaser could refer to §208 (data collection and reporting) of these specifications for guidance.*

*Finally, assume that this purchaser is particularly interested in monitoring the satisfaction level of the families of enrolled children with special health care needs. In this case, the purchaser could use §208(b)(5) of these specifications:*

**“§208. Data Collection and Reporting ...**

**(b) Data Specific to Children with Special Health Care Needs —**  
Contractor shall collect and report to Purchaser, on a [ ] basis, in such form and manner as Purchaser specifies, the following data (to the extent that such data are not required under applicable provisions of **Part 9** of MEDICAIDSPECS:...

(5) the number and percentage of families or caregivers of enrolled children with special health care needs who are dissatisfied with the

accessibility or quality of the services specified in the child's care plan under §105, grouped by zip code of residence within Contractor's service area;..."

*In order to include this policy in its contract, the purchaser could, without modifying its current format, adapt the illustrative language as follows (italicized):*

**“8.01** The HEALTH PLAN shall provide the STATE upon the STATE's request in the format determined by the STATE and for the time frame indicated by the STATE, the following information...

i.) Summaries of all written complaints received by the HEALTH PLAN under this contract...

ii.) *the number of families or caregivers of enrolled children with special health care needs from whom the HEALTH PLAN has received a written complaint regarding the accessibility or quality of the services specified in the child's care plan, grouped by zip code of residence within the HEALTH PLAN's service area.*”

### ***Related CHSRP Activities***

*CHSRP has developed optional specifications for the purchase of Medicaid services from MCOs on behalf of all Medicaid-eligible children, whether or not they have special health care needs, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).<sup>5</sup> The optional specifications set forth in this document for children with special health care needs are designed to complement CHSRP's general Medicaid Pediatric Purchasing Specifications. Where appropriate, these optional specifications include cross-references to the general Medicaid Pediatric Purchasing Specifications, which are cited as “MEDICAIDSPECS.”*

*In addition, CHSRP is developing a number of sample purchasing specifications that overlap with this document. These include specifications with respect to:*

- *children with behavioral health needs;*
- *child development services (August 2000);*
- *children in foster care;*
- *individuals who are homeless (June 2000);*
- *access standards (July 2000);*
- *cultural competence standards; and*
- *data and information collection and reporting.*

*As these specifications are completed, they will be posted on CHSRP's website, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).*

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<sup>5</sup> CHSRP has also developed a set of sample purchasing specifications for use by State Children's Health Insurance Program (SCHIP) agencies that parallel the Medicaid pediatric purchasing specifications. SAMHSA's Center for Substance Abuse Treatment has conducted Team-Building Workshops on coverage of behavioral health benefits in SCHIP plans.

## ***Issues Not Addressed in This Technical Assistance Document***

*These specifications do not address issues relating to cultural competence. CHSRP is developing sample purchasing specifications with respect to this critical set of issues. When these specifications are completed, they will be posted on the CHSRP website, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp), for the benefit of interested state purchasers and other potential users.*

*These specifications do not address two types of payment issues: (1) the determination of capitation rates paid to MCOs by state purchasers on behalf of enrolled children with special health care needs; and (2) payment methodologies used by MCOs with respect to network and out-of-network providers. Part 3 reviews these issues in some detail and suggests other sources of information for interested purchasers. However, Part 3 does not contain illustrative language on either of these issues. It is anticipated that such language will be developed in the future. For language used by state purchasers relating to these issues, see CHSRP's *Negotiating the New Health System*, 3<sup>rd</sup> Ed. (1999), Vol. 2, Part 4, Table 7.1 (payment to plans) and Table 7.2, (plan payment to providers), [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).*

*As in the case of the Medicaid Pediatric Purchasing Specifications, these specifications do not specify any procedural time frames. Instead, a bracket ([ ]) is supplied as a placeholder, indicating that the state purchaser should insert a timeframe of its choosing.*

*The Balanced Budget Act of 1997, P.L. 105-33 (BBA), made a number of changes in the managed care provisions of the federal Medicaid statute. HCFA has issued two proposed rules to implement these BBA changes: a notice of proposed rulemaking (NPRM) relating to Medicaid requirements for MCOs, 63 Fed. Reg. 52022, (September 29, 1998), and an NPRM relating to the annual, external independent review of the timeliness, access, and quality of Medicaid MCO services, 64 Fed. Reg. 67223 (December 1, 1999). These purchasing specifications are consistent with the available interpretations of the BBA provisions as reflected in HCFA's letters to state Medicaid directors and in HCFA's revised Preprint Renewal Submittal for a section 1915(b) Waiver (September 23, 1999), [www.hcfa.gov/medicaid](http://www.hcfa.gov/medicaid). However, these specifications are not, and should not be viewed as, an official interpretation of the BBA or of HCFA's policy guidances.*

*As discussed in footnote 1, HCFA has issued, in draft form, "Interim Review Criteria for Children with Special Needs" (Draft, June 4, 1999). The "Interim Review Criteria" are being used by HCFA to review state proposals to enroll children with special health care needs into managed care plans on a mandatory basis under the terms of section 1915(b) waivers. Policies in the "Interim Review Criteria" are incorporated into these purchasing specifications at various points, including the definition of child with special health care needs and requirements relating to care plans. The National Academy for State Health Policy conducted a study of children with special health care needs in Medicaid managed care. The study's purpose was to investigate*

*current state practices in the delivery of care to children with special health care needs and to determine how they relate to Congressional and HCFA policies for protecting such children in Medicaid managed care. The "Interim Review Criteria" form the framework for this report.<sup>6</sup>*

*Because HCFA interpretations of the 1997 BBA amendments are still under development, and because states are continuing to explore different approaches to the coverage of children with special health care needs through managed care, these specifications must necessarily be considered a work in process. As HCFA regulations and administrative guidance are issued in final form, and as definitive experience is gained by state agencies and managed care plans, these purchasing specifications will be revised accordingly.*

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<sup>6</sup> See Kaye et al., Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria, National Academy for State Health Policy (June 2000), <http://www.hcfa.gov/medicaid/needsrpt.pdf>.



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## Part 1. Services for Children with Special Health Care Needs

### §101. In General

### §102. Identification of Children with Special Health Care Needs

### §103. Scope of Benefit

### §104. Care Coordination Services

### §105. Care Plan

### §106. Guidelines

### §107. Coverage Determination Standards and Procedures

### §108. Definitions

### §101. In General

*Commentary: There is no single definition of children with special health care needs that is commonly accepted. Definitions vary among states that enroll this population in Medicaid managed care as well as within states (e.g., definitions used by a state Title V agency may vary from that used by the same state's Medicaid agency). A recent GAO report gives the following example of this variation: "...children in Michigan must meet the Title V definition of special needs, while those in Oregon must receive SSI or be in foster care." General Accounting Office, Medicaid Managed Care: Challenges in Implementing Safeguards for Children with Special Needs (March 2000), GAO/HEHS-00-37, footnote 8, p. 8, [www.gao.gov](http://www.gao.gov). For a review of the definitions of children with special health care needs used by 6 states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico), see Tables 3 and 4, pp 17-33, of Kaye et al., Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria, National Academy for State Health Policy, (June 2000) <http://www.hcfa.gov/medicaid/needsrpt.pdf>.*

*For purposes of this document, children with special health care needs are defined in §108(c) as "children under 21 who have a chronic physical, developmental, or behavioral condition, and require health and related services of a type or amount beyond that which is required by children generally." This language is drawn from the definition in McPherson et al., "A New Definition of Children with Special Health Care Needs," Pediatrics (July 1998) p. 137, which was endorsed in a work group convened by MCHB and AMCHP in October, 1998 and by the American Academy of Pediatrics (AAP). Using this definition, a recent analysis estimates that 18% of U.S. children under 18 years old had an existing special health care need in 1994-5. Newacheck, et al., "Access to Health Care for Children with Special Health Care Needs," Pediatrics (April 2000) p. 760-766, [www.pediatrics.org](http://www.pediatrics.org).*

*For pediatrics, the standard of care for children with special health care needs is that of a "medical home" – an approach to providing care that is accessible,*

*family-centered, comprehensive, continuous, coordinated, compassionate, and culturally competent. A detailed explanation of this concept may be found in AAP, Managed Care and Children with Special Needs: Medical Home Checklist (1998), <http://www.aap.org/advocacy/medhome/resourcesmedhomechecklist.htm>. The purpose of the purchasing specification is to translate the concept of a medical home into an enforceable set of contractual duties that interested purchasers may wish to use in developing purchasing agreements with managed care organizations that serve children with special health care needs. This translation occurs at two levels: that of the Contractor, and that of the individual provider. **Part 1** speaks to the Contractor's duties to operate in a manner consistent with the medical home approach; **§204A** addresses the duties of individual network providers to furnish a medical home to such children in their practices.*

(a) **Duty to Provide a Medical Home** — Contractor shall, for each enrolled child with special health care needs (as defined in **§108(c)**) identified under subsection (b), comply with the requirements of:

- (1) subsection (c) (relating to Contractor's Basic Service Duties);
- (2) subsection (d) (relating to Family Participation); and
- (3) **Part 2** (relating to Service Delivery Duties).

(b) **Duty to Identify Enrolled Children with Special Health Care Needs** — Contractor, and each provider participating in Contractor's provider network, shall comply with the requirements of **§102** relating to identification of enrolled children with special health care needs.

(c) **Basic Service Duties**<sup>7</sup> — For each enrolled child with special health care needs (as defined in **§108(c)**), Contractor shall:

- (1) cover and furnish, or arrange for the furnishing of, the items and services enumerated under **§103(a)** in manner consistent with the coverage determination standards and procedures under **§107**;
- (2) comply with the access standards specified in **§205**;
- (3) comply with the child health guidelines enumerated in **§106**,<sup>8</sup> including guidelines relating to continuity of care;

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<sup>7</sup> This duty is derived from Ad Hoc Task Force on Definition of the Medical Home, AAP, "The Medical Home," 90 *Pediatrics* No. 5 (November 1992), p. 774. For additional information, see AAP's Medical Home Program for Children with Special Needs (MHPCSN) at [www.aap.org/advocacy/medhome.htm](http://www.aap.org/advocacy/medhome.htm).

<sup>8</sup> An alternative option would be to delete paragraph (3) and any reference to child health guidelines. Under this option, the contractor would have a duty only to furnish covered services in accordance with specified coverage determination standards and procedures.

(4) under **§105**, develop a care plan for the child and furnish items and services, including care coordination services, to the child as specified in the plan;

(5) ensure that the child's primary care provider complies with the requirements relating to providing a medical home under **§204A**;

(6) comply with the requirements of **§206** regarding relationships with other agencies; and

(7) comply with requirements of **§208** relating to data collection and reporting.

**(d) Family Participation**

(1) **In General** — Contractor, and each provider participating in Contractor's provider network, shall facilitate the participation of the family or caregiver of an enrolled child with special health care needs (as defined in **§108(c)**) in:

(A) the identification of the child as a child with special health care needs under **§102**;

(B) the identification and selection of providers, consistent with **§203**, who can provide continuity of care for the child; and

(C) the development, implementation, and review and update of a care plan for the child described in **§105**.

(2) **Responsibility of Care Coordinator to Family** — Contractor shall ensure that a care coordinator selected or assigned (under **§104(b)**) to an enrolled child with special health care needs (as defined in **§108(c)**) shall comply with the requirements of:

(A) **§104(d)(1)** (relating to learning about the child's diagnosis and treatment needs and the needs of the family or caregiver in supporting the child);

(B) **§104(d)(2)** (relating to informing about the contents of the care plan developed under **§105**);

(C) **§104(d)(3)** (relating to assisting in accessing items and services that are duty of Contractor);

(D) **§104(d)(4)** and **(5)** (relating to assisting in accessing and identifying payment sources for items and services that are not duty of Contractor);

(E) **§104(d)(10)** (relating to tracking the child's progress under the child's care plan under **§105** and recommending any updates or revisions to such plans based on the experience of the child and the child's family or caregiver);

(F) **§104(d)(12)** (relating to accessing, under **§209(c)**, Contractor's grievance procedures and the state fair hearing process);

(G) **§104(d)(13)** (relating to assisting in documenting, establishing, and maintaining the child's eligibility for public program benefits); and

(H) **§104(d)(14)** (relating to informing about participation in voluntary networks of families or caregivers and in the Family Advisory Board).

*Commentary: The following illustrative language would require Contractor to establish and maintain a Family Advisory Board internal to the Contractor. Another option would be for the state to establish and maintain such a Board to advise its Medicaid or other purchasing agency as well as the MCOs with which the state agency contracts. This option is not reflected in these purchasing specifications because it can not be implemented through language in a contract between the state agency and the MCO. Instead, such Board would have to be established under state law or regulation, or through administrative action by the sponsoring agency. For a summary of ongoing advisory committees used by 6 states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico), see Table 21, pp. 158-162, of Kaye et al., Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria, National Academy for State Health Policy (June 2000), <http://www.hcfa.gov/medicaid/needsrpt.pdf>.*

**(3) Family Advisory Board** — Contractor shall establish and maintain a Family Advisory Board that:

(A) consists of up to [ ] individuals who are parents or caregivers of an enrolled child with special health care needs (as defined in **§108(c)**) and who volunteer to participate as members of the Board;

(B) meets as needed (but no less frequently than [ ]) to:



- (i) discuss concerns of families or caregivers of enrolled children with special health care needs;
- (ii) review the results of any enrollee satisfaction surveys conducted by Contractor under §207(c)(5);
- (iii) review any data collected and reported to Purchaser under §208(b);
- (iv) review the disposition by Contractor under §209 of grievances and appeals filed by families or caregivers of children with special health care needs; and
- (v) review Contractor's enrollee information materials under §202; and

(C) has an opportunity on a [ ] basis to meet with Contractor's Chief Executive Officer and [drafter insert reference to Contractor's Medical Director and other appropriate officials] to advise the CEO [and other officials] on matters of concern to the Board.

## **§102. Identification of Children with Special Health Care Needs**

*Commentary: These purchasing specifications assume that the MCO with which Purchaser is contracting enrolls a general population of children and families, not just children with special health care needs. In order to trigger any duties Purchaser may wish to impose on Contractor with respect to those enrolled children with special health care needs, Contractor must know whether a particular enrolled child has special health care needs. Often a child's disability is itself the basis for the child's categorical eligibility for Medicaid; for example, most states automatically extend Medicaid eligibility to children who qualify for Supplemental Security Income (SSI) payments based on disability.<sup>9</sup> In addition, a child's eligibility category may be an indicator of special health care needs (e.g., children receiving foster care payments under Title IV-E). In these cases, the state Medicaid agency (or another state or local agency) is likely to know the child's special needs status. In other cases, however, the basis for the child's Medicaid eligibility does not reflect the child's special needs.*

*The illustrative language in the following section is intended to assist purchasers in designing approaches to identifying these children from among the general*

<sup>9</sup> For a discussion of Medicaid eligibility rules for children with special health care needs, see Schneider et al., Medicaid Eligibility for Individuals with Disabilities (May 2000), <http://www.kff.org/content/1999/2150/>.

population of enrolled children. For a review of the sources of information used by 4 states (Colorado, Delaware, Massachusetts, and Michigan) to identify children with special health care needs, see Table 6, pp. 44-52 of Kaye et al., *Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria*, National Academy for State Health Policy, (June 2000) <http://www.hcfa.gov/medicaid/needsrpt.pdf>.

To facilitate the exchange of information regarding the identity of children with special health care needs, Purchasers may wish to consider establishing interagency agreements or other arrangements with state Title V children with special health care needs programs, state mental health agencies, state or local education agencies and Part C lead agencies that have programmatic responsibilities for children with disabilities, developmental delays, and special health care needs. Purchasers could transmit such information to Contractors at the time of enrollment of a Medicaid-eligible child with special health care needs. Of course, the exchange and transmission of such information is subject to confidentiality and informed consent requirements applicable under state or federal law. For references to applicable federal rules, see §209(d) and (e).

**(a) Duty of Purchaser to Assist in Identification of Children with Special Health Care Needs<sup>10</sup>**

(1) **Purchaser Information** — Purchaser shall make available to Contractor on a [ ] basis the name and Medicaid eligibility number of each enrolled child whom Purchaser has identified from [drafter insert reference to Purchaser's Medicaid information system] as a child with special health care needs (as defined in §108(c)).

(2) **Information from Other State Agencies<sup>11</sup>** — Purchaser shall make available to Contractor on a [ ] basis the name and Medicaid eligibility number of each enrolled child with respect to whom the [drafter insert name of State Title V Agency, State Child Welfare Agency, or other appropriate state agency] (with the prior written consent of the child's family or caregiver) have notified Purchaser that the child is:

(A) receiving services under an IEP (as defined in §108(f)) or an IFSP (as defined in §108(g));

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<sup>10</sup> HCFA's "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs" (October 1998), [www.hcfa.gov/medicaid/smd-snpf.htm](http://www.hcfa.gov/medicaid/smd-snpf.htm), provides that states should consider "[d]eveloping mechanisms to use a 'health needs assessment' process or other process (such as review of past Medicaid claims data) to identify existing or undiagnosed medical conditions."

<sup>11</sup> For an analysis of MCO contracts involving children under the jurisdiction of state child welfare agencies, see Wehr, et al., *Managing Child Welfare: An Analysis of Contracts for Child Welfare Service Systems* (1999), GW CHSRP, [www.samhsa.gov](http://www.samhsa.gov).

(B) receiving services under a plan for the child under §504 of the Rehabilitation Act of 1973, 29 U.S.C. §794, 45 C.F.R. §84.33 or 34 C.F.R. §104.33; or

(C) receiving services under [*drafter insert reference to state or local program for children with special health care needs*].

