January 19, 2001

Dear State Medicaid Director:

This letter encloses revised Federal review criteria for children with special health care needs (CSHCN) who are mandatorily enrolled in Medicaid managed care programs. The goal of the revised review criteria is to provide the necessary assurances that CSHCN benefit from appropriate safeguards in Medicaid waiver and demonstration programs. These revised criteria build upon the “Draft Interim Review Criteria (DIRC) for Special Needs Children” that was released on June 4, 1999.

Section 1915(b)(1) of the Social Security Act requires that programs that waive freedom-of-choice of provider must “not substantially impair access to services of adequate quality when medically necessary.” These revised criteria represent HCFA’s articulation of the safeguards necessary to ensure that access to needed services is not impaired for this vulnerable population within a mandatory managed care environment. As such, these revised criteria – as with the DIRC – will apply to:

- Existing section 1915(b) waiver programs upon next renewal;
- Existing section 1915(b) waiver programs upon modifications that mandatorily move beneficiaries that were in fee-for-service Medicaid into capitated MCOs;
- New section 1915(b) waiver program or new section 1115 demonstrations;
- Section 1115 demonstrations upon the end of a 3-year extension period authorized by section 4757 of the Balanced Budget Act of 1997; and
- Section 1115 demonstrations otherwise extended (“non-section 4757”).

In all these instances, the criteria apply to managed care programs in which Medicaid beneficiaries are mandatorily enrolled (or default-enrolled) into capitated Managed Care Organizations (MCOs)/Prepaid Health Plans (PHPs). In States operating mixed-model MCO/PHP and Primary Care Case Management programs, the revised criteria must be addressed for the MCO/PHP component only.

Upon the release of the DIRC, we informed States and other stakeholders that the revised document would be informed by the results of a series of case studies conducted by the National Academy of State Health Policy, our experience working with States using the draft document, and comments from interested parties. That work has now been completed; thus the attached revised document reflects the input of States, advocates, providers, and MCOs. The revised document is also consistent with the requirements addressing populations with special health care needs in the quality provisions (subpart D) of the Final Medicaid Managed Care Rule, released pursuant to the Balanced Budget Act of 1997. The Final Medicaid Managed Care Rule outlines the State’s responsibilities for
its overall quality strategy for all managed care enrollees and the State’s responsibility to address the quality and appropriateness of care delivered to enrollees with special health care needs.

We will soon be working to incorporate this revised document into a new addendum to Section F of the section 1915(b) Waiver Pre-Print, replacing the addendum that currently incorporates the DIRC. Use of the Pre-Print itself remains optional; however, each item in the addendum must be fully addressed in order to obtain HCFA approval to mandatorily enroll beneficiaries into MCOs/PHPs under the circumstances described above.

Throughout this process, HCFA has learned a great deal about State efforts already in place to ensure that CSHCN receive the Medicaid services to which they are entitled. We look forward to these revised criteria further demonstrating States’ and HCFA’s commitment to this population.

Thank you for your past efforts in applying the DIRC and for your attention to the revised criteria. If you or your staff have any comments or questions, please contact Clarke Cagey of my staff on (410) 786-7700 or ccagey@hcfa.gov.

Sincerely,

/s/

Timothy M. Westmoreland
Director

Enclosure

cc:
HCFA Regional Administrators

HCFA Associate Regional Administrators
   For Medicaid and State Operations

Lee Partridge
Director, Health Policy Unit
American Public Human Services Association

Joy Wilson
Director, Health Committee
National Conference of State Legislatures

Matt Salo
Director of Health Legislation
National Governors’ Association
When addressing these criteria, States should ensure that each of the following are addressed, as appropriate: the State’s responsibilities in managed care programs enrolling children with special health care needs; the State’s requirements for MCOs/PHPs enrolling children with special health care needs; and how the State monitors its own actions and that of its contracting MCOs and PHPs. Please also note additional resources that may be helpful to States, which are included as endnotes to this document.

Public Process

• The State has in place a public process for the involvement of relevant parties (e.g., advocates, providers, families, caregivers, consumer groups, State agencies, MCOs/PHPs) that treat or otherwise serve children with special health care needs. The State seeks the participation of these parties during the development and ongoing operation of the managed care program.

• The State assures that MCOs/PHPs have a process to seek input from these same groups on relevant operational and monitoring issues on a regular basis.