*Commentary: HCFA's "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "The State identifies and/or requires MCOs/PHPs to identify children with special needs." (p.1-2). HCFA's draft criteria do not specify an instrument for the identification. However, there are a number of tools Purchaser may wish to consider for use in identifying children with special health care needs. The following illustrative language assumes that such a tool would be administered by Contractor. There are other approaches to identifying children with special health care needs, including reliance upon an enrollment broker to perform this function; Purchasers interested in this option would address the issue in their contracts with the enrollment broker.*

*A number of screening tools are available or under development. One tool is the Living with Illness Screening Tool developed by the Child and Adolescent Health Measurement Initiative (CAHMI) of the Foundation for Accountability (FACCT), [www.facct.org](http://www.facct.org). Another tool is QuICCC (Questionnaire for Identifying Children with Chronic Conditions), containing 39 questions for the family or caregiver (or the 19-question version of this instrument, called QuICCC-R); see R.E. Stein et al., "The Questionnaire for Identifying Children with Chronic Conditions: A Measure Based on a Noncategorical Approach," Pediatrics (April 1997), pp. 513-521. The National Association of Children's Hospitals and Related Institutions (NACHRI), in conjunction with 3M, has developed a classification system using Clinical Risk Groups (CRGs); see Muldoon et al, "Profiling Health Service Needs of Populations Using Diagnosis-based Classification Systems," Journal of Ambulatory Care Management (1997), 20, pp. 1-18.*

## **(b) Identification of Children with Special Health Care Needs**

(1) **Newborns** — Contractor shall comply with the following requirements in the case of a newborn child whose mother is enrolled in Contractor:

(A) **Newborns with Congenital Anomalies**<sup>12</sup> — In the case of a newborn child with a congenital anomaly that is identified prior to the child's birth or is apparent to the child's treating physician at birth, Contractor shall:

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<sup>12</sup>For more information on the National Birth Defects Prevention Network (NBDPN) recent report on "Birth Defect Surveillance Data from Selected States 1989-1996," see Teratology 61:86-158 (2000). This review collected data from 29 state birth defect surveillance programs for 47 specific birth defects.

(i) ensure that a physician designated by Contractor<sup>13</sup> conducts an initial assessment (as defined in paragraph (5)) within [ ] days of the child's birth; and

(ii) if, as a result of the initial assessment conducted under clause (i), the physician is able to make a determination that the newborn is an enrolled child with special health care needs (as defined in §108(c)), Contractor shall:

(I) comply with the requirements of §105 relating to the development of a care plan with respect to the newborn child; and

(II) refer the newborn child to [*drafter insert reference to appropriate Part C Lead Agency under the IDEA, 20 U.S.C. §1400 et seq.*] for a developmental assessment.

**(B) Newborns with No Apparent Anomalies** — In the case of a newborn child who is not described in subparagraph (A) and who is an enrolled child, the requirements of paragraph (3) relating to newly enrolled children without an IFSP or an IEP shall apply to Contractor and the providers participating in Contractor's provider network.

(C) If a newborn child described in subparagraph (A) is determined not to be a child with special health care needs, Contractor shall comply with the requirements of paragraph (6) (relating to second opinions).

## **(2) Newly Enrolled Children with IFSP or IEP**

(A) If, at the time of enrollment of a child with special health care needs, Contractor or a provider participating in Contractor's provider network knows that the child is receiving services under an IFSP (as defined in §108(g)) or an IEP (as defined in §108(f)), Contractor shall comply with the requirements of §105(b) relating to the development of a care plan by the child's primary care provider.

(B) The requirements of subparagraph (A) shall apply whether or not a care plan has been developed for the newly enrolled child

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<sup>13</sup> Depending upon the time frame selected and the child's course of treatment, this could be a hospital staff physician or the child's primary care provider under §203.

prior to the child's enrollment through another managed care organization.

**(3) Newly Enrolled Children without IFSP or IEP** — In the case of a newly enrolled child who is not described in paragraph (2), and in the case of a newborn who is described in paragraph (1)(B):

(A) Contractor shall conduct an initial assessment (as defined in paragraph (5)) within [ ] days of the child's enrollment;

(B) if, as a result of the initial assessment conducted under subparagraph (A), the primary care provider is able to make a determination that the child is a child with special health care needs (as defined in §108(c)), Contractor shall comply with the requirements of §105 relating to the development of a care plan;

(C) if, subsequent to the initial assessment conducted under subparagraph (A), the primary care provider determines that additional diagnostic procedures covered under §103(a) are necessary to enable the provider to make a determination that the child is a child with special health care needs, Contractor shall furnish or arrange for the furnishing of such diagnostic procedures within [ ] days of the initial assessment, unless the child's family or caregiver does not give written consent prior to such diagnostic procedures;

(D) if, as the result of additional diagnostic procedures under subparagraph (C), the child is determined to be a child with special health care needs, Contractor shall:

(i) comply with the requirements of §105 relating to the development and implementation of a care plan;<sup>14</sup> and

(ii) consistent with §104(d)(7), ensure that the child's primary care provider or care coordinator refers the child to [drafter insert reference to responsible agencies under Part B and Part C of the IDEA, 20 U.S.C. §1400 et seq.], as appropriate, for the development of an IFSP (as defined in §108(g)) or IEP (as defined in §108(f)); and

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<sup>14</sup> Note that under §105(b)(4), the Contractor's duty to develop a care plan includes the duty to refer a child to the responsible agencies under Parts B and C of the Individuals with Disabilities Education Act, 20 U.S.C. §1400 et seq. The public agencies responsible for the development of IFSPs must hold the first meeting with the child and the family within 45 days of receiving a referral, 34 C.F.R. §303.321(e).

(E) if, as the result of additional diagnostic procedures under subparagraph (C), the child is determined not to be a child with special health care needs, Contractor shall comply with the requirements of paragraph (6) (relating to second opinions).

(4) **Other Enrolled Children** — In the case of an enrolled child who has not been identified by Contractor as a child with special health care needs under paragraphs (1), (2), or (3), Contractor shall comply with the requirements of §105 relating to the development and implementation of a care plan if:

(A) a provider participating in Contractor’s provider network has determined, on the basis of an encounter with the child, that the child is a child with special health care needs;

(B) the child, or the child’s family or caregiver, has identified the child as having a chronic physical, developmental, or behavioral condition and a provider participating in Contractor’s provider network has determined that the child is a child with special health care needs; or

(C) the child has been identified as a child with special health care needs under paragraph (6) (relating to second opinions).

(5) **Initial Assessment Defined** — An initial assessment is an encounter between an enrolled child and a primary care provider participating in Contractor’s provider network at which the provider administers [*drafter insert specification for encounter form*] appropriate to the age of the child. The initial assessment may be conducted by a provider participating in Contractor’s provider network during an EPSDT screening encounter described in §102(b)(1) of MEDICAIDSPECS.

(6) **Second Opinion** — If in the case of a child described in paragraphs (1), (3), or (4), the child is determined not to be a child with special health care needs (as defined in §108(c)), Contractor shall:

(A) offer the family or caregiver of the child an opportunity for a second opinion from a pediatric specialist (as defined in §108(j)):

(i) participating in Contractor’s provider network selected by the family or caregiver; or

(ii) if no pediatric specialist participating in Contractor's provider network is qualified to make the determination with respect to the child, from pediatric specialist selected

by the child's family or caregiver and the child's primary care provider under §203(b);

(B) pay for the services of the pediatric specialist selected under subparagraph (A) (and any diagnostic procedures ordered by the specialist in connection with the second opinion); and

(C) ensure that if, in the opinion of the specialist, the child is a child with special health care needs, the initial determination and the second opinion are reviewed by Contractor's Medical Director and, within [ ] of the second opinion, the Medical Director makes a final determination as to whether Contractor has a duty to the child under paragraph (3)(D) relating to the development and implementation of a care plan.

(6) **Inquiries into Existence of Disability** — In carrying out its duties to identify children with special health care needs under this subsection, Contractor shall comply with the requirements of §209(b) relating to unnecessary inquiries into the existence of a disability.

### §103. Scope of Benefit

*Commentary: It is common for states to “carve out” from their general Medicaid MCO contracts some of the services that children with special health care needs require. For example, a CHSRP review of 54 state contracts found three different types of Medicaid coverage for behavioral health services: (1) direct coverage (on a fee-for-service basis) under the state Medicaid plan; (2) coverage through a general service agreement with an MCO; and (3) coverage through a managed behavioral health carve-out agreement. Rosenbaum et al., Negotiating the New Health System, Special Report: Mental Illness and Addiction Disorder Treatment and Prevention, GW Center for Health Policy Research, March 1998, p. 27.*

*Under current law, states may elect not to contract with MCOs for the full range of services to which beneficiaries are entitled under their state Medicaid plans. Instead, they may contract with an MCO for the provision of some services and “carve out” others. These “carve out” services, in turn, may be covered on a fee-for-service basis or through a risk contract with another MCO, or both. For example, in 1997 about two-thirds of the states excluded mental health services, dental services, and health-related services from their contracts with Medicaid MCOs. Ruth Almeida and Harriette Fox, 1997 State Medicaid Managed Care Policies Affecting Children, Maternal and Child Health Policy Research Center (March 1998), p. 6. Accordingly, the following illustrative language assumes that a state purchaser elects to “carve out” some services of importance to children with special health care needs from the purchasing agreement and to cover those services either directly under its state plan or through another contractor.*

(a) **Covered Items and Services** — Contractor shall furnish, or arrange for the furnishing of, to each enrolled child with special health care needs (as defined in §108(c)) who is eligible for benefits under [drafter insert reference to state Medicaid program]:

(1) the items and services<sup>15</sup> enumerated in **Part 1** of “MEDICAIDSPECS”; and

(2) care coordination services described in §104.

**(b) Items and Services for Which Purchaser Remains Responsible**

(1) **Items and Services Covered by Purchaser** — Contractor has no duty under [drafter insert name of purchasing document] to furnish, or arrange for the furnishing of, the following items and services:

(A) [drafter insert list of items and services covered under state Medicaid plan (or, in the case of EPSDT services, eligible for federal matching payments) but excluded from coverage under this purchasing agreement];

(2) **Duty of Contractor** — Contractor shall notify an enrolled child with special health care needs (as defined in §108(c)) (and the child’s family or caregiver) regarding the items and services described in paragraph (1) by complying with the requirements of:

(A) §202(b)(1) and (b)(2) relating to provision of information to enrolled children with special health care needs; and

(B) §104(d)(3) relating to the responsibilities of the child’s care coordinator to assist the child in accessing items and services specified in the child’s care plan that are described in paragraph (1).

**§104. Care Coordination Services**

*Commentary: The following illustrative language assumes that the Purchaser wishes to provide care coordination services to children with special health care needs through the contracting MCOs in which they are enrolled. It should be noted that states are not required to offer care coordination services to Medicaid*

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<sup>15</sup> Among the items and services to which Medicaid-eligible children are entitled is the EPSDT benefit, which contains coverage of particular importance to CSHCN. See National Health Law Program, *Medicaid Managed Care and Children with Special Needs: An EPSDT Checklist*, <http://www.nhelp.org/pubs/mc1997checklist-epsdt.html>.

For additional information on the Medicaid benefits package, see Schneider and Garfield, *Medicaid Benefits* (July 2000) Kaiser Commission on Medicaid and the Uninsured, [www.kff.org](http://www.kff.org).



*beneficiaries generally or to this population in particular, and some states do not cover these services for this population. In addition, not all MCOs are organized to provide care coordination services to children with special health care needs or other enrolled populations through separate care coordinators; instead, they rely upon the treating physician to perform care coordination functions. Finally, if a state Medicaid program elects to cover care coordination services for this population, it may also elect to "carve out" such services from its purchasing agreements with MCOs and provide them on a fee-for-service basis through the state Title V agency or other state or local agencies, or through private organizations. For a review of the care coordination models used by Colorado, Delaware, New Mexico, Oregon, and Washington, see Rosenbach and Young, Care Coordination in Medicaid Managed Care: A Primer for States, Managed Care Organizations, Providers, and Advocates (March 2000) [www.chcs.org](http://www.chcs.org).*

*The federal Medicaid statute and implementing regulations do not contain a "care coordination services" category. Thus, it is not possible to state with certainty that the care coordination services set forth in the following illustrative language would qualify for federal Medicaid matching funds. That determination can be made only by HCFA. HCFA's published guidance on coverage of case management services is set forth in State Medicaid Manual at §4302<sup>16</sup>, [www.hcfa.gov/pubforms/pub45pdf/smm4t.htm](http://www.hcfa.gov/pubforms/pub45pdf/smm4t.htm).*

(a) **In General** — Contractor shall comply with the requirements of this section relating to:

- (1) assignment or selection of a care coordinator (as defined in §108(b)) under subsection (b); and
- (2) the duties of the care coordinator (as defined in §108(b)) under subsection (d).

*Commentary: The following illustrative language assumes that the family or caregiver of an enrolled child with special health care needs has the option of refusing to accept a care coordinator for the child. It also assumes that the family or caregiver has the option of declining to accept the particular care coordinator that Contractor wishes to assign to the child. The language would not, however,*

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<sup>16</sup>HCFA's State Medicaid Manual §4302.2H explains that when case management services are found to be medically necessary, states have several options: (1) EPSDT: "Case management services may be provided to persons participating in the EPSDT program by an existing service provider such as a physician or clinic referring the child to a specialist; (2) Administrative Case Management: "Case management services may be provided to EPSDT participants by the Medicaid agency or another state agency, such as Title V, the Health Department, or an entity with which the Medicaid agency has an interagency agreement." and (3) Targeted Case Management Services: "The service must meet the statutory definition of case management services as defined in §1915(g)" (e.g., "services which will assist individuals eligible under the plan in gaining access to needed medical, social, educational, and other services"), [www.hcfa.gov/pubforms/pub45pdf/smm4t.htm](http://www.hcfa.gov/pubforms/pub45pdf/smm4t.htm).

*require Contractor to hire or subcontract with any particular care coordinator in order to meet the wishes of the family or caregiver. The family or caregiver's choice would be limited to those care coordinators (including a primary care provider, if the family or caregiver so chooses) available within Contractor's provider network under §204.*

## **(b) Assignment or Selection of Care Coordinator**

### **(1) In General**

(A) Contractor shall, within [ ] days of the date described in paragraph (5), notify in writing the family or caregiver of an enrolled child with special health care needs (as defined in §108(c)) of the identity of the care coordinator that Contractor proposes to assign to the child to furnish care coordination services under subsection (d).

(B) This paragraph shall not be construed to require Contractor to assign to a child a care coordinator who does not participate in Contractor's provider network under §204(e) or with whom Contractor does not have an out-of-network arrangement under §204(f).

**(2) Option to Receive Care Coordination Services from Primary Care Provider<sup>17</sup>** — Contractor shall allow the family or caregiver of an enrolled child with special health care needs to select as the child's care coordinator a primary care provider participating in Contractor's provider network who is willing to assume the responsibilities enumerated under subsection (d) with respect to the child.

**(3) Option to Receive Care Coordination Services from Care Coordinator** — Contractor shall allow the family or caregiver of an enrolled child with special health care needs to receive care coordination services from a care coordinator (as defined in §108(b)) other than a primary care provider if the care coordinator is selected by the child's primary care provider in consultation with the child's family or caregiver.

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<sup>17</sup> This policy is based upon the following principles from the AAP's managed care policy statement: "The primary care pediatric health professionals should assume the role of the care coordinator (i.e., the physician who assures that all referrals are medically necessary). The function of the PCP might be transferred to a pediatric medical subspecialist for certain children with complex physical and/or mental health problems (e.g., those with special health care needs such as children with cystic fibrosis, juvenile rheumatoid arthritis) if the specialist assumes responsibility and financial risk for primary and specialty care. For certain physical, developmental, mental health, and social problems, the PCP may seek the assistance of a multidisciplinary team with participation by appropriate public programs (e.g., Title V program for children with special health care needs)." See "Care Coordination: Integrating Health and Related Systems of Care for Children with Special Health Care Needs," 104 *Pediatrics* No. 4 (October 1999), p. 978-981.

(4) **Option to Refuse a Care Coordinator** — Contractor shall not assign an enrolled child with special health care needs to a care coordinator (as defined in §108(b)) unless the child’s family or caregiver (or, in the case of an adolescent, the adolescent):

(A) agrees in writing to receive care coordination services under this section from a care coordinator; and

(B) has selected a care coordinator under paragraph (2) or consulted with a primary care provider under paragraph (3).

(5) **Date** — The date described in this paragraph is the earlier of:

(A) the effective date of enrollment of the child; or

(B) the date on which the enrolled child has been identified as a child with special health care needs (as defined in §108(c)) by a provider participating in Contractor's provider network (whether or not such provider is the child’s primary care provider).

(6) **Responsibilities of Care Coordinator** — If a care coordinator has been selected by or assigned to an enrolled child or the child’s family or caregiver under paragraphs (2) and (3), Contractor shall ensure that the care coordinator carries out the duties required under subsection (d).

**(c) Use of State Title V CSHCN Program Personnel**

(1) **Option** — Contractor may meet the requirements of subsection (b) through the use of care coordinators (as defined under §108(b)) affiliated with [drafter insert name of State Title V CSHCN Agency].

(2) **Written Agreement** — If Contractor elects to use care coordinators under paragraph (1), Contractor shall enter into a written agreement with [drafter insert name of State Title V CSHCN Agency] under §206(b)(3).

*Commentary: The experiences of families of children with special health care needs enrolled in an MCO under a Medicaid demonstration project has enabled evaluators to identify certain issues relating to care coordinators. Discussions with parent focus groups found that “virtually none of the parents knew where or to whom they may file a complaint. Most parents said they would talk to their care manager if they had a problem.” In addition, “Few parents recalled having completed a Plan of Treatment for their child, and the majority said they had never seen or heard of a Plan of Treatment. Of the few parents who were familiar with it, most said they had been asked by their care managers to sign the document, but with no explanation of its contents. Some parents added that the Plan of Treatment was not updated frequently enough, and thus was seldom a*

*reflection of their child's current needs." Abt Associates, Evaluation of the District of Columbia's Demonstration Program, "Managed Care System for Disabled and Special Needs Children," Second Annual Report (December 18, 1998), Submitted to Office of Strategic Planning, Health Care Financing Administration. The following illustrative language addresses these and other matters.*

(d) **Responsibilities of Care Coordinator**<sup>18</sup>— Contractor shall ensure that, in the case of an enrolled child with special health care needs (as defined under **§108(c)**) who has selected a care coordinator under subsection (a), the care coordinator, consistent with **§107(b)** relating to utilization management, shall:

(1) make every effort to meet with the family or caregiver of the child, in person or by telephone, within [ ] days of being assigned, in order to learn about the child's diagnosis and treatment needs and the needs of the family or caregiver in supporting the child;

(2) assist:

(A) the primary care provider in developing the child's care plan under **§105(b)(1)(D)**; and

(B) the child (and the child's family or caregiver) in understanding the contents of the plan;

(3) assist the child in accessing items and services specified in the child's care plan under **§105** that are:

(A) the duty of Contractor under **§103(a)**; and

(B) required under each of the following plans (if any) that has been developed for the child:

(i) an IFSP (as defined in **§108(g)**);

(ii) an IEP (as defined in **§108(f)**);

(iii) a plan developed for the child by [*drafter insert name of state child welfare agency*]; and

(iv) [*drafter insert references to other applicable treatment plans*];

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<sup>18</sup> HCFA's "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "The State has required the MCOs/PHPs to provide case management services to children with special needs" (p. 3).

(4) if requested by the child (or, except in the case of an adolescent, the child's family or caregiver), assist the child, in manner consistent with **§209(d)** (relating to confidentiality protections), in accessing items and services that are specified in the child's care plan under **§105** and are the responsibility of Purchaser under **§103(b)**;

*Commentary: The illustrative language in paragraph (5) assumes that the MCO's care coordinator has the responsibility for assisting an enrolled child's family or caregiver in having payment made for services covered under a state's Medicaid program that are not the duty of the MCO. Another approach would be for the family or caregiver to be referred to appropriate state or local agencies.*

(5) if requested by the child (or, except in the case of an adolescent, the child's family or caregiver), assist the child, in manner consistent with **§209(d)** (relating to confidentiality protections), in accessing and identifying payment sources for items and services that are specified in the child's care plan under **§105** and not the responsibility of Contractor under **§103(a)** or Purchaser under **§103(b)**;

(6) consistent with **§203(f)**, assist the child in accessing pediatric specialists (as defined in **§108(j)**) and other providers participating in Contractor's provider network that are identified in the child's care plan under **§105**;

(7) refer the child to the [*drafter insert reference to responsible agencies under Part B and Part C of the Individuals with Disabilities Education Act, 20 U.S.C. §1400 et seq.*] unless the child is receiving services under an IEP (as defined in **§108(f)**) or an IFSP (as defined in **§108(g)**);

(8) if appropriate, in the case of a child age 16 or older, refer the child to the state Vocational Rehabilitation Agency under Title I of the Rehabilitation Act of 1973, 29 U.S.C. §720 et seq., 34 C.F.R. 300.347(b);

(9) facilitate, consistent with the confidentiality protections under **§209**, the exchange of information and medical records among Contractor, the child's primary care provider, and [*drafter insert reference to responsible agencies under Part B and Part C of the Individuals with Disabilities Education Act, 20 U.S.C. §1400 et seq.*];

(10) meet (in person or by telephone) with the child and the child's family or caregiver in order to track the child's progress under the child's care plan under **§105** and, based on the experience of the child and the child's family or caregiver, make recommendations to the child's primary care provider with respect to updating the care plan under **§105(b)(5)**;

(11) establish working arrangements with care coordinators or case managers (other than those employed by, or under contract to, Contractor) who have responsibilities with respect to the child;

(12) assist the child (and the child's family or caregiver) in:

(A) understanding the child's entitlement to a fair hearing under 42 C.F.R. §430.220 and to the continuation of services pending the fair hearing under 42 C.F.R. §430.230 and, in the case of denial, termination, or reduction of items and services covered under **§103(a)**, in effectuating these entitlements; and

(B) accessing, under **§209(c)**, Contractor's grievance procedures and the state fair hearing process;

(13) assist the child (and the child's family or caregiver) in documenting, establishing, and maintaining the child's eligibility for [*drafter insert reference to state Medicaid program*], the Supplemental Security Income (SSI) program under Title XVI of the Social Security Act, 42 U.S.C. §1381 et seq., and other public program benefits;

(14) inform the child's family or caregiver of the manner in which the child's family or caregiver may participate in:

(A) voluntary networks organized for mutual support by families or caregivers of children with special health care needs; and

(B) the Family Advisory Board established and maintained by Contractor under **§101(d)(3)**; and

(15) in the case of a child with special health care needs who is an adolescent as defined in **§108(a)**, assist the adolescent in identifying and overcoming transitional issues relating to accessing items and services described in paragraph (3).<sup>19</sup>

*Commentary: In tracking a child's progress under a care plan, the child's care coordinator will need to have access to information regarding the services provided to the child. The following illustrative language assumes that Contractor will have such information with respect to the services received by the child from providers participating in Contractor's provider network, and that*

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<sup>19</sup> For a discussion of care for adolescents with special health care needs, see American Academy of Pediatrics, "Transition of Care for Adolescents with Special Health Care Needs," *Pediatrics* (December 1996) Vol. 98, No. 6, p. 1203. For a discussion of transitional issues affecting the health of adolescents generally, see *Children Now, Partners in Transition: Adolescents and Managed Care* (April 2000), [www.childrennow.org](http://www.childrennow.org).

*Purchaser will have information with respect to services received from providers outside of Contractor's provider network that bill Purchaser for the care they furnish to the child.*

**(e) Duty of Purchaser to Assist in Tracking Use of Out-of-Plan Services** — Purchaser shall make available on request, to the care coordinator of an enrolled child with special health care needs (as defined **§108(c)**), information relating to the payment by Purchaser of claims for items or services furnished to the child by providers not participating in Contractor's provider network.

## **§105. Care Plan**

*Commentary: The following illustrative language would require Contractor to develop a care plan for each enrolled child with special health care needs. Children with special health care needs exhibit a wide variety of health conditions and disabilities. Care plans will vary depending upon the complexity of a child's health care needs: children with multiple diagnoses are likely to require more extensive care plans than those with less complex needs. Care plans will also vary over time as the needs of such children change. The following illustrative language is designed to identify the elements of a care plan regardless of the complexity of the child's needs at any given point in time.*

*Interested purchasers may wish to consider the use of abbreviated care plans for children with less complex needs. For example, the American Academy of Pediatrics (AAP) recommends that, in the case of children with less complex health care needs, the care plan be incorporated onto the child health invoice (also known as the diagnosis or reimbursement form) in order to minimize the administrative burden on primary care physicians. Another alternative would be to limit the requirement for the preparation of a care plan to those children with more complex medical needs.*

**(a) Duty to Develop Care Plan for Enrolled Children with Special Health Care Needs** — Contractor shall, consistent with the family participation requirements under **§101(d)(1)(C)**, comply with the requirements of subsections (b), (c), and (d) in the case of an enrolled child:

- (1) whom Contractor (or a provider participating in Contractor's provider network) has identified as a child with special health care needs (as defined in **§108(c)**) under **§102(b)**; or
- (2) with respect to whom Purchaser has notified Contractor under **§102(a)**.

*Commentary: The illustrative language below assumes that the child's primary care provider is responsible for the development of the child's care plan. Another approach is to vest responsibility for development of the plan in a*

*multidisciplinary team. This approach is reflected in GW CHSRP, Optional Purchasing Specifications: Medicaid Managed Care for Children with Behavioral Health Needs (forthcoming).*

(b) **Development of Care Plan**<sup>20</sup> — In the case of an enrolled child described in subsection (a), Contractor shall ensure that, within [ ] days of the date described in paragraph (3), the child’s primary care provider shall, consistent with the consultation requirements of paragraph (1) and the family participation requirements of paragraph (2), develop and, consistent with paragraph (5), update a care plan for the child that complies with the requirements of subsection (c).

(1) **Consultation** — In developing a care plan under this subsection, a primary care provider shall take into consideration:

(A) any requirements (whether or not relating to health care items or services) contained in an IFSP (as defined in §108(g)) or an IEP (as defined in §108(f)) obtained from:

(i) the child's family or caregiver; or

(ii) with the written consent of the family or caregiver, the educational agency referred to in §108(f) or the early intervention agency referred to in §108(g);

(B) the findings of any other formal or informal assessment or evaluation of the child by a health care professional, or the contents of any care plan developed for the child by another Contractor, within [ ] months prior to the effective date of the child’s enrollment;

(C) the professional judgment of a pediatric specialist (as defined in §108(j)), if any, familiar with the child’s special health care needs; and

(D) the professional judgment of the child’s care coordinator (as defined in §108(b)) under §104.

(2) **Child and Family Participation** — In developing a care plan under this subsection, a primary care provider shall:

(A) allow full participation in the development of the plan by:

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<sup>20</sup> HCFA’s "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "The State requires an assessment of each child’s needs and implementation of a treatment plan based on that assessment" (p. 3).



(i) the child's family or caregiver; and

(ii) unless clinically inappropriate or age-inappropriate, the child; and

(B) obtain the signature of the child's family or caregiver certifying that the family or caregiver has fully participated in the development of the plan and concurs in its diagnostic and treatment recommendations.

(3) **Date** — The date described in this paragraph is the earlier of:

(A) the effective date of enrollment of the child; or

(B) the date on which the enrolled child has been identified as a child with special health care needs (as defined in §108(c)) by a provider participating in Contractor's provider network (whether or not such provider is the child's primary care provider).

(4) **Access to Care Plan** — Contractor shall ensure that each care plan developed under this subsection:

(A) in the case of an enrolled child with special health care needs who is not an adolescent, is promptly made available to the child's family or caregiver (as defined in §108(e));

(B) in the case of an enrolled child with special health care needs who is an adolescent, is promptly made available to the adolescent and to the adolescent's family or caregiver;

(C) is explained to the enrolled child (and the child's family or caregiver) by the child's care coordinator consistent with §104(d)(1);

(D) is incorporated into the enrolled child's medical record;

(E) is not disclosed to any person or entity with respect to which disclosure is prohibited under:

(i) 42 C.F.R. Part 2 (pertaining to the confidentiality of data related to alcohol or substance abuse);

(ii) 42 C.F.R. §§431.300 – 431.307;

(iii) the requirements of 34 C.F.R. Part 99.31 implementing the Family and Educational Rights and Privacy Act (FERPA); and

(iv) the confidentiality protections in the Individuals with Disabilities Education Act, 34 C.F.R. §§300.560 – 300.577, and §§303.400 – 303.425; and

(F) is disclosed to a person or entity that is not described in subparagraph (E) only with the prior written consent (specific to the person or entity to which the care plan is to be disclosed) of the child's family or caregiver.

*Commentary: The following illustrative language would require periodic updating of the care plan of each enrolled child with special health care needs. The updates would have to be done at a frequency determined by the contracting MCO and the purchaser through negotiations. The duty on the Contractor to update periodically would expire when the enrollee is no longer a child with special health care needs as defined in §108(c) -- i.e., is age 21 or older, or no longer has special health care needs.*

**(5) Updating of Care Plan** — Contractor shall ensure that the care plan of an enrolled child with special health care needs is:

(A) reviewed and updated, no less frequently than at least every [ ] months, by the child's primary care provider on the basis of:

(i) the provider's assessment of the child's health and developmental status and needs;

(ii) the recommendations of the child's care coordinator under §104(d)(10); and

(iii) the views of the child's family or caregiver; and

(B) is incorporated into the child's medical record after each update under subparagraph (A).

*Commentary: In some states, the care plan serves as a payment authorization, specifying the items and services that do not require prior approval from the Contractor's utilization control procedures. In Michigan, the Individualized Health Care Plan (IHCP) for a child functions as the payment authorization. Kids Care of Michigan Provider Manual (9/30/98) pp. 1-12. For illustrative language implementing this approach, see §107(a)(5).*

(c) **Contents of Care Plan** — A care plan for an enrolled child with special health care needs (as defined in §108(c)) developed under subsection (b) shall specify:

(1) the items and services enumerated under §103(a) that are appropriate to prevent the deterioration of the child’s condition(s) and to promote the development or maintenance of age-appropriate functioning by the child;

(2) the items and services carved out under §103(b) that are appropriate to prevent the deterioration of the child’s condition(s) and to promote the development or maintenance of age-appropriate functioning by the child; and

(3) the health education and support services that are:

(A) indicated for the child’s family or caregiver; and

(B) covered under §103(a).

*Commentary: Federal Medicaid law, §1903(c) of the Social Security Act, 42 U.S.C. §1396b(c), makes clear that States must pay for items and services covered under their state Medicaid plan even if the item or service is also required under a child’s IEP or IFSP: “Nothing in this title shall be construed as prohibiting or restricting, or as authorizing the Secretary [of HHS] to prohibit or restrict, payment [for services covered under Medicaid to a child with special health care needs] because such services are included in the child’s [IEP or IFSP].”*

*This statutory provision does not require a state to cover, under its state Medicaid plan, items or services that are optional under federal Medicaid law, even if those items and services could be covered under Medicaid and are required under the child’s IEP or IFSP. Note however, that the Medicaid EPSDT benefit covers all services for which federal matching funds are available that an eligible child is discovered to need as a result of an EPSDT screening, “whether or not such services are covered under the State [Medicaid program],” §1905(r)(5) of the Social Security Act, 42 U.S.C. §1396d(r)(5).*

*Thus, if a Medicaid-eligible child receives an EPSDT screen, and that screen indicates that a service described in that child’s IEP (or IFSP) is medically necessary, the State Medicaid program is required to pay for the service (so long as the service is matchable under federal law). As discussed in the commentary to §103, the state Medicaid program may elect to cover some or all EPSDT services through contracts with MCOs. If the child is enrolled in an MCO, and the state has chosen to purchase the service through the MCO, the MCO is obligated to provide the service, even though the service is enumerated in the child’s IEP (or IFSP).*

*Under current law, Medicaid is “the payer of first resort for medical services provided to children with disabilities pursuant to the [IDEA].” However, Medicaid coverage is not unlimited. For example, there are limits on what states may claim for school health-related transportation services for children with IEPs. See HCFA Letter to State Medicaid Directors, May 21, 1999, [www.hcfa.gov/medicaid/smd52199.htm](http://www.hcfa.gov/medicaid/smd52199.htm).*

*A General Accounting Office report concluded: “Both Medicaid and IDEA have an obligation to children with disabilities to ensure that they receive services that will best address their developmental needs, and coordination is essential to meet this obligation. State and local efforts, however, require federal guidance to communicate Medicaid’s coverage and documentation requirements....Recognizing this need, HCFA is developing additional guidance, which it expects to issue in the year 2000.” GAO, Medicaid and Special Education: Coordination of Services for Children with Disabilities is Evolving (December 1999) GAO/HEHS-00-20, p. 18.*

*HCFA has issued a clarification of its policy vis-à-vis state claiming for school health-related transportation services for children with IEPs under the IDEA in (1) a Letter to State Medicaid Directors (May 21, 1999), [www.hcfa.gov/medicaid/smd52199.htm](http://www.hcfa.gov/medicaid/smd52199.htm) and (2) a draft Guide on Medicaid School-Based Administrative Claiming (February 2000), [www.hcfa.gov](http://www.hcfa.gov). There has been some critical commentary on the draft Guide; for example, the Department of Education has recommended that HCFA revise the draft because, in its view, the draft “could be harmful by limiting access by school districts to Medicaid reimbursement for some activities that should be claimable....” HCFA testified before the Senate Finance Committee that “[o]nce we have reviewed the feedback, we expect to make changes before issuing a final Guide.” Testimony of Tim Westmoreland, Director, HCFA Center for Medicaid and State Operations (April 5, 2000), [www.senate.gov/~finance/4-5hcfa.htm](http://www.senate.gov/~finance/4-5hcfa.htm).*

**(d) Coordination of Care Plans with IFSPs or IEPs** — In the case of an enrolled child with special health care needs (as defined in **§108(c)**) who is receiving services under an IFSP (as defined in **§108(g)**) or an IEP (as defined in **§108(f)**) (whether or not at the time of enrollment), Contractor shall:

- (1) furnish, or arrange for the furnishing of, the items and services that are:
  - (A) enumerated under **§103(a)**;
  - (B) covered under **§107**; and
  - (C) required under the child’s IFSP or the IEP;

(2) ensure that the child’s primary care provider incorporates the items and services described in paragraph (1) into the child’s care plan under subsection (c);

(3) furnish, or arrange for the furnishing of, the items and services described in paragraph (1) through providers selected by Contractor (whether or not such providers are identified in, or furnish services to the child under, the IFSP or IEP);

(4) ensure that the child's care coordinator carries out the requirements of **§104(d)(3)**; and

*Commentary: The following illustrative language would clarify that the “natural environment” and “least restrictive environment” requirements of federal IDEA law apply to Contractors in the delivery of services through their own provider networks. In some states, early intervention services are provided by free-standing, state-certified agencies that do not participate in MCO provider networks. The following language would not impose any obligations upon Contractors with respect to services furnished to enrolled children by such free-standing, out-of-network agencies.*

(5) ensure that:

(A) in the case of a child receiving services under an IFSP, the child, consistent with the Individuals with Disabilities Education Act, 20 U.S.C. §§1435(a)(16), 1436(d)(5), 34 C.F.R. §303.344(d)(1), shall receive items and services that Contractor furnishes under paragraph (1) in natural environments (as defined in **§108(h)**); and

(B) in the case of a child receiving services under an IEP, whether or not in an educational setting, the child shall receive the following items and services (to the extent that Contractor furnishes such items and services under paragraph (1)) consistent with the least restrictive environment requirement of the Individuals with Disabilities Education Act, 20 U.S.C. §1412(a)(5), 34 C.F.R. §300.550(b) (64 *Fed Reg* 12547 (March 12, 1999)):

(i) physical therapy;

(ii) speech therapy;

(iii) occupational therapy;

(iv) assistive technology services; and

(v) mental health services.

## §106. Guidelines

*Commentary: The development of clinical practice guidelines specific to children with special health care needs is in evolution. Some clinical performance measures have been developed for some conditions characteristic of children with special care needs, including chronic pediatric asthma, pediatric HIV, and schizophrenia in children and adolescents. For a database that relates these and other conditions to clinical performance measures, see the Agency for Health Care Policy and Research's CONQUEST 2.0, <http://www.ahrq.gov/qual/conquest.htm>. The illustrative language below reflects the recommendations of expert reviewers involved in the development of these purchasing specifications.*

(a) **Guidelines** — Contractor shall furnish or arrange for the furnishing of items and services covered under §103(a) to an enrolled child with special health care needs (as defined in §108(c)) in a manner which is consistent with [*drafter insert one or more of the following guidelines*]:

(1) the health supervision guidelines enumerated in §006(a)(1) of the Overview of MEDICAIDSPECS;<sup>21</sup>

(2) *A Guide to Substance Abuse Services for Primary Care Clinicians*, Treatment Improvement Protocol Series 24, BKD234 (1997)  
[www.health.org/pubs/catalog/series.htm#CSATtip](http://www.health.org/pubs/catalog/series.htm#CSATtip);

(3) *Comprehensive Case Management for Substance Abuse Treatment*, Treatment Improvement Protocol Series 27, BKD251(1998)  
[www.health.org/pubs/catalog/series.htm#CSATtip](http://www.health.org/pubs/catalog/series.htm#CSATtip); or

(4) *Screening and Assessing Adolescents for Substance Use Disorders*. Treatment Improvement Protocol Series 31, BKD306 (1999)  
[www.health.org/pubs/catalog/series.htm#CSATtip](http://www.health.org/pubs/catalog/series.htm#CSATtip).