Definition of Children with Special Health Care Needs

• Using health status/functioning or a categorical basis, the State has developed a definition or definitions of children with special health care needs. At a minimum, the State’s definition must include the following five subsets (inasmuch as such groups are enrolled in a mandatory capitated managed care program).


Medicaid-eligible children under age 19 who are:

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

Identification and Enrollment

• To ensure that the safeguards in this document are applied, the State identifies and/or requires MCOs/PHPs to identify children with special health care needs once they are enrolled in an MCO/PHP. The State indicates which entity is to determine if a child is identified as having a special health care need.⁴
• For foster-care children only, the State describes the enrollment provisions that address the broader, unique issues occurring because of out-of-home, out-of-geographic area placement.

• The State explains the processes it has for identifying any child in one of the five groups described in the Definition section, including: relevant information on screening tools; linkages with other State agencies (e.g., Child Protective Services and Title V); Medicaid claims data; new member outreach; and client surveys.

• The State performs outreach activities that are targeted specifically to reach children with special health care needs and their families, caregivers, providers, and other interested parties regarding the managed care program.

• The State ensures that enrollment counselors have information and training to assist children with special health care needs in selecting appropriate MCOs/PHPs and providers based on their medical needs, including information on how to access up-to-date provider listings. The State articulates the processes it has in place to facilitate interaction between families and enrollment selection counselors.

• Auto-assignment processes assign children with special health care needs to an MCO/PHP that includes their current primary care provider and/or specialists or to an MCO/PHP that is capable of providing a medical home.\(^5\)

• A child with special health care needs can disenroll into fee-for-service or transfer enrollment into another MCO/PHP for good cause or without cause. The State describes the process for disenrollment or transfer under these circumstances. The State ensures that such disenrollment information is appropriately factored into its quality assurance efforts.

• If an MCO/PHP requests to disenroll or transfer enrollment of an enrollee to another plan, the reasons for reassignment are not discriminatory in any way -- including adverse change in an enrollee’s health status and non-compliant behavior of individuals with mental health and substance abuse diagnoses -- against the enrollee. The State describes the corrective action that would take place in instances of any discrimination.

• The State has processes in place for children with special health care needs who have lost and then regained Medicaid eligibility to re-enroll, if desired, with their most recent MCO/PHP.

**Provider and Specialist Capacity**

• The State consults with its Title V agency to determine how "experienced provider" will be interpreted.

• The State ensures that the MCOs/PHPs in a geographic area have sufficient experienced providers with the ability to meet the unique needs of children with special health care needs (e.g., primary care, specialists, ancillary therapists, hospitals, and mental health providers).

• The State describes how it monitors access to experienced providers, including those who provide specialty care to children.

• The State requires particular specialist types to be included in the MCO/PHP network, taking into account the necessity of including pediatric subspecialties to provide care for children with special health care needs. If necessary primary or specialty care cannot be provided within the network, arrangements are made for enrollees to access these providers (for Medicaid services covered by the contract).
• The State has provisions in MCOs/PHPs contracts that allow children with special needs who use specialists frequently for their health care to be allowed to maintain these types of specialists as PCPs or be allowed direct access/standing referral to specialists for the needed care.6

• The State describes how it monitors to ensure access to specialty medical equipment and supplies that may be required by children with special health care needs. The State describes how it resolves situations in which there are disputes regarding supplies and equipment.

### Coordination

• The State requires a timely and comprehensive assessment of each child’s health care needs and implementation of a treatment plan based on that assessment, for any of the five subsets of children described above. The State describes the process for ensuring that children receive these assessments, which include face-to-face physical examinations of children with special health care needs by MCO/PHP providers.

• The State provides or requires the MCOs/PHPs to provide case management or care coordination services to children with special health care needs. The State identifies what entity is held accountable for providing these services.

• The State has a process for coordination with other systems of care that receive Federal funding (for example, Medicare, HRSA Title V grants, Ryan White CARE Act, SAMHSA Mental Health and Substance Abuse Block Grant Funds) and other State and local funding sources (state education agency, child welfare/other social services, Part C lead agency).

• The State requires the MCOs/PHPs to coordinate health care services for children with special health care needs with the services of other agencies (e.g., mental health and substance abuse, public health department, transportation, home and community based care, developmental disabilities, Title V, local schools, IDEA programs, and child welfare), and with families, caregivers, and advocates.