(b) **Other Requirements** — Contractor shall comply with the requirements of **Part 1B** of MEDICAIDSPECS relating to the delivery of covered items and services.

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<sup>21</sup> Among the guidelines enumerated in §006(a)(1) of MEDICAIDSPECS are: (1) Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, 2<sup>nd</sup> Edition (2000); (2) Guidelines for Adolescent Preventive Services (GAPS)(1995); and (3) AAP's Guidelines for Health Supervision III (1997). Note that a version of Bright Futures that is specific to children with special health care needs is under development through HRSA's Maternal and Child Health Bureau (MCHB).

## §107. Coverage Determination Standards and Procedures<sup>22</sup>

*Commentary: The December 17, 1997 letter from HCFA to State Medicaid Directors regarding the BBA Medicaid managed care amendments states that each risk contract with an MCO "...must include provisions that address the responsibility of the managed care entity to furnish care and services when medically necessary in sufficient detail to ensure that beneficiaries receive needed services to which they are entitled under the contract." Note that, under §103, interested Purchasers and contracting MCOs could negotiate a list of items and services for which the MCOs would assume responsibility when medically necessary. In deciding whether the MCO is responsible for furnishing or paying for one of the listed items or services in the case of any individual enrolled child, a coverage determination is made. Thus, an item or service may be covered under §103 but not furnished or paid for because of an adverse coverage determination. The following section sets forth illustrative language framing coverage determinations for children with special health care needs.*

*The following illustrative language does not contemplate automatic authorization of coverage for items and services requested from Contractor by a Title V CSHCN program on behalf of an enrolled child. However, the illustrative language in §101A(b)(6) of MEDICAIDSPECS, would provide a role for the Title V CSHCN program with respect to submission of opinions and evidence in connection with coverage determination decisions. In addition, Contractor could not, under §101A(c)(4) of MEDICAIDSPECS, deny coverage for an item or service on the ground that the item or service is identified in a plan of care developed by a Title V CSHCN program.*

### (a) Coverage Determination Standards and Procedures

(1) **In General** — Contractor shall comply with the requirements of §§101A–103A of MEDICAIDSPECS and the requirements of this section relating to the standards and procedures used in determining whether an item or service is covered with respect to an enrolled child with special health care needs (as defined in §108(c)), except that:

- (A) the requirements of paragraph (3) shall apply with respect to Contractor's coverage determinations regarding prescription drugs; and
- (B) the requirements of paragraph (4) shall apply with respect to Contractor's coverage determinations regarding medical equipment.

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<sup>22</sup> See also Ireys, H.T., Wehr, E., and Cooke, R.E. Assuring High Quality of Care for Persons with Developmental Disabilities and Other Special Health Care Needs: Specifications for a Definition of Medical Necessity, The Johns Hopkins University, June 1999, <http://www.jhsph.edu/centers/cshcn/publications.html>.

**(2) Personnel Qualified to Make Coverage Determinations** — In the case of an enrolled child with special health care needs (as defined in §108(c)), Contractor shall ensure that at least one individual with expertise or experience in the clinical management of the child’s health care need participate in the determination as to whether the item or service is covered.

*Commentary: The following language assumes that, in the case of prescriptions written by a physician participating in Contractor’s provider network, the prescription would be covered as prescribed by the physician if the drug is covered under the negotiated benefit package under §103(a). The language also assumes that, under applicable state law, Contractor would not be authorized to substitute generic drugs for brand name drugs prescribed by the treating physician whenever the physician specifies in writing that substitution is not appropriate through the use of such phrases as "do not substitute" or "no substitution."*

### **(3) Coverage of Prescription Drugs**

**(A) Duty** — In the case of a child with special health care needs (as defined in §108(c)), Contractor shall cover and furnish, or arrange for the furnishing of, a prescription drug if the drug is:

(i) covered under §103(a) (and is not carved out under §103(b));<sup>23</sup> and

(ii) prescribed by:

(I) the child’s primary care provider; or

(II) a pediatric professional (as defined in §108(i)) participating in Contractor’s provider network.<sup>24</sup>

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<sup>23</sup> In the case of individuals with HIV, HCFA has written to State Medicaid directors: “If your State includes drugs and covers the HIV population in managed care, these drugs must be available in managed care formularies. If your State excludes prescription drugs from managed care contractual requirements and capitation rates, the requirements of the drug rebate program are then applicable. States should examine their existing contracts to determine if prescription drugs are covered through managed care plans, what (if any) benefit restrictions may apply, and whether the capitation rates should be adjusted to account for the introduction of new drugs such as the protease inhibitors. The above considerations may not be broadly applicable if people with HIV/AIDS are specifically excluded from managed care (even on a voluntary basis), or the enrollment of HIV/AIDS-infected beneficiaries, or not widely distributed among plans. Under these circumstances, States may ‘carve out’ the prescription of, and payment for, drugs used in the treatment of HIV/AIDS (including protease inhibitors) from managed care contracts and capitation rates.” Letter from Sally K. Richardson, Director, Medicaid Bureau, to State Medicaid Directors, June 19, 1996.

<sup>24</sup> An alternative option would be to add pediatric specialists participating in the state Title V CSHCN program to the list of providers whose prescriptions for drugs Contractor must cover and pay for.



(B) **Substitution** — In carrying out subparagraph (A) with respect to a prescription, Contractor shall not, consistent with [*drafter insert reference to state law on drug substitution*] substitute, or arrange for the substitution of, a generic version for a prescribed brand name drug if the child's primary care provider or a pediatric professional has indicated in writing on the prescription that substitution is inappropriate.

#### (4) Coverage of Medical Equipment<sup>25</sup>

(A) In the case of a child with special health care needs (as defined in §108(c)), Contractor shall cover and furnish, or arrange for the furnishing of, an item of medical equipment if the item is:

(i) covered under §103(a) (and is not carved out under §103(b)); and

(ii) prescribed by:

(I) the child's primary care provider; or

(II) a pediatric professional (as defined in §108(i)) participating in Contractor's provider network.<sup>26</sup>

(B) Coverage of an item of medical equipment shall include the cost of:

(i) customizing the item in a manner appropriate to the physical characteristics and medical needs of the child;

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<sup>25</sup> In a Letter to State Medicaid Directors dated September 4, 1998, HCFA sets forth interpretive guidance clarifying policies concerning Medicaid coverage of medical equipment (ME) and the use of lists in making such coverage determinations. The Letter provides that "...a State will be in compliance with federal Medicaid requirements only if, with respect to an individual applicant's request for an item of ME, the following conditions are met:

- The process is timely and employs reasonable and specific criteria by which an individual item of ME will be judged for coverage under the State's home health services benefit. These criteria must be sufficiently specific to permit a determination of whether an item of ME that does not appear on a State's pre-approved list has been arbitrarily excluded from coverage based solely on a diagnosis, type of illness, or condition.
- The State's process and criteria, as well as the State's list of pre-approved items, are made available to beneficiaries and the public.
- Beneficiaries are informed of their right, under 42 C.F.R. Part 431, Subpart E, to a fair hearing to determine whether an adverse decision is contrary to the law cited above."

States are not required to contract for the provision of ME with MCOs; however, a State Medicaid agency may find itself liable for items of medical equipment that are omitted from a purchasing agreement or that are denied due to coverage rules inconsistent with the September 4 letter.

<sup>26</sup> An alternative option would be to add pediatric specialists participating in the state Title V CSHCN program to the list of providers whose prescriptions for ME Contractor must cover and pay for.

(ii) training the child (and the child's family or caregiver) in the use of the item; and

(iii) maintaining the item.

**(5) Exclusion from Prior Authorization** — In the case of an enrolled child with special health care needs (as defined in **§108(c)**), Contractor shall not require prior authorization with respect to:

(A) any item or service (including any direct access visit to a pediatric specialist (as defined in **§108(j)**) enumerated in the child's care plan under **§105**,<sup>27</sup>

(B) in the case of a child with special health care needs with respect to whom a care plan is not in effect, items and services:

(i) described in **§103A(d)** of MEDICAIDSPECS,<sup>28</sup> and

(ii) to the extent not described in clause (i), any item or service enumerated in **§103(a)** that is related to the treatment of an ongoing chronic or disabling condition that has been diagnosed by the child's primary care provider or by a pediatric specialist (as defined in **§108(j)**) participating in Contractor's provider network.

**(b) Role of Care Coordinator in Utilization Management**<sup>29</sup>

*Commentary: There is no consensus on the appropriate role for a care coordinator in the MCO's decision-making as to whether an item or service will be covered for an enrollee for whom the care coordinator is responsible. Some believe that, because of his or her knowledge of the enrollee's circumstances, the care coordinator is the most appropriate person to make coverage determinations affecting that enrollee. Others believe that the care coordinator's primary responsibility is to advocate within the MCO on behalf of the enrollee, and that requiring the care coordinator to manage the enrollee's utilization of services would be inconsistent with this responsibility. The following illustrative language attempts to strike a balance between these two views by authorizing the care coordinator, with the consent of the child's family or caregiver, to provide*

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<sup>27</sup> An alternative option would be to exclude from prior authorization only a subset of the items and services specified in the child's treatment plan, such as the number of direct access visits to pediatric specialists and any prescription drug requirements.

<sup>28</sup> Among the 14 classes of items and services excluded from prior authorization under **§103A(d)** of MEDICAIDSPECS are emergency services, urgent care, and EPSDT screens.

<sup>29</sup> An alternative option would be to limit the prohibition on participation of the care coordinator in utilization management to cases in which the child's primary care provider is also the child's care coordinator.

*information to the personnel making the coverage determination but not to participate directly in the determination itself.*

**(1) Prohibition on Participation in Coverage Determination —**

Contractor shall ensure that no care coordinator (as defined in §108(b)) participate directly in a determination as to whether an item or service sought by an enrolled child with special health care needs (as defined in §108(c)) will be covered under [*drafter insert name of purchasing document*].

**(2) Provision of Information for Coverage Determination —**

Contractor may authorize a care coordinator to provide to the individuals responsible for coverage determinations under this section information material to the determination regarding an enrolled child with special health care needs for whom the care coordinator is responsible, but only if the child or the child's family or caregiver consents to the provision of such information.<sup>30</sup>

## **§108. Definitions**

(a) Adolescent – a child age [ ]<sup>31</sup> through 20.

(b) Care coordinator – an individual who has demonstrated experience and appropriate training in the coordination of medical and related services to children with special health care needs and who is one of the following:

(1) a physician<sup>32</sup> (including the primary care provider selected by an enrolled child under §203(b));

(2) a registered nurse;

(3) a social worker;

(4) a family counselor;

(5) a service coordinator assigned by an early intervention program under Part C of the Individuals with Disabilities Education Act (IDEA) 20 U.S.C. §1400 et seq.; or

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<sup>30</sup> An alternative option would be to authorize the provision of such information to individuals responsible for coverage determinations whether or not the child or the child's family or caregiver consents.

<sup>31</sup> Bright Futures uses an age range from 11 through 20. Guidelines for Adolescent Preventive Services (GAPS) uses a range from 12 through 20. The Medicaid EPSDT benefit extends to all Medicaid-eligible children under age 21, §1905(a)(4)(B) of the Social Security Act, 42 U.S.C. §1396d(a)(4)(B).

<sup>32</sup> See AAP, "Care Coordination: Integrating Health and Related Systems of Care for Children with Special Health Care Needs," 104 Pediatrics No. 4 (October 1999), pp. 978-981.

(6) a health educator.

*Commentary: The following definition combines criteria used by HRSA's Maternal and Child Health Bureau for purposes of Title V with the definition in the Medicaid statute (which is also the definition used in HCFA's "Draft Interim Review Criteria for Children with Special Needs," June 4, 1999). The six categories listed in the following illustrative language reflects the Medicaid statute under §1932(a)(2)(A) of the Social Security Act, 42 U.S.C. §1396u-2(a)(2)(A), as added by the Balanced Budget Act of 1997 (BBA), P.L. 105-33. A recent GAO analysis of this statutory definition concludes that "it does not cover some Medicaid-eligible children whose health conditions could merit recognition as exceptional and whose treatment in a managed care setting deserves to be closely monitored." General Accounting Office, Medicaid Managed Care: Challenges In Implementing Safeguards for Children with Special Needs (March 2000) GAO/HEHS-00-37, p. 15, [www.gao.gov](http://www.gao.gov)*

(c) Child with special health care needs – a child under 21<sup>33</sup> who has a chronic physical, developmental, or behavioral condition, and requires health and related services of a type or amount beyond that which is required by children generally,<sup>34</sup> including a child who, consistent with §1932(a)(2)(A) of the Social Security Act, 42 U.S.C. §1396u-2(a)(2)(A):

(1) is eligible for Supplemental Security Income (SSI) benefits under Title XVI of the Social Security Act, 42 U.S.C. §1381 et seq.;

(2) is a child with special health care needs described in §501(a)(1)(D) of the Social Security Act, 42 U.S.C. §701(a)(1)(D);

(3) is a child described in §1902(e)(3) of the Social Security Act, 42 U.S.C. §1396a(e)(3);<sup>35</sup>

(4) is a child receiving foster care maintenance payment under §472 of the Social Security Act, 42 U.S.C. §672;

(5) is a child receiving adoption assistance under §473 of the Social Security Act, 42 U.S.C. §673; or

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<sup>33</sup> Although the following statutory categories are limited to children under age 19, the definition in the illustrative language above extends to children under age 21, the line of demarcation for the EPSDT services benefit.

<sup>34</sup> These criteria are drawn from Merle McPherson et al., "A New Definition of Children with Special Health Care Needs," 102 Pediatrics No. 1, July 1998, p. 137. The assessment tools described in footnote 12 are aligned with this definition.

<sup>35</sup> This refers to a child who is under 18, qualifies as disabled for purposes of the Supplemental Security Income (SSI) program, and requires the level of care provided by an institution but can appropriately be cared for at home or in the community.

(6) a child who is in foster care or otherwise in an out-of-home placement.<sup>36</sup>

(d) Contractor – the managed care organization doing business as [*drafter insert name*] that has entered into an agreement with Purchaser under [*drafter insert name of purchasing document*].

(e) Family or caregiver<sup>37</sup> – a natural or adoptive parent of a child, a grandparent or stepparent with whom the child lives, or an individual or entity that is a foster parent, legal guardian or other individual or agency with legal authority or responsibility to care for the child.

(f) Individualized educational program (IEP)<sup>38</sup> – a plan of services developed by an educational agency pursuant to the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §1401(11), 34 C.F.R. §§300.15, 300.347, which sets forth the special education and related services required by a child.

(g) Individualized family services plan (IFSP)<sup>39</sup> – a plan of services developed by an early intervention agency pursuant to the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§1401(12), 1436(d), 34 C.F.R. §§303.14, 303.340, 303.344, which sets forth the early intervention services required by a child and the child’s family or caregiver.

(h) Natural environment – as defined in the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§1435(a)(16), 1436(d)(5), 34 C.F.R. §§303.12(b), 303.18, a setting, including the home, that is natural or normal for the child’s age peers who have no disabilities.

*Commentary: In applying the primary care provider selection requirements under §203, the following definitions in (i) and (j) draw a distinction between a "pediatric professional" and a "pediatric specialist". As used by the American Academy of Pediatrics and in these specifications, the term "pediatric professionals" refer to physicians who are trained as specialists in pediatrics, including pediatric medical subspecialists and pediatric surgical specialists.*

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<sup>36</sup> An alternative option would be to add one or more of the following categories of children within which there is a high prevalence of chronic conditions: (1) recipients of family preservation and support services from a state child welfare agency pursuant to 42 U.S.C. §629 et seq.; (2) homeless (as defined in §1401(n) of MEDICAIDSPECS) or at risk of being homeless; or (3) a member of family of a migratory agricultural worker (as defined in §1401(r) of MEDICAIDSPECS) or a seasonal agricultural worker (as defined in §1401(y) of MEDICAIDSPECS); (4) is under age 3 and is eligible for early intervention services under the Individuals with Disabilities Education Act, 20 U.S.C. §§1400 et seq., 34 C.F.R. §§303.16, 303.300; or (5) is age 3 or over and is eligible for special education and related services under the Individuals with Disabilities Education Act, 20 U.S.C. §§1400 et seq., 34 C.F.R. §300.7.

<sup>37</sup> An alternative option would be to define “parent” and “foster parent” as the terms are defined for purposes of an IEP at 34 C.F.R. §300.20 or for purposes of an IFSP at 34 C.F.R. §303.19.

<sup>38</sup> For additional regulatory requirements relating to an IEP, see 34 C.F.R. §§300.340 - 300.361.

<sup>39</sup> For additional regulatory requirements relating to an IFSP, see 34 C.F.R. §§303.340 - 303.345.

*Pediatric professionals could serve as primary care providers. On the other hand, "pediatric specialists" would not serve as primary care providers, but enrolled children would have access to such specialists through the child's care plan and under the access requirements in §205. While "pediatric professionals" are a subset of "pediatric specialists," the latter category includes practitioners and clinics other than pediatricians, including child psychiatrists and psychologists.*

(i) Pediatric professional – a physician who is trained as a specialist in pediatrics, including a pediatric medical subspecialist and a pediatric surgical specialist.

(j) Pediatric specialist – a provider (as defined in subsection (l)), including a pediatric professional (as defined in subsection (i)) who is a physician, child psychiatrist, child psychologist, or other health care practitioner who, with respect to the diagnosis, treatment, or management of a child's (or adolescent's) illness, injury or condition, has specialized expertise (as evidenced by certification or licensure or other means of formal recognition) relating to the particular illness, injury, or condition of the child (or adolescent).<sup>40</sup>

(k) Primary care provider – a provider (as defined in subsection (l)) that meets the requirements of §502(c) of Part 5 of MEDICAIDSPECS.

(l) Provider – a health care practitioner, clinic, hospital, school, or other entity licensed by the State to furnish medical, dental, mental health, or other health care services.

(m) Provider network – the set of providers that have entered into enforceable written agreements with Contractor that comply with the requirements of [drafter insert name of purchasing document] to furnish, or arrange for the furnishing of, covered items and services under §103(a) to enrolled children.

(n) Purchaser – [drafter insert name of state purchasing agency].

(o) Refer – as used in this document, the terms “refer” and “referral” shall not be construed to authorize payment by Contractor for an item or service or obligate Contractor to pay for an item or service.

(p) Other terms – see **Part 14** of MEDICAIDSPECS.

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<sup>40</sup> An alternative option is to enumerate as “other entities” one or more of the following: (1) hospitals with the highest level of designation of advanced newborn intensive care capacity; (2) hospitals with a pediatric intensive care unit; (3) hospitals offering pediatric psychiatric care; (4) centers of excellence; and (5) specialty providers of multidisciplinary care in a single integrated unit.

## Part 2. Delivery of Services for Children with Special Health Care Needs

- §201. Enrollment and Disenrollment
- §202. Information to Enrolled Children
- §203. Provider Selection and Assignment
- §204. Provider Network
- §204A. Medical Home
- §205. Access Standards
- §206. Relationships with Other State and Local Agencies
- §207. Quality Measurement and Improvement
- §208. Data Collection and Reporting
- §209. Enrolled Child Safeguards
- §210. Remedies for Noncompliance
- §211. Other Applicable Federal and State Requirements

### §201. Enrollment and Disenrollment

*Commentary: The selection of primary care providers and pediatric specialists is an issue of great importance to children with special health care needs and their families. There are two basic approaches to beneficiary choice in Medicaid managed care. The more common is to offer the beneficiary a choice between two or more MCOs and, once enrolled in an MCO, a choice among primary care providers. The other approach is to offer the beneficiary a choice among primary care providers and, once that selection has been made, to assign a beneficiary to an MCO based on its affiliation with the provider. Both of these approaches are reflected in **Part 4** of MEDICAIDSPECS, referenced in **§203** below.*

*The following illustrative language can be used by purchasers in implementing either approach. However, in the case of purchasers that elect to offer a choice between MCOs, the criteria under which beneficiaries choose among plans (rather than practitioners) would not be reflected in an agreement such as this between a purchaser and an MCO. Instead, they might set forth in an agreement between a purchaser and an enrollment broker or in state Medicaid plan provisions or regulations. The AAP recommends that “every effort is made for Medicaid beneficiaries to make an informed choice when choosing a managed care plan. Such efforts should include the use of face-to-face counselors. When participants do not choose, and must be assigned to a plan, the criteria used to assign them should include current and previous relationships with primary care and specialty clinicians, location of clinicians, assignment of other family or household members, choices by other members in the service area, and capacity of managed care organizations to provide special care or services appropriate for the participants.”*

*See AAP's Medicaid Policy Statement, <http://www.aap.org/policy/RE9918.html>.*

**(a) Enrollment and Disenrollment Procedures**

(1) **In General** — Contractor shall comply with the requirements of **Part 2** of MEDICAIDSPECS to the extent consistent with the requirements of this section.

(2) **Nondiscrimination** — Contractor shall comply with the requirements of **§1301(b)(1)** of MEDICAIDSPECS prohibiting discrimination in enrollment on the basis of health status or the need for health services.

(3) **Involuntary Disenrollment** — Contractor shall comply with the requirements of subsection (e) relating to involuntary disenrollment of a child with special health care needs (as defined in **§108(c)**) for reasons other than loss of eligibility for Medicaid.

**(b) Duties Related to Children Receiving Treatment at Time of Enrollment** — In the case of a child with special health care needs (as defined in **§108(c)**) who at the time of enrollment is receiving services under an IEP (as defined under **§108(f)**) or IFSP (as defined under **§108(g)**), Contractor shall comply with the requirements of **§105(d)**.

**(c) Duties Related to Children at Time of Disenrollment** — Contractor shall comply with the requirements of **§§204-205** of MEDICAIDSPECS.

**(d) Voluntary Disenrollment**

(1) **Inaccurate Provider Information** — Consistent with **§401(d)** of MEDICAIDSPECS, Contractor agrees that Purchaser has the authority and the responsibility to disenroll from Contractor for cause an enrolled child with special health care needs (as defined in **§108(c)**) if:

(A) Contractor fails to provide to the child (and the child’s family or caregiver) accurate, current information regarding participation of providers in Contractor’s provider network; and

(B) the family or caregiver relies upon such information when enrolling the child with Contractor.

(2) **No Appropriate Pediatric Specialist** — In a case described in **§203(f)(2)(C)** (relating to disenrollment in the event that no pediatric specialist is available), Contractor shall promptly notify the family or caregiver of the enrolled child with special health care needs (as defined in **§108(c)**) of the manner in which the family or caregiver may request disenrollment by Purchaser.



**(e) Involuntary Disenrollment<sup>41</sup>**

*Commentary: The following illustrative language assumes that under the State's Medicaid program, the authority to disenroll a beneficiary from an MCO rests with the Purchaser Medicaid Agency, or with the enrollment broker used by the Agency, but not with the MCO.*

**(1) In General** — Contractor may not request that Purchaser terminate enrollment of an enrolled child with special health care needs (as defined in **§108(c)**) who is eligible for [*drafter insert reference to state Medicaid program*] and who has not requested to disenroll.

**(2) Request to Purchaser** — Contractor may request that Purchaser terminate the enrollment of an enrolled child with special health care needs (as defined in **§108(c)**) who is eligible for [*drafter insert reference to state Medicaid program*] and who has not requested to disenroll only if Contractor documents to Purchaser, in such form and manner as Purchaser specifies, each of the following:

(A) the child is engaging in disruptive or abusive behavior;

(B) the child's behavior does not result from a mental illness or addiction disorder;

(C) the child's behavior will seriously impair Contractor's ability to furnish items and services to the child or to other enrollees; and

(D) if the child, is under treatment, arrangements have been made to ensure completion of, or avoid interruption of, the treatment.

**(3) Notice** — If Purchaser, based on a request by Contractor under paragraph (2), terminates the enrollment of an enrolled child:

(A) Purchaser shall notify, in writing, Contractor and the enrolled child (and the enrolled child's family or caregiver) of the termination at least [ ] days prior to the effective date of termination; and

(B) Contractor shall arrange (at Contractor's expense) for the transfer of the child's medical records to the successor managed care plan or provider assuming responsibility for care of the child

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<sup>41</sup> HCFA's "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "If an MCO/PHP requests to disenroll or transfer enrollment of an enrollee to another plan, the reasons for reassignment are not discriminatory in any way – including adverse change in an enrollee's health status and non-compliance behavior for individuals with mental health and substance abuse diagnoses – against the enrollee" (p. 2).

within [ ] days of request by the child’s family or caregiver or successor managed care plan or provider.

## §202. Information to Enrolled Children

*Commentary: The following illustrative language would require Contractor to provide information to newly enrolled children with special health care needs through an enrollee handbook (including content and understandability requirements), a provider directory, and other means specified in the illustrative language at Part 3 of MEDICAIDSPECS, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp) Subsection (b) would supplement these generic requirements for an enrollee handbook with additional elements specific to children with special health care needs.*

(a) **In General** — Contractor shall comply with the requirements of **Part 3** of MEDICAIDSPECS to the extent consistent with the requirements of this section.

(b) **Contents of Enrollee Handbook** — Contractor’s enrollee handbook shall contain the following information relating to the delivery of services for a child with special health care needs:

- (1) items and services covered under **§103(a)**;
- (2) items and services that remain the duty of Purchaser under **§103(b)**;
- (3) an explanation of the manner and frequency in which [*drafter insert reference to state's Medicaid EPSDT benefit*] covered under **§103(a)** are to be furnished;
- (4) specific instructions on where and how to obtain the items and services that remain the duty of Purchaser under **§103(b)**, including:
  - (A) how to access transportation services; and
  - (B) the manner in which the child should present for care in emergency rooms that are staffed by personnel unfamiliar with the child’s special health care needs;<sup>42</sup>
- (5) development and implementation of a care plan described in **§105**;
- (6) access to primary care providers and pediatric specialists under **§203**;
- (7) assistance available from a care coordinator under **§104(d)**;

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<sup>42</sup> For additional information, see “Emergency Preparedness for Children with Special Health Care Needs,” 104 *Pediatrics* No. 4 (October 1999), or [www.pediatrics.org/cgi/content/full/104/4/e53](http://www.pediatrics.org/cgi/content/full/104/4/e53).

(8) accommodations made by Contractor as required by the Americans with Disabilities Act, 42 U.S.C. §12101 et seq.;

(9) grievance and appeal procedures under [*drafter insert reference to relevant provisions in purchasing document*] and state fair hearing rights under §209(c); and

(10) opportunities for participation on the Family Advisory Board established and maintained by Contractor under §101(d)(3).

### **§203. Provider Selection and Assignment**

(a) **In General** — Contractor shall comply with the requirements of **Part 4** of MEDICAIDSPECS to the extent consistent with the requirements of this section.

*Commentary: The following illustrative language would require Contractors to give families and caregivers of enrolled children the option of choosing as the child's primary care provider for their medical home either (1) a primary care practitioner or (2) a physician who is trained as a specialist in pediatrics, including a pediatric medical subspecialist and a pediatric surgical specialist, termed a "pediatric professional" as recommended by the American Academy of Pediatrics. The language would also require Contractors to ensure access by enrolled children to appropriate "pediatric specialists" for specialty services. While there is some overlap between "pediatric professionals" and "pediatric specialists," the latter category includes practitioners and clinics other than pediatricians, including child psychiatrists and psychologists. For further detail, see §§108(i) and (k).*

(b) **Selection of a Primary Care Provider** — In the case of an enrolled child with special health care needs (as defined in §108(c)), Contractor shall offer the family or caregiver of such enrolled child (or in the case of an adolescent, the adolescent) the option of designating as the child's primary care provider a provider described in paragraph (1) who meets the requirements of paragraph (2).

(1) A provider described in this paragraph is a provider participating in Contractor's provider network who furnishes a medical home to an enrolled child under §204A(c) and who is:

(A) a primary care provider (as defined in §108(k)); or

(B) a pediatric professional (as defined in §108(i)).

(2) The requirements of this paragraph are that the provider:

(A) has the capacity, in light of other patient care responsibilities, to assume primary care provider responsibilities under [*drafter insert reference to relevant provisions of purchasing agreement*] for the child;<sup>43</sup>

(B) has the expertise to provide primary care services to a child with special health care needs; and

(C) meets the travel and service waiting time requirements under **§205(b)**.

*Commentary: The following illustrative language assumes voluntary enrollment by a child with special health care needs into the MCO. In states operating Medicaid managed care programs under a § 1932 state plan option, children with special needs are expressly exempted from mandatory enrollment, including auto- or default enrollment, into an MCO, §1932(a)(2)(A) of the Social Security, 42 U.S.C. §1396u-2(a)(2)(A). Under the illustrative language below, a child would be assigned to a primary care provider by the MCO only if the child had voluntarily enrolled in the MCO and, having been offered a choice of primary care providers under subsection (b) above, had not selected a primary care provider within a specified period of time.*

**(c) Assignment of Non-Selecting Children to Primary Care Providers** — Consistent with **§403(a)(2)(B)** of MEDICAIDSPECS, in the event that the family or caregiver of an enrolled child with special health care needs (as defined in **§108(c)**) (or in the case of an adolescent, the adolescent) does not select a primary care provider under subsection (b) within [ ] days of enrollment, Contractor shall assign the enrolled child to:

(1) a primary care provider participating in Contractor’s provider network who:

(A) meets the requirements of subsection (b)(1); and

(B) is accessible to the child under **§205(b)**; or

(2) a pediatric specialist participating in Contractor’s provider network who:

(A) meets the requirements of subsection (b)(2); and

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<sup>43</sup> The Illinois Supreme Court ruled that a Medicaid MCO may be liable for institutional negligence in case where a child enrolled in the MCO was assigned to a primary care physician with a patient panel of 4,527 and became permanently disabled as the result of the failure of the physician to schedule an appointment with the child on a timely basis. Jones v. Chicago HMO LTD., Illinois Supreme Court (Docket No. 86830, filed May 18, 2000).

(B) is accessible to the child under §205(c).

(d) **Reselection of a Primary Care Provider** — In the case of an enrolled child with special health care needs (as defined in §108(c)) who has selected (or been assigned to) a primary care provider under subsections (b) and (c), if the primary provider is no longer willing to assume the responsibilities of a primary care provider for the child, Contractor shall:

(1) permit the family or caregiver of the child (or in the case of an adolescent, the adolescent) to select another primary care provider under subsection (b); or

(2) if the family or caregiver (or adolescent) does not select a primary care provider under subsection (b) within [ ] days of notification by Contractor of the right to select another primary care provider, assign the child under subsection (c).

(e) **Reassignment of a Child with Special Health Care Needs to a Primary Care Provider**

(1) **Grounds for Reassignment** — In the case of an enrolled child with special health care needs (as defined in §108(c)) who has selected a primary care provider under subsection (b), or who has been assigned to a primary care provider under (c), Contractor may reassign the child to another primary care provider only if the primary care provider meets the requirements of subsection (b)(2) and one of the following three conditions applies:

(A) the child or the child's family or caregiver has requested reassignment to a different primary care provider;

(B) the child's current primary care provider no longer participates in Contractor's provider network;<sup>44</sup> or

(C) the child's current primary care provider:

(i) reduces the number of enrolled children the provider will accept as patients for the remaining term of the provider's written agreement with Contractor relating to participation in Contractor's provider network; or

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<sup>44</sup> An alternative option would be to require Contractor to comply with applicable state continuity of care legislation, if any, in a case in which an enrolled child's behavioral health provider terminates participation in Contractor's network. The National Conference of State Legislatures reports that 23 states have enacted legislation relating to continuity of care. 2000 State by State Guide to Managed Care Law (September 1999), Table §2.6.

(ii) is, after [ ] months of responsibility as a primary care provider with respect to the child, no longer willing to assume such responsibility and certifies in the child's medical record that reassignment of the child to another primary care provider will not:

(I) compromise the treatment of the child's special health care needs; or

(II) interrupt the child's access to covered prescription drugs; or

(III) disrupt the child's access to pediatric specialists.

(2) **Notification** — Contractor shall not involuntarily reassign an enrolled child under paragraph (1) unless Contractor has notified the child (and the child's family or caregiver) in writing at least [ ] weeks prior to the effective date of the reassignment of:

(A) the effective date of the child's reassignment to a different primary care provider; and

(B) the name, mailing address, phone number, practice site, practice hours, and the bus, subway line, or other public transportation serving the practice site.

**(f) No Pediatric Specialist Available as Specialty Care Provider<sup>45</sup>**

*Commentary: This illustrative language addresses the inability of an enrolled child with special health care needs to find an accessible pediatric specialist who participates in Contractor's provider network to treat the child's special health care needs in a timely manner. In such a circumstance, the language below suggests three alternatives: (1) the MCO could refer the child to an appropriate pediatric specialist not participating in the network; (2) the child's family or caregiver could select a non-participating pediatric specialist; or (3) the child could be allowed to disenroll. Purchasers and potential Contractors should review these alternatives carefully for operational and fiscal feasibility in light emerging state case law on institutional negligence (see Jones v. Chicago HMO LTD., Illinois Supreme Court (Docket No. 86830, May 18, 2000).*

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<sup>45</sup> HCFA's "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "The State has provisions in MCOs/PHPs contracts which allow children with special needs who utilize specialists frequently for their health care to be allowed to maintain these types of specialists as PCPs or be allowed direct access to specialists for the needed care" (p. 3).

**(1) No Appropriate Pediatric Specialist** — With respect to an enrolled child with special health care needs (as defined in §108(c)), Contractor shall comply with the requirements of paragraph (2) if:

(A) no pediatric specialist (as defined in §108(j)) who participates in Contractor's provider network and who meets the travel and service waiting time requirements under §205(c) and has the capacity to assume the responsibilities of providing specialty care services identified in the child's care plan under §105 to the child; or

(B) a pediatric specialist who has been treating the child terminates (voluntarily or involuntarily) participation in Contractor's provider network and there is no other pediatric specialist described in subparagraph (A) to whom Contractor is able to refer the child.

**(2) Duty to Arrange for Pediatric Specialist** — In a case described in paragraph (1), Contractor shall:

(A) refer the child to an appropriate pediatric specialist who does not participate in Contractor's provider network and who meets the travel and service waiting time requirements under §205(c) and has the capacity to assume the responsibilities of providing specialty care services identified in the child's care plan under §105 to the child;

(B) permit the family or caregiver to select for the child a pediatric specialist who does not participate in Contractor's provider network and reimburse the specialist for items and services covered under §103(a) in the same amount that the specialist would be paid under [*drafter insert reference to state Medicaid program*] on a fee-for-service basis for furnishing the item or service; or

(C) permit the family or caregiver to request the voluntary disenrollment of the child from Contractor under §201(d)(2) (relating to disenrollment).

**(3) Notice** — In the case described in paragraph (1), Contractor shall, within [ ] of the inability to find a pediatric specialist or the termination, notify the family or caregiver of the child of Contractor's duties under paragraph (2):

(A) in writing; or

(B) through the child's care coordinator under §104(d)(5).

## §204. Provider Network

(a) **In General** — Contractor shall comply with the requirements of:

- (1) **Part 5** of MEDICAIDSPECS<sup>46</sup> to the extent consistent with the requirements of this section;
- (2) the requirements of this section relating to primary care providers, pediatric specialists, care coordinators, composition of network, out-of-network arrangements, provider selection and retention, and reimbursement; and
- (3) the requirements of **§204A** (relating to written agreements with providers to furnish a medical home for enrolled children).

(b) **Primary Care Providers** — Consistent with **§502** of MEDICAIDSPECS, Contractor shall ensure that the number of primary care providers (as defined in **§108(k)**) participating in Contractor’s provider network (or accessible through out-of-network arrangements) is sufficient, consistent with the travel time and service waiting time requirements of **§205(b)**, to enable Contractor to meet its duty under **§101(a)** to provide a medical home to each enrolled child with special health care needs (as defined in **§108(c)**). In determining sufficiency, Contractor may include pediatric professionals (as defined in **§108(i)**) selected by families or caregivers under **§203(b)(1)(A)**.

(c) **Pediatric Specialists** — Contractor shall ensure that the number of pediatric specialists (as defined in **§108(j)**) participating in Contractor’s provider network (or accessible through out-of-network arrangements) is sufficient, consistent with the travel time and service waiting time requirements of **§205(c)**, to enable each enrolled child with special health care needs (as defined in **§108(c)**) to have access under **§105(c)(4)** and **§205(c)** to an appropriate pediatric specialist for specialist services identified in the child’s care plan under **§105(b)**.<sup>47</sup>

(d) **Care Coordinators Participating in Contractor’s Provider Network** — Contractor shall include in its provider network a number of care coordinators (as defined in **§108(b)**) that is sufficient to ensure that each care coordinator shall be responsible

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<sup>46</sup> **§501** of MEDICAIDSPECS sets forth illustrative language on general requirements for MCO provider networks, including: **§501(b)** (written agreements with participating providers); **§501(c)** (credentialing requirements and profiling); **§501(d)** (cultural competence of practitioners); **§501(f)** (racial, ethnic, and cultural diversity); **§501(g)** (access to providers); and **§501(j)** (provider integrity). In addition, **§505** of MEDICAIDSPECS would require all providers participating in MCO provider networks to comply with the Americans with Disabilities Act (ADA) and section 504 of the Rehabilitation Act of 1973.

<sup>47</sup> An alternative option would be to require Contractor to include in its provider network a sufficient number of pediatric specialists (as defined in **§108(j)**).



under §104(d) for no greater than [ ]<sup>48</sup> enrolled children with special health care needs at any given time.

**(e) Composition of Provider Network**

*Commentary: In general, MCOs have two options for developing the provider capacity to deliver covered services to enrollees. They could recruit all of the needed primary care and specialist practitioners and facilities into one or more provider networks. Or, in cases where they are unable to recruit the necessary type or number of providers into their networks, they could arrange for referrals of enrollees to out-of-network providers. From the MCO's standpoint, the inclusion of practitioners and facilities in their provider networks is generally preferable because it gives them more ability to control the cost and quality of the services which they have contracted to deliver. From the purchaser's standpoint, the most important consideration would be ensuring that the necessary practitioners and facilities are accessible to enrolled beneficiaries for covered services in a timely manner, and that if the necessary practitioners are not participating in contractor's network, they are actually accessible to enrollees.*

*The following illustrative language is drafted to permit purchasers and contractors to negotiate among these different options. For example, a purchaser and contractor could agree that sufficient numbers of each of the necessary types of providers will be included in the contractor's network. They could then use subsection (g) as a checklist for delineating the desired composition of the network. If all provider types so designated were included in the contractor's network, the language at subsection (f) regarding out-of-network arrangements would be unnecessary. In the alternative, a purchaser and contractor might decide that particular types of providers cannot, given market circumstances, realistically be recruited into the contractor's provider network. In such cases, language such as that suggested at subsection (f) may be necessary to ensure the accessibility of such out-of-network providers to enrollees.*

**(1) Duty** — Contractor shall ensure that Contractor's provider network (as defined in §108(m)) at all times includes providers of each of the types specified in subsection (g) in sufficient numbers to ensure compliance with the access requirements of §205.

**(2) Providers Not Participating** — If Contractor is unable to secure the participation of providers of each of the types specified in subsection (g) in sufficient numbers to ensure compliance with the access requirements

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<sup>48</sup> The Guidance for Applicants (GFA), No. SM-99-005, for the Child Mental Health Initiative issued January 1999 by the Substance Abuse and Mental Health Services Administration (SAMHSA), PHS, DHHS, at page 8 suggests a case manager to enrolled child ratio of no more than 10 to 1 for those children with "the most serious disturbance and complex needs" and a ratio of no more than 15 to 1 for those children with "less serious disturbance and complex needs." See also Association of Maternal and Child Health Programs (AMCHP), Care Coordination Principles (forthcoming)

of §205, Contractor shall enter into out-of-network arrangements under subsection (f) with respect to the providers necessary to carry out Contractor's duty under paragraph (1).

**(f) Out-of-Network Arrangements**

(1) **In General** — Contractor shall make arrangements that meet the requirements of §510 of MEDICAIDSPECS and paragraph (2) with the providers described in subsection (e)(2).

(2) **Arrangements** — Contractor shall ensure that, with respect to each of the providers who do not participate in Contractor's provider network through whom Contractor furnishes items or services covered under §103(a) to enrolled children with special health care needs (as defined in §108(c)):

(A) Contractor has on file a letter from the provider representing the provider's intent to treat enrolled children with special health care needs if referred by Contractor or a provider participating in Contractor's provider network; and

(B) Contractor has verified that the provider:

(i) participates in [*drafter insert name of state Medicaid program*]; or

(ii) does not furnish items or services to [*drafter insert name of state Medicaid program*] beneficiaries on a fee-for-service basis but holds a valid Medicaid provider number.

*Commentary: The following illustrative language is intended to allow purchasers and contractors to negotiate the types of providers that contractor will make available to enrolled children with special health care needs. As discussed above, these providers may participate in contractor's provider network or may furnish services out of network. The mix between participating and out-of-network providers will vary over time depending upon market conditions, provider preferences, contractor business strategies, and other factors. The listing of providers identified in the following paragraphs (1) through (3) is found in Peggy McManus, Maternal and Child Health Policy Research Center, Evaluating Managed Care Plans for Children with Special Health Needs: A Purchaser's Tool, [www.ichp.edu](http://www.ichp.edu). Note that under the illustrative language at §205, contractors would also be subject to requirements relating to sufficient numbers of certain types of providers to ensure accessibility to covered services.*

(g) **Types of Providers** — For purposes of subsections (e) and (f), the types of providers described in this subsection are:

(1) primary care practitioners in each of the following:

- (A) pediatrics;
- (B) adolescent medicine;
- (C) family medicine;
- (D) obstetrics/gynecology; and
- (E) internal medicine;

(2) pediatric medical subspecialists in each of the following:

- (A) allergy and immunology;
- (B) cardiology;
- (C) child and adolescent psychiatry;
- (D) critical care;
- (E) dermatology;
- (F) developmental/behavioral medicine;
- (G) emergency medicine;
- (H) endocrinology;
- (I) gastroenterology;
- (J) genetics;
- (K) hematology/oncology;
- (L) infectious disease;
- (M) neonatology/perinatology;
- (N) nephrology;
- (O) neurology;

- (P) physical medicine and rehabilitation;
  - (Q) pulmonology; and
  - (R) radiology;
- (3) pediatric surgical subspecialists in each of the following:
- (A) anesthesiology;
  - (B) neurosurgery;
  - (C) ophthalmology;
  - (D) oral surgery;
  - (E) orthopedics;
  - (F) otolaryngology;
  - (G) pediatric surgery;
  - (H) plastic surgery;
  - (I) pulmonology; and
  - (J) urology;
- (4) hospitals or medical centers specializing in the care of children;
- (5) the following practitioners with pediatric expertise:
- (A) nurses;
  - (B) child and adolescent psychologists and other mental health practitioners;
  - (C) social workers;
  - (D) physical therapists;
  - (E) occupational therapists;
  - (F) speech therapists;

- (G) respiratory therapists;
- (H) home health providers;
- (I) nutritionists;
- (J) dentists;
- (K) orthodontists; and
- (L) psychiatrists.

(6) care coordinators (as defined in **§108(b)**);

(7) the following programs:

(A) inpatient mental health treatment furnished by [*drafter insert names of fully accredited psychiatric community hospitals*];

(B) residential treatment furnished by [*drafter insert names of programs*];

(C) therapeutic group home services furnished by [*drafter insert names of programs*]; and

(D) intensive day treatment services furnished by [*drafter insert names of programs*]; and

(8) entities that furnish early intervention services to infants, toddlers, and their families under Part C of the Individuals with Disabilities Education Act, 20 U.S.C. §1431 et seq.

**(h) Provider Selection and Retention** — Consistent with **§501(c)** of MEDICAIDSPECS, Contractor:

(1) shall not discriminate against providers who care for children with special health care needs (as defined in **§108(c)**) in:

(A) selecting or retaining physicians and other providers for participation in Contractor's provider network; and

(B) referring enrolled children to providers for treatment; and

(2) shall, in reviewing the practice revenues and expenses (actual or projected) of a physician or other provider participating in Contractor's provider network, take into account the professional time and skill (and

the related costs) attributable to the treatment of children with special health care needs (as defined in §108(c)) for purposes of determining the physician's or provider's:

(A) compensation; or

(B) continued participation in the network.

**(i) Reimbursement**

*Purchasers may find it useful to review Negotiating the New Health System (3<sup>rd</sup> Ed.) which provides other options relating to payment terms used by state agency purchasers in contracting with Medicaid MCOs in 1996. These options may be found at Table 7.2, Vol. 2, Part 4, pages, 7-94 through 7-174, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).*

**(1) In General** — Contractor shall comply with the requirements of paragraphs (2) through (4).

*Commentary: §1932(f) of the Social Security Act, 42 U.S.C. §1396u-2(f) requires that MCOs pay health care providers for delivering items and services covered under Medicaid risk contracts on a timely basis consistent with §1902(a)(37)(A) of the Act, 42 U.S.C. §1396a(a)(37)(A) (e.g., 90 percent of clean claims are paid within 30 days of receipt), unless the provider and the MCO agree to an alternate payment schedule.*

**(2) Prompt Payment to Providers Participating in Contractor's Provider Network** — Contractor shall make payment for items and services covered under §103(a) furnished to an enrolled child with special health care needs by a provider that participates in Contractor's provider network in a manner that is no less prompt than that required under §1932(f) of the Social Security Act, 42 U.S.C. §1396u-2(f).

**(3) Prompt Payment to Providers Not Participating in Contractor's Provider Network**<sup>49</sup> — Contractor shall make payment for items and services covered under §103(a) furnished to an enrolled child with special health care needs by a provider that does not participate in Contractor's provider network in a manner that is no less prompt than that required under §1932(f) of the Social Security Act, 42 U.S.C. §1396u-2(f).

**(4) Financial Risk** — With respect to any arrangement for the compensation of a physician participating in Contractor's provider

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<sup>49</sup> An alternative option would be to require Contractor to reimburse the out-of-network provider at the same rate that the state's Medicaid program would pay the provider for the item or service on a fee-for-service basis.

network for the furnishing of items and services covered under §103(a) to enrolled children with special health care needs (as defined §108(c)), Contractor shall comply with the requirements of §1903(m)(2)(A)(x) of the Social Security Act, 42 U.S.C. §1396b(m)(2)(A)(x), 42 C.F.R. §417.479, relating to physician incentive plans.

#### §204A. Medical Home

*Commentary: As discussed in the commentary before §101, the pediatric standard of care for children with special health care needs is that of a “medical home” – an approach to providing care that is accessible, family-centered, comprehensive, continuous, coordinated, compassionate, and culturally competent. See AAP, Managed Care and Children with Special Needs: Medical Home Checklist (1998), <http://www.aap.org/advocacy/medhome/resourcesmedhomechecklist.htm>. The illustrative language in **Part I** sets forth the Contractor's duties to operate in a manner consistent with the medical home approach. This section addresses the duties of individual network providers to furnish a medical home to such children in their practices through the written agreement between the Contractor and the provider. The Purchaser, while not a party to these written agreements, may specify minimum requirements for such agreements through the main purchasing agreement with Contractor. These requirements would ensure that the elements of the purchasing agreement that affect the medical home approach -- e.g., guidelines (§106), access standards (§205), and care coordination (§105) -- apply directly to the providers who serve as primary care providers for such children (whether these providers are primary care providers or pediatric specialists).*

(a) **In General** — Consistent with §501(b) of Part 5 of MEDICAIDSPECS, Contractor shall enter into and maintain an enforceable written agreement with each provider participating in Contractor's provider network that meets the requirements of subsection (b) and the requirements of §204(i) (relating to reimbursement).

(b) **Written Agreements with Providers**<sup>50</sup> — The enforceable written agreement between Contractor and a provider participating in Contractor's provider network shall:

(1) set forth the provider's duties relating to:

(A) a medical home under subsection (c);

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<sup>50</sup> For examples of a written agreement between an MCO and a physician, see American Academy of Pediatrics, Model Managed Care Agreement (1998); American Medical Association, Model Managed Care Contract, 2<sup>nd</sup> Ed. (2000), [www.ama-assn.org/ama/upload/mm/38/mmcmsa.pdf](http://www.ama-assn.org/ama/upload/mm/38/mmcmsa.pdf).

(B) the submission of accurate and complete data to Contractor as required under §208;

(C) other provisions under [*drafter insert name of Purchasing Agreement*]; and

(D) requirements under applicable federal and state law;

(2) requires performance of the duties specified in paragraph (1):

(A) as a condition of participation in Contractor's provider network; and

(B) in consideration of payment by Contractor (consistent with §204(i)); and

(3) requires Contractor to supply, within [ ] days of the effective date of disenrollment of a child with special health care needs under §201(d) (relating to voluntary disenrollment) and §201(e) (relating to involuntary disenrollment), accurate and complete information to the provider regarding the disenrollment.

**(c) Provider's Duty to Furnish a Medical Home** — The duties of a provider participating in Contractor's provider network who functions as a primary care provider with respect to an enrolled child with special health care needs (as defined in §108(c)) are to:

(1) furnish items and services covered under §103(a) in a manner that ensures continuity of care consistent with:

(A) the guidelines specified in §106(a); and

(B) the access standards specified in §205;

(2) participate in the formulation, updating, and implementation of the child's care plan under §105 in order to monitor the growth and development of the child and furnish necessary items and services;

(3) coordinate the provision of primary care with the provision of specialty and other services to the child by:

(A) assuming the responsibilities of the child's care coordinator under §104(b)(2); or

(B) assisting the child's care coordinator in carrying out the responsibilities enumerated under §104(d); and



(4) maintain a medical record for the enrolled child that tracks the furnishing of primary care and specialized medical and health services to the child.

## §205. Access Standards

*Commentary: Many contracts between State Medicaid agencies and MCOs contain language relating to the accessibility of covered services. See CHRSP, Negotiating the New Health System, 3<sup>rd</sup> Edition (1999), Table 3.7, Volume 3, Part 2, pp. 3-358 - 3-441. For illustrative language on access standards for all populations by type of service (e.g., preventive, routine, and specialty services), see CHRSP, Optional Purchasing Specifications: Access to Services (June 2000), Part A-1. Both references can be found at [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp). The following illustrative language is specific to access by children with special health care needs to primary care providers and to pediatric specialists. It is designed to be incorporated into contractual access provisions of more general applicability.*

(a) **In General** — Contractor shall comply with the requirements of **Part 6** of MEDICAIDSPECS to the extent the requirements are consistent with this section.

*Commentary: For a summary of primary care provider access standards (including capacity requirements) used by 6 states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico), see Table 9, pp. 82-85, of Kaye et al., Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria, National Academy for State Health Policy, (June 2000) <http://www.hcfa.gov/medicaid/needsrpt.pdf>.*

### (b) Access to Primary Care Providers

(1) **Travel Time in Urban Areas** — In the case of an enrolled child with special health care needs (as defined in **§108(c)**) living in [*drafter insert name of urban area(s) within Contractor's service area*], Contractor shall ensure that at least one<sup>51</sup> primary care provider under **§204(b)** participating in Contractor's provider network is located within [ ] minutes travel time (using ground transportation) of the child.

(2) **Travel Time in Rural Areas** — In the case of an enrolled child with special health care needs (as defined in **§108(c)**) living in [*drafter insert name of rural area(s) within Contractor's service area*], Contractor shall ensure that at least one primary care provider under **§204(b)** participating in Contractor's provider network is:

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<sup>51</sup> An alternative option would be to increase the minimum number of providers so that an enrolled child has a choice of two or more providers within a reasonable travel time.

(A) located at a practice site within:

(i) [drafter insert travel time] of the child using ground transportation; or

(ii) if the child's family or caregiver certifies in writing to Contractor that the child is willing to travel for a period of time longer than that specified in clause (i), such longer period of time; or

(B) accessible via telemedicine.

(3) **Service Waiting Times** — Contractor shall ensure that an enrolled child with special health care needs (as defined in §108(c)) receives an appointment for items or services (other than emergency or urgent care services)<sup>52</sup> covered under §103(a) appropriate to the child's health care needs from a primary care provider participating in Contractor's provider network within:

(A) [ ] days of request (by telephone or in person) in [drafter insert name of urban area(s) within Contractor's service area]; and

(B) [ ] days of request (by telephone or in person) in [drafter insert name of rural area(s) within Contractor's service area].

**(c) Access to Pediatric Specialists for Specialty Services**

*Commentary: A number of states have enacted legislation that impose standards on MCOs with respect to patient access to specialists. For a recent summary of these provisions, see Molly Stauffer, National Conference of State Legislatures, 2000 State by State Guide to Managed Care Law (September 1999), Table 2-4, and Families USA Foundation, Hit and Miss: State Managed Care Laws (July 1998), Table 1, [www.familiesusa.org](http://www.familiesusa.org). Interested purchasers should consider the following illustrative language in light of any appropriate state law.*

(1) **In General** — Contractor shall comply with the requirements of this subsection regarding access of enrolled children with special health care needs (as defined in §108(c)) to pediatric specialists (as defined in §108(j)).

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<sup>52</sup> For definitions of emergency services and urgent care, see §§1401(l), (z) of MEDICAIDSPECS, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).

**(2) Standing Referrals to Pediatric Specialists for Specialty Care Services**

(A) **In Urban Areas** — In the case of an enrolled child with special health care needs living in [*drafter insert name of urban area(s) within Contractor's service area*], Contractor shall, consistent with **§107(a)(5)**, provide for the direct access visits specified in the child's care plan under **§105(c)**, without prior authorization from the child's primary care provider or Contractor, to pediatric specialists specified in the care plan, whether or not such specialists participate in Contractor's provider network.

(B) **In Rural Areas** — In the case of an enrolled child with special health care needs living in [*drafter insert name of rural area(s)-within Contractor's service area*], Contractor shall consistent with **§107(a)(5)**, provide for the direct access visits (whether face-to-face or via telemedicine) specified in the child's care plan under **§105(c)**, without prior authorization from the child's primary care provider or Contractor, to pediatric specialists specified in the care plan, whether or not such specialists participate in Contractor's provider network.

(C) **Service Waiting Times** — Contractor shall ensure that the direct access visits described in subparagraphs (A) and (B) are scheduled to occur within [ ] days of request by an enrolled child with special health care needs or the child's family or caregiver.

**(3) Other Referrals to Pediatric Specialists for Specialty Care Services** — In the case of a request for, or referral to, a pediatric specialist for an item or service (other than an emergency service or urgent care) covered under **§103(a)** that is not subject to a standing referral under paragraph (2), Contractor shall ensure that the encounter with the specialist is:

(A) in the case of a child with special health care needs living in [*drafter insert name of urban area within Contractor's service area*], scheduled to occur within [ ] days of request by an enrolled child with special health care needs, the child's family or caregiver, or the child's primary care provider; and

(B) in the case of a child with special health care needs living in [*drafter insert name of rural area within Contractor's service area*], scheduled to occur (whether face-to-face or via telemedicine) within [ ] days of request by an enrolled child with special health care needs, the child's family or caregiver, or the child's primary care provider.

## §206. Relationships with Other State and Local Agencies<sup>53</sup>

*Commentary: This section sets forth illustrative language for memoranda of understanding between contracting MCOs and state agencies other than the purchaser that have responsibility for children with special health care needs. These are: state Title V CHSCN agencies, state substance abuse and mental health agencies, and state educational agencies. There are other state agencies that have responsibility for children with special health care needs, including state child welfare agencies and state developmental disabilities agencies. For illustrative language setting forth memoranda of understanding between contractor and these agencies, see §707 and §708, respectively, of Part 7 of MEDICAIDSPECS.*

*Note also that HCFA, in a letter to State Medicaid Directors dated November 25, 1998, observed that Medicaid agencies have an opportunity to “work with Ryan White grantees and managed care organizations to ensure a continuum of care for persons with HIV disease that avoids duplication of services and provides optimal service by qualified providers to beneficiaries.” See [www.hcfa.gov/medicaid/smd-11258.htm](http://www.hcfa.gov/medicaid/smd-11258.htm).*

*For a summary of requirements for coordination agreements by MCOs with state agencies 6 states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico), see Table 15, pp. 136-138, of Kaye et al., Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria, National Academy for State Health Policy (June 2000), <http://www.hcfa.gov/medicaid/needsrpt.pdf>.*

**(a) In General** — Contractor shall comply with the requirements of **Part 7** of MEDICAIDSPECS, to the extent consistent with the requirements of this section.

### **(b) Relationship with State Title V Program for Children with Special Health Care Needs**

*Commentary: The following illustrative language addresses the relationship between contractor and the division within the State Title V agency that administers the CSHCN program. For illustrative language relating to the non-CSHCN Title V populations, see §703 of Part 7 of MEDICAIDSPECS. Some State Title V CSHCN Programs pay for or provide medical care directly to children with special health care needs; others furnish care coordination and referrals but do not pay for or provide medical care. The following illustrative language is designed to accommodate both types of arrangements.*

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<sup>53</sup> HCFA's "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "The State requires the MCO/PHP to coordinate health care services for special needs children with: providers of mental health, substance abuse, local health department, transportation, home- and community-based waiver, developmental disabilities, and Title V services" (p. 3)

(1) **Referral of Disenrolled Children** — In the case of an enrolled child with special health care needs (as defined in §108(c)) whose enrollment is terminated due to ineligibility for [drafter insert name of State Medicaid program], Purchaser<sup>54</sup> shall, at the time of disenrollment, notify:

(A) the child and the child’s family or caregiver in writing of the availability of medical, care coordination, or other services from:

(i) the [drafter insert name of State Title V CHSCN Program]; or

(ii) in the case of services not available directly from [drafter insert name of State Title V CHSCN Program], providers subcontracting with or funded by the [Title V CHSCN Program]; and

(B) the [Title V CHSCN Program] of the name, address, and phone number of the child.

*Commentary: State Title V Agencies are required to report annually on their progress toward achieving the targets they set for 18 national Performance Measures and 6 Outcome Measures. Performance Measure #2 concerns the degree to which the State Title V CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients. See [www.mchdata.net](http://www.mchdata.net). The illustrative language in subsection (c) is designed to enable interested Purchasers to ensure that their State Title V CSHCN Program receives the information it needs to assess its progress on Performance Measure #2 directly from the Contractor. In the alternative, Purchasers may wish to require that Contractors report the necessary information to them so that they can transfer it to the State Title V CSHCN Program. For illustrative language reflecting this alternative approach, see §208(c).*

(2) **Notification to Title V CSHCN Program Relating to Covered Items and Services and National Title V “Core” Performance Measures** — Contractor shall notify the [drafter insert name of State Title V CSHCN Program] regarding Contractor’s duty, if any, under §103(a) to furnish, or arrange for the furnishing of, the following classes of services to enrolled children with special health care needs:

(A) medical and surgical subspecialty services;

(B) occupational therapy and physical therapy services;

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<sup>54</sup> An alternative option would be for the purchaser to delegate this duty to Contractor.

- (C) speech, hearing, and language services;
- (D) respiratory services;
- (E) durable medical equipment and supplies;
- (F) home health care;
- (G) nutrition services;
- (H) care coordination; and
- (I) early intervention services.

**(3) Written Agreement for Care Coordination Services between Contractor and State Title V Program for Children with Special Health Care Needs** — If Contractor elects to furnish care coordination services covered under §104(c) through [*Title V CHSCN Program*], Contractor shall enter into and maintain an enforceable written agreement with [*Title V CHSCN Program*] that sets forth the responsibilities of care coordinators under §104.

**(4) Memorandum of Understanding with State Title V Program for Children with Special Health Care Needs**

(A) **In General** — Contractor shall enter into a memorandum of understanding with [*drafter insert name of State Title V Program for Children with Special Health Care Needs*] if the Program is willing to enter into such a memorandum, which shall have the same term as [*drafter insert name of purchasing document*], and which shall address the matters enumerated in subparagraph (B).

**(B) Elements of Memorandum of Understanding**

(i) The responsibility of Contractor and the responsibility of the Program (or the Program's grantees or subcontractors) for the furnishing of, and the payment for, items and services that:

(I) are covered under §103(a) with respect to enrolled children with special health care needs (as defined in §108(c)); and

(II) the Program routinely furnishes (or arranges through grantees or subcontractors for the

furnishing of) to children with special health care needs;

(ii) The responsibility of Contractor and the responsibility of the Program (or the Program's grantees or subcontractors) for the furnishing of, and the payment for, items and services that:

(I) are not covered under **§103(b)** with respect to enrolled children with special health care needs; and

(II) the Program routinely furnishes (or arranges through grantees or subcontractors for the furnishing of) to children with special health care needs;

(iii) The responsibility of Contractor (if any) and the responsibility of the Program (or the Program's grantees or subcontractors) (if any) for payment for treatment of a member of the family of an enrolled child with special health care needs, or a caregiver of the child, who is not enrolled under [*drafter insert name of purchasing agreement*], but who requires treatment in order to effectively treat a condition or developmental disability or delay of the child;

(iv) The responsibility of the Program (or the Program's grantees or subcontractors) for the identification of enrolled children with special health care needs to Purchaser (if any under **§102(a)(2)**), and the responsibility of Contractor to notify the Program of the identity of enrolled children determined to be children with special health care needs;

(v) The responsibility of Contractor and the responsibility of the Program (or the Program's grantees or subcontractors) for arrangements for reciprocal referrals of enrolled children with special health care needs;

(vi) The responsibility of Contractor and the responsibility of the Program (or the Program's grantees or subcontractors) for making information regarding the arrangements under clauses (i) through (v) available to the families and caregivers of enrolled children with special health care needs;

(vii) The responsibility of Contractor and the responsibility of the Program (or the Program's grantees or subcontractors) for the exchange of data and information relating to items and services furnished to enrolled children with special health care needs, subject to *[drafter insert reference to applicable consent requirements under state law]*;

(viii) The responsibility of Contractor and the responsibility of the Program (or the Program's grantees or subcontractors) for the designation of individuals responsible for coordinating the implementation of the memorandum; and

(ix) The manner in which disputes between Contractor and the Program regarding the terms of the memorandum will be resolved.

**(c) Relationship with State Substance Abuse and Mental Health Services Agency**

*Commentary: The following illustrative language also appears in §709 of MEDICAIDSPECS.*

**(1) Referral of Disenrolled Children** — In the case of an enrolled child with special health care needs (as defined in **§108(c)**) whose enrollment is terminated due to ineligibility, Purchaser<sup>55</sup> shall, at the time of disenrollment, notify:

(A) the child and the child's family or caregiver in writing of the availability of services from:

(i) the *[drafter insert name of State Mental Health and Substance Abuse Agency]*; or

(ii) in the case of services not available directly from the *[State Mental Health and Substance Abuse Agency]*, providers subcontracting with or funded by the *[State Mental Health and Substance Abuse Agency]*; and

(B) the *[State Mental Health and Substance Abuse Agency]* of the name, address, and phone number of the child.

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<sup>55</sup> An alternative option would be for the purchaser to delegate this duty to contractor.



## **(2) Memorandum of Understanding with State Mental Health and Substance Abuse Agency**

(A) **In General** — Contractor shall enter into a memorandum of understanding with [*drafter insert name of State Mental Health and Substance Abuse Agency*] if the Agency is willing to enter into such a memorandum, which shall have the same term as [*drafter insert name of purchasing document*], and which shall address the matters enumerated in subparagraph (B).

### **(B) Elements of Memorandum of Understanding**

(i) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the furnishing of, and the payment for, items and services that:

(I) are covered under **§103(a)** with respect to enrolled children with special health care needs; and

(II) the Agency routinely furnishes (or arranges through grantees or subcontractors for the furnishing of) to children with special health care needs;

(ii) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the furnishing of, and the payment for, items and services that:

(I) are not covered under **§103(b)** with respect to enrolled children with special health care needs; and

(II) the Agency routinely furnishes (or arranges through grantees or subcontractors for the furnishing of) to children with special health care needs;

(iii) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for payment for treatment of a member of the family of an enrolled child with special health care needs, or a caregiver of the child, who is not enrolled under [*drafter insert name of purchasing agreement*], but who requires treatment in order to effectively treat a condition or developmental disability or delay of the child;

(iv) The responsibility of the Agency (or the Agency's grantees or subcontractors) for the identification of enrolled children with special health care needs to Purchaser (if any under §102(a)(2)), and the responsibility of Contractor to notify the Agency of the identity of enrolled children determined to be children with special health care needs;

(v) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for arrangements for reciprocal referrals of enrolled children with special health care needs;

(vi) The responsibility of Contractor and the responsibility of the Agency for making information regarding the arrangements under clauses (i) through (v) available to the families and caregivers of enrolled children with special health care needs;

(vii) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the exchange of data and information relating to items and services furnished to enrolled children with special health care needs, subject to [drafter insert reference to applicable consent requirements under state law];

(viii) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the designation of individuals responsible for coordinating the implementation of the memorandum; and

(ix) The manner in which disputes between Contractor and the Agency regarding the terms of the memorandum will be resolved.

#### **(d) Relationship with State Education Agency and Part C Lead Agency**

*Commentary: The following illustrative language could be used to frame a memorandum of agreement between a Medicaid MCO and the State Educational Agency or Part C Lead Agency. Of course, Local Educational Agencies (LEAs) also play a role in the development and implementation of IEPs for children with disabilities. In some states, LEAs participate in the Medicaid program as providers and are reimbursed on a fee-for-service basis for the covered services they furnish to eligible children under IEPs. Because there could be numerous LEAs within the service area of a Medicaid MCO, particularly if it enrolls children throughout the state, and because not all of those LEAs may have significant numbers of Medicaid-eligible children with IEPs, the following*

language does not address agreements between MCOs and LEAs. Interested purchasers could, however, modify the following language to encourage memoranda of understanding between MCOs and one or more of the LEAs within their service areas. In addition, an MCO may choose to include an LEA as a provider in the MCO's provider network; in this circumstance, the written provider agreement provisions under §204(h)(2) could apply. This illustrative language may also be found in §706 of MEDICAIDSPECS.

(1) **Interagency Agreement** — Contractor shall ensure that Contractor and each provider participating in Contractor's provider network complies with:

(A) [drafter insert the requirements, if any, applicable to Purchaser under its interagency agreement with the State Educational Agency under Part B of the Individuals with Disabilities Education Act, 20 U.S.C. §1412(a)(12), 34 C.F.R. §300.142(b) and (e), relating to furnishing or paying for services]; and

(B) [drafter insert the requirements, if any, applicable to Purchaser under its interagency agreement with the State Lead Agency under Part C of the Individuals with Disabilities Education Act, 20 U.S.C. §1435(a)(10), relating to furnishing or paying for services].

(2) **Memorandum of Understanding with State Education Agency or Part C Lead Agency**

(A) **In General** — Contractor shall enter into a memorandum of understanding with [drafter insert name of State Educational Agency or Part C Lead Agency] if the Agency is willing to enter into such a memorandum, which shall have the same term as this [drafter insert name of purchasing document], and which shall address the matters enumerated in subparagraph (B).

(B) **Elements of Memorandum of Understanding**

(i) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the furnishing of, and the payment for, items and services that:

(I) are covered under §103(a) with respect to enrolled children under IEPs (as defined in §108(f)) or under IFSPs (as defined in §108(g)); and

(II) the Agency routinely furnishes (or arranges through grantees or subcontractors for the furnishing of) to children under IEPs or IFSPs;

(ii) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the furnishing of, and the payment for, items and services that:

(I) are not covered under **§103(b)** with respect to enrolled children under IEPs (as defined in **§108(f)**) or under IFSPs (as defined in **§108(g)**); and

(II) the Agency routinely furnishes (or arranges through grantees or subcontractors for the furnishing of) to children with IEPs or IFSPs;

(iii) The responsibility of Contractor, in the case of a coverage determination affecting an enrolled child with special health care needs for whom the Agency has responsibility, to:

(I) take into account the opinions of, and evidence supplied by, the Agency with respect to the determination **§101A(b)(6)** of MEDICAIDSPECS; and

(II) notify the Agency under **§102A(c)(3)** of MEDICAIDSPECS of the determination;

(iv) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for payment for treatment of a member of the family of an enrolled child under an IEP or IFSP, or a caregiver of the child, who is not enrolled under [*drafter insert name of purchasing agreement*], but who requires treatment in order to effectively treat a condition or developmental disability or delay of the child;

(v) The responsibility of the Agency (or the Agency's grantees or subcontractors) for the identification of enrolled children with an IEP or IFSP to Purchaser under **§102(a)(2)**, and the responsibility of Contractor to notify the Agency of the identity of enrolled children whom Contractor has determined may require an IEP or IFSP;

(vi) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for arrangements for reciprocal referrals of enrolled children with IEPs or IFSPs;

(vii) The responsibility of Contractor and the responsibility of the Agency for making information regarding the arrangements under clauses (i) through (vi) available to the families and caregivers of enrolled children with special health care needs;

(viii) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the exchange of data and information relating to items and services furnished to enrolled children with IEPs or IFSPs consistent with the confidentiality requirements in **§209(e)**;

(ix) The responsibility of Contractor and the responsibility of the Agency (or the Agency's grantees or subcontractors) for the designation of individuals responsible for coordinating the implementation of the memorandum; and

(x) The manner in which disputes between Contractor and the Agency regarding the terms of the memorandum will be resolved.

## **§207. Quality Measurement and Improvement<sup>56</sup>**

*Commentary: The following illustrative language assumes that the costs to Contractors of conducting quality measurement and improvement activities, including the clinical focus studies specified by Purchaser, will be factored into the capitation rate paid by Purchaser to Contractor on behalf of each enrolled child with special health care needs. For a summary of performance measures used by 6 states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico), see Table 11, pp. 105-108 of Kaye et al., Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria, National Academy for State Health Policy, (June 2000) <http://www.hcfa.gov/medicaid/needsrpt.pdf>.*

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<sup>56</sup> See National Policy Center for Children with Special Health Care Needs, Measurements of Quality of Care for Children with Special Health Care Needs (July 2000), [www.jhsph.edu/chscn](http://www.jhsph.edu/chscn).

(a) **In General**<sup>57</sup> — Contractor shall comply with the requirements of **Part 8**<sup>58</sup> of MEDICAIDSPECS to the extent consistent with the requirements of this section.

(b) **Clinical Focus Studies** — Contractor shall, on a [ ] basis, conduct, or arrange for the conduct of, the following focus studies relating to the furnishing of clinical services under **§103(a)** to children with special health care needs (as defined **§108(c)**):

- (1) the extent to which providers participating in Contractor’s provider network are applying the child health supervision guidelines enumerated in **§106** in treating enrolled children with special health care needs;
- (2) the implementation of care plans developed under **§105**;
- (3) the provision of items and services for the treatment of [*drafter specify chronic childhood conditions that reflect Purchaser’s research priorities*]; and
- (4) [*drafter insert other focus study topics reflecting research priorities of other state agencies*].

(c) **Other Focus Studies** — Contractor shall, on a [ ] basis, conduct, or arrange for the conduct of, the following focus studies relating to the availability and accessibility of services under **§103(a)** to children with special health care needs (as defined **§108(c)**):

- (1) the extent to which the standards relating to access to primary care providers and pediatric specialists specified in **§205** are met;
- (2) the providers participating in Contractor’s provider network from whom enrolled children with special health care needs most frequently receive covered services;
- (3) the provision of care coordination services under **§104(d)** for enrolled children with special health care needs;
- (4) the rate at which enrolled children with special health care needs are involuntarily disenrolled from Contractor under **§201(e)**;
- (5) the level of satisfaction of families or caregivers of enrolled children with special health care needs, as measured by [ ]<sup>59</sup>, with the

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<sup>57</sup> HCFA’s "Draft Interim Review Criteria for Children with Special Needs" (June 4, 1999) provides: "The State has some specific performance measures for children with special needs (for example, CAHPS for children with special needs, HEDIS measures stratified by special needs children, etc.)" (p. 3).

<sup>58</sup> **Part 8** of MEDICAIDSPECS includes illustrative language regarding quality measurement and improvement (**§802**), and utilization review (**§805**), external quality review (**§806**).

accessibility and quality of the services covered under [*drafter insert name of purchasing document*]; and

(6) [*drafter insert other study topics reflecting research priorities of other state agencies*].

## **§208. Data Collection and Reporting<sup>60</sup>**

(a) **In General** — Contractor shall comply with:

(1) the requirements of §907 of MEDICAIDSPECS (relating to encounter data) and the remainder of Part 9<sup>61</sup> of MEDICAIDSPECS; and

(2) the requirements of subsections (b) and (c), but only to the extent Contractor does not meet such requirements through the data collected and reported under paragraph (1).

*Commentary: The following illustrative language assumes Contractor is collecting and reporting encounter data, as articulated in §907 of MEDICAIDSPECS. A recent GAO analysis reaffirmed that encounter data regarding patients with disabilities "is essential for effective monitoring. The information can play an important role in quality assurance, estimates of future service use, research, and program planning. Developing comprehensive, consistent data on services provided under capitated managed care takes time and effort, and can be expensive. However, it can permit states to identify areas in which service utilization rates are overly low or high." General Accounting Office, Medicaid Managed Care: Challenges In Implementing Safeguards for Children with Special Needs (March 2000) GAO/HEHS-00-37, p. 31, [www.gao.gov](http://www.gao.gov). Of course, the precise definition of encounter data tends to vary from state to state. One purpose of the following language is to provide a checklist of data elements relating to children with special health care needs from which purchasers may wish to draw in designing their general requirements*

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<sup>59</sup> Purchasers may wish to consider requiring Contractor to administer the Child Medicaid-Managed Care Questionnaire of the Consumer Assessment of Health Plan Survey (CAHPS), developed by the Agency for Healthcare Research and Quality to measure Medicaid beneficiary satisfaction with managed care plans. See <http://www.ahrq.gov/qual/cahps/cahpques.htm>.

<sup>60</sup> Under current federal law and regulation, Medicaid MCOs are *not* required to collect and report data using the Health Plan Employer Data and Information Set (HEDIS). Even in those MCOs which do use HEDIS, there are limitations in HEDIS for monitoring the health of children with chronic health conditions. See Kuhlthau et al., *Assessing Managed Care for Children with Chronic Conditions*, Health Affairs (July/August 1998) pp. 42-52.

<sup>61</sup> Part 9 of MEDICAIDSPECS includes illustrative language on the following issues: §904 (access data); §905 (quality data); §906 (aggregate utilization data); §907 (encounter data); §908 (complaint and grievance data); §909 (expenditure and claims data); §910 (data relating to practitioners); §911 (confidentiality of data); §912 (public access to data); §913 (ownership of data); §914 (information system); and §915 (purchaser access to data).

*relating to encounter data collection and reporting. Another option for purchasers would be to supplement their general encounter data collection by requiring contractors to report data specific to children with special health care needs that the state is not already collecting. The following illustrative language would accommodate both approaches to avoiding duplication of data requirements.*

(b) **Data Specific to Children with Special Health Care Needs**<sup>62</sup> — Contractor shall collect and report to Purchaser, on a [ ] basis, in such form and manner as Purchaser specifies, the following data (to the extent that such data are not required under the encounter data provisions of §907 of MEDICAIDSPECS):

(1) the number of enrolled children identified to or by Contractor as children with special health care needs (as defined in §108(c)), broken down by:

(A) age;

(B) gender;

(C) race or ethnicity;

(D) receipt of Supplemental Security Income (SSI) benefits;

(E) diagnostic category; and

(F) enrollment in [*drafter insert name of State Title V CSHCN Program*];

(2) the number of enrolled children identified to or by Contractor as children who are in foster care;

(3) the number of enrolled children who receive early intervention services under an IFSP (as defined in §108(g));

(4) the number of enrolled children who receive health or related services under an IEP (as defined in §108(f));

(5) the number and percentage of families or caregivers of enrolled children with special health care needs who are dissatisfied with the accessibility or quality of the services specified in the child's care plan

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<sup>62</sup>These data elements are derived in part from Maternal and Child Health Bureau, HRSA, Measuring Success: National Agenda for Children with Special Health Care Needs (forthcoming on MCHB's website <http://www.mchb.hrsa.gov/cshcnmc.html>).



under **§105**, grouped by zip code of residence within Contractor's service area;

(6) the number of enrolled children with special health care needs who disenroll due to:

(A) inability to select a primary care provider under **§203(b)**;

(B) inability to access to pediatric specialist under **§203(c)**; and

(C) dissatisfaction with the accessibility or quality of the services specified in the child's care plan under **§105**;

(7) the results of:

(A) the clinical studies under **§207(b)**; and

(B) the other studies under **§207(c)**;

(8) the number and types of emergency services (as defined under **§1401(i)** of MEDICAIDSPECS) furnished to enrolled children with special health care needs during the [ ] period; and

(9) the number of each of the following types of adverse incidents not reported under paragraph (8) (relating to emergency services) involving children with special health care needs during the [ ] period, including:

(A) suicide or attempted suicide;

(B) adverse drug reaction (including drug overdose);

(C) alcohol poisoning;

(D) child abuse; and

(E) [*drafter insert other types of adverse incidents appropriate to enrolled CSHCN subpopulations, such as children with behavioral health needs (e.g., erroneous prescription of psychotropic medication)*].

*Commentary: State Title V Agencies report annually on their progress toward achieving the targets they set for 18 national Performance Measures and 6 national Outcome Measures with respect to the children with special health care needs for whom they have responsibility. See [www.mchdata.net](http://www.mchdata.net). One approach to collecting this information is reflected in **§206(b)(2)**, under which Contractors would report this data directly to the State Title V CSHCN Program. The*

*illustrative language below embodies an alternative approach under which the Contractor reports to the Purchaser the data that the State Title V CSHCN Program requires in order to prepare its progress reports. The illustrative language would require that the data be supplied to Purchaser because the Title V CSHCN Agency is not a party to the purchasing agreement; however, Purchasers may establish arrangements for transfer of this data to the Title V CSHCN Agency under the interagency agreement under §1902(a)(11)(B) of the Social Security Act, 42 U.S.C. §1396a(a)(11)(B).*

**(c) Data Relating to National Title V Performance and Outcome Measures**

— Contractor shall collect and report to Purchaser, on a [ ] basis, in such form and manner as Purchaser specifies, the data required by the [Title V CSHCN Agency] to report on its progress in achieving the State targets for performance and outcomes under Title V of the Social Security Act, 42 U.S.C. §701 et seq.

**§209. Enrolled Child Safeguards<sup>63</sup>**

**(a) In General** — Contractor shall comply with the requirements of:

- (1) **Part 10** of MEDICAIDSPECS to the extent consistent with the requirements of this section;
- (2) Americans with Disabilities Act, 42 U.S.C. §12101 et seq. 28 C.F.R. Part 35 and 36;<sup>64</sup>
- (3) §504 of the Rehabilitation Act of 1973, 29 U.S.C. §794, 45 C.F.R. Part 85; and
- (4) Title VI of the Civil Rights Act of 1964, 42 U.S.C. §2000d, 45 C.F.R. §80.1 et seq.

**(b) Unnecessary Inquiries** — Consistent with **§009(d)** of MEDICAIDSPECS, Contractor shall ensure that any communication with an enrolled child with special health care needs (as defined in **§108(c)**) does not make unnecessary inquiries into the existence

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<sup>63</sup> Section 4705 of the Balanced Budget Act (P.L. 105-33) requires HCFA to prepare a report to Congress in consultation with states, managed care organizations, NASHP, representatives of beneficiaries with special health care needs, and experts in specialized health, on “safeguards, if any, that may be needed to ensure that the health care needs of individuals with special health care needs and chronic conditions who are enrolled with Medicaid managed care organizations are adequately met.” A draft report, released July 2, 1999, is currently being reviewed and updated for submission to Congress.

<sup>64</sup> See Rosenbaum et al., “The Americans with Disabilities Act: Implications for Managed Care for Persons with Mental Illness and Addiction Disorders,” Issue Briefs #5 and #6, Managed Behavioral Health Care Issue Brief Series, GW Center for Health Services Research and Policy (October 1999), [www.samhsa.gov](http://www.samhsa.gov).

of a disability in violation of the Americans with Disabilities Act, 42 U.S.C. §12101 et seq.<sup>65</sup>

(c) **Due Process** — Contractor shall comply with the requirements of §1902(a)(3) of the Social Security Act, 42 U.S.C. §1396a(a)(3), and implementing regulations at 42 C.F.R. §§431.200 et seq., relating to notice, fair hearing, and continuation of coverage rights of an enrolled child with special health care needs (as defined in §108(c)) in the event of:

- (1) a denial, termination, or reduction of an item or service covered under §103(a); or
- (2) the failure to furnish an item or service covered under §103(a) with reasonable promptness.

(d) **Confidentiality Protections for Enrolled Adolescents** — Contractor shall comply with §1002 of Part 10 of MEDICAIDSPECS.

(e) **Other Safeguards for Children with Special Health Care Needs** — Contractor shall comply with:

- (1) the requirements of 34 C.F.R. Part 99.31 implementing the Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. §1232(g); and
- (2) the confidentiality protections in the Individuals with Disabilities Education Act with respect to an:
  - (A) IEP at 20 U.S.C. §1417(c), 34 C.F.R. §§300.560 – 300.577; and
  - (B) IFSP at 20 U.S.C. §1439(a)(2), 34 C.F.R. §§303.400 – 303.425

## §210. Remedies for Noncompliance

(a) **In General** — Contractor shall comply with the requirements of **Part 12** of MEDICAIDSPECS.

(b) **Enrolled Children as Intended Third Party Beneficiaries** — Contractor agrees and affirms that an enrolled child with special health care needs (as defined in §108(c)) is an intended third-party beneficiary to [*drafter insert name of purchasing*

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<sup>65</sup> HCFA's "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs" (October 1998), [www.hcfa.gov/medicaid/smd-snpf.htm](http://www.hcfa.gov/medicaid/smd-snpf.htm), provides that states should consider that "[c]ommunications with MCO enrollees must be consistent with the ADA prohibition on unnecessary inquiries into the existence of a disability."

*document*], and that such child, and the child’s family or caregiver on the child’s behalf, is entitled to all of the rights and remedies available to third party beneficiaries under state or other law.<sup>66</sup>

**§211. Other Applicable Federal and State Requirements** — Contractor shall comply with the requirements of **Part 13** of MEDICAIDSPECS.

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<sup>66</sup> The legal doctrine of third party beneficiary holds that individuals who are not party to a contract may, under certain circumstances, enforce performance of duties in the contract on the part of the parties to the contract. While varying from state to state, this doctrine is reflected in both state court decisions and state laws, and applies to both private and public contracts. See Calamari and Perillo, Contracts 3<sup>rd</sup> Ed. 1987, §§17-4,17-7. The illustrative language would clarify the applicability of the law of the Purchaser’s state. Note that a federal court has recently ruled that the parents of Medicaid-eligible children with behavioral health needs enrolled in Medicaid MCOs under a section 1915(b) waiver have a private right of action to seek enforcement of certain beneficiary protections, such as the requirement that covered services be made available with “reasonable promptness,” *Kirk T. v. Houstoun*, No. Civ. A. 99-3253 (E.D. Pa., September 28, 1999).

### Part 3. Payment Issues

As noted in the introduction, these purchasing specifications do not address two sets of payment issues: (1) those relating to the determination of capitation rates paid to MCOs by state purchasers on behalf of enrolled children with special health care needs; and (2) payment methodologies used by MCOs with respect to network and out-of-network providers. For language used by state purchasers relating to both of these issues, see Table 7.1 (Plan Payment Terms) and Table 7.2 (Provider Payment Terms) in CHSRP's *Negotiating the New Health System*, 3<sup>rd</sup> Ed. (1999), Vol. 2, Part 4, [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp). In developing language on these issues, purchasers may wish to take into account the following considerations.

**Payments to Plans from Purchasers.** Federal Medicaid law requires that payment rates in risk contracts between state Medicaid agencies and MCOs be set on "an actuarially sound basis." Medicaid-eligible children generally tend to have greater unmet health care needs than other children, and Medicaid-eligible children with special health care needs tend to have even higher acuity levels. This means that, in developing "actuarially sound" capitation rates for MCOs that enroll such children, state purchasers should ensure that the levels of payment will supply an efficient MCO with the resources necessary to address the service needs of this population. In short, in order to be "actuarially sound," capitation rates for this population should be adjusted to reflect the higher risk that an MCO assumes in accepting treatment responsibility for such children.

In a letter to State Medicaid Directors dated October 5, 1998, HCFA notes that "[t]he manner in which States decide to reimburse MCOs and providers for the delivery of services plays a major factor in how those systems of care operate and how enrollees access services." HCFA suggests that "States should consider ... developing rates of payment to MCOs, prior to enrollment of persons with special health care needs, that assure adequate payments." HCFA also suggests that "States should consider...providing appropriate financial incentives to providers and MCOs to encourage appropriate delivery of care to persons with special health care needs. Such approaches also must recognize that serving individuals with special health care needs takes more time and resources than with healthier patients ...."<sup>67</sup>

HCFA has not specified, and there is no professional consensus on, a methodology for adjusting capitation payments to Medicaid MCOs enrolling children with special health care needs or subsets of such children. Instead, there is a great deal of experimentation underway at the state level. For a summary of factors used by 6 states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico) in varying capitation rates, see Table 17, pp. 144-150, of Kaye et al., *Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria*, National Academy for State Health Policy (June 2000), <http://www.hcfa.gov/medicaid/needsrpt.pdf>.

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<sup>67</sup> HCFA letter to State Medicaid Directors, October 5, 1998, "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs," [www.hcfa.gov/medicaid/smd-snpf.htm](http://www.hcfa.gov/medicaid/smd-snpf.htm), p. 12.

*Other sources of information that interested purchasers may wish to consult are:*

- *National Academy for State Health Policy, Medicaid Managed Care: A Guide for the States, 4<sup>th</sup> Ed., Volume IV: Innovations in Payment Strategies to Improve Plan Performance (October 1999).*
- *Holahan, et al., Medicaid Managed Care Payment Methods and Capitation Rates: Results of a National Survey (1999), <http://newfederalism.urban.org/html/occa26.html>.*
- *Schwalberg, R., The Development of Capitation Rates under Medicaid Managed Care Programs: A Pilot Study (Volumes I and II), Washington DC: Health Systems Research, Inc. prepared for the Henry J. Kaiser Family Foundation (November, 1997), [www.kff.org](http://www.kff.org).*
- *Hoag, et al., "Setting Rates for Medicaid Managed Behavioral Health Care: Lessons Learned," Health Affairs, Vol. 19/4 (July/August 2000), pp. 121-133.*
- *Neff et al., "Protecting Children with Chronic Illness in a Competitive Marketplace" JAMA (1995) 274:23, pp. 1866-1869.*
- *List, D. and Ireys, H. "Studies of Service Use by Children with Special Health Care Needs: What Have We Learned in 20 Years?" (submitted for publication), [www.jhsph.edu/cshcn](http://www.jhsph.edu/cshcn).*
- *Hwang et al., "Comparison of Risk Adjusters for Children with Chronic Illnesses" (submitted for publication), [www.jhsph.edu/cshcn](http://www.jhsph.edu/cshcn).*

**Payments to Providers from Plans.** *These purchasing specifications, at §204(i)(2) - (4), contain illustrative language addressing some of the issues relating to MCO payments to providers, both participating and out-of-network. The language converts federal Medicaid requirements relating to prompt payment and physician incentives into Contractor duties. The language does not, however, speak to the adequacy or reasonableness of the rates or amounts paid to providers by MCOs. This is because the federal Medicaid statute specifies reimbursement arrangements between MCOs and providers only in the case of Federally Qualified Health Centers (FQHCs).*

*For other sources of information that purchaser may wish to consult:*

- *American Academy of Pediatrics, Model Managed Care Agreement, Section Five, pages 12-18 (1998); and*
- *Andrews, et al., Pediatric carve-outs: The use of disease-specific conditions as risk adjusters in capitated payment systems, Archives of Pediatric and Adolescent Medicine 151(3): (1997), p. 236-242.*

## **Compliance Measures: Parts 1 and 2**

**Compliance Measures: Contractor shall make available to Purchaser upon request:**

### **(1) Information Regarding Coverage Determinations**

**(A) All protocols, provider manuals, memoranda, and other materials used by Contractor to make coverage determinations or to instruct providers on coverage, coverage determination standards and procedures, and prior authorization procedures under this purchasing agreement.**

### **(2) Enrollment Materials**

**(A) Instrument used by providers participating in Contractor's network in performing initial assessments of newly enrolled children to determine whether they have special health care needs; and**

**(B) Manuals, protocols, guidance, or other materials in which Contractor describes how an initial assessment is to be conducted and how confidentiality regarding the information obtained from the assessment is to be maintained.**

### **(3) Care Plans and Care Coordinators**

**(A) Manuals, protocols, guidance, or other materials in which Contractor describes:**

- (1) the development and implementation of a care plan; and**
- (2) the responsibilities of an enrolled child's care coordinator.**

**(B) The number of enrolled children with respect to whom Contractor has developed a care plan and the number of such plans signed by the family or caregiver of the enrolled child.**

### **(4) Provider Network Information**

**(A) Credentialing rules and other criteria for selection of pediatric specialists participating in Contractor's provider network;**

**(B) Copies of agreements with providers participating in Contractor's provider network;**

**(C) Provider Manual pertaining to Contractor operations; and**

**(D) Letters of documentation of referral arrangements.**

**(5) Information Regarding Access to Pediatric Specialists**

**(A) The following information relating to each pediatric specialist participating in Contractor's provider network:**

- (i) Name;**
- (ii) Area of practice;**
- (iii) Provider number;**
- (iv) Address (including zip code) of each practice site at which the specialist offers services;**
- (v) Current office telephone number(s) of each practice site; and**
- (vi) Office hours of each practice site; and**

**(B) The pediatric professionals participating in Contractor's provider network who are willing to serve as primary care providers for children with special health care needs;**

**(C) Pediatric specialists not participating in Contractor's provider network to whom enrolled children with special health care needs are referred.**

**(6) Information Regarding Relationships with Other State and Local Agencies**

**(A) Copies of memoranda of understanding executed by Contractor with State Title V Program for CSHCN, State Substance Abuse and Mental Health Services Agency, and State Education Agency and State Part C Lead Agency.**

**(7) Clinical and Other Studies**

**(A) Copies of any clinical and other studies conducted by or on behalf of Contractor relating to the quality of items and services furnished to children with special health care needs.**

**(8) Findings and Reports from External Reviews and Accreditation**

**(A) Copies of any findings or reports from external quality reviews under §1932(c)(2) of the Social Security Act, 42 U.S.C. §1396u-2(c)(2); and**

**(B) Copies of any findings or reports of accreditation surveys relating to Contractor.**