### Quality of Care

• The State has specific performance measures for children with special health care needs (for example, Consumer Assessment of Health Plans [CAHPS] for children with special health care needs; Health Employer Data Information Set [HEDIS] measures stratified by children with special health care needs, etc.).7

• The State has specific performance improvement projects that address issues for children with special health care needs.

### Other Policy Guidance

• To the extent appropriate, the State has adequately addressed any policy guidance that HCFA has issued to date relevant to children with special health care needs.

### Payment Methodology

• The State develops a payment methodology that accounts for children with special health care needs enrolled in
capitated managed care.

- The State provides information on any future plans it may have to institute additional risk adjustment for children with special health care needs, including intentions to work with other appropriate State agencies to develop such risk adjustment methodologies.

**Plan Monitoring**

- The State has in place a process for monitoring children with special health care needs enrolled in MCOs/PHPs for access to services (including EPSDT and also day-to-day services such as wheelchairs, in-home therapy, and other supplies), quality of care, coordination of care, and enrollee satisfaction.

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

- The State’s MCO/PHP contracts specify what constitute medically necessary services for children with special health care needs, and it makes these specifications available to families and advocates. The State’s specifications address the extent to which the MCO/PHP is responsible for covering services related to a child’s ability to achieve age-appropriate growth and development. Also, the specifications allow approval/authorization of services in a timely fashion.

- The State monitors MCOs/PHPs service authorization policies to ensure that the criteria are consistent with the medical necessity contract specifications and any practice guidelines adopted by the MCO/PHP that are relevant to children with special health care needs.

**ENDNOTES (REFERENCES AND RESOURCES FOR REVIEW CRITERIA)**

1 In the Balanced Budget Act of 1997 (BBA), Congress identified these five groups of children as ones to be excluded from mandatory enrollment in managed care under the BBA’s state plan amendment process, although it continued to permit their enrollment through waiver or demonstration authority. States should be aware that the BBA “definition” does not include all children who may have a special health care need. In developing a definition, States should consult with appropriate stakeholders, and may want to consider the following definition, which has been endorsed by the Health Resources and Services Administration, DHHS; the American Academy of Pediatrics, and the Association of Maternal & Child Health Programs:

“Children with special health care needs are those who have a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

2 Children who are eligible for Medicaid under 1902 (e)(3) are an optional Medicaid eligibility group (also known as “Katie Beckett” children) who require a level of care provided in institutions but reside in the community. States that do not include this optional category may cover similar children under a home and community-based waiver. As Congress spoke only to those children eligible through 1902(e)(3) in the BBA, these criteria only apply to such children when the optional eligibility category is used.

3 Title V of the Social Security Act provides formula block grants to 59 States and territories to develop service systems for women and children. A minimum of 30 percent of the block grant funds must be used to provide and promote family centered, coordinated care for children with special health care needs and to facilitate the development of community-based systems for such children and their families. State Title V CSHCN programs use a broad range of activities to carry out this responsibility and meet the needs of CSHCN in their state. These activities include: direct service provision of medical, specialty services and enabling
services such as case management; consultative services concerning the care of CSHCN; health care management activities at both the individual and systems level; and managing resources, including negotiating and reimbursing providers for specific services and benefits. States should take into consideration that the group of Title V children in the “BBA definition” must be eligible for Medicaid.

4 The identification of children with special health care needs is an ongoing process and serves many purposes including enrolling children in the appropriate MCO, assessing their health care needs and assigning them to the appropriate primary care provider, and monitoring quality of care. There are efforts underway to develop efficient tools and strategies for identifying and monitoring children with special health care needs. One strategy is the use of Living with Illness Screening Tool (which was developed by the Foundation for Accountability (FACCT), Child and Adolescent Health Measurement Initiative (CAHMI) (For additional information, contact www.facct.org). Another tool is the QuICCC (Questionnaire for Identifying Children with Chronic Conditions), which contains 39 questions for the family or care giver (or the 19-question version of this instrument, called QuICCC-R) (For additional information, 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). An additional strategy is using Clinical Risk Groups (CRGs), a classification system developed by the National Association of Children’s Hospital and Related Institutions (NACHRI) in conjunction with 3M (see Muldoon, J; Neff, J; Gay J; (1997) Profiling Health Service Needs of Populations using Diagnosis Based Classification System, Journal of Ambulatory Care Management, 20, 1-18. These strategies can be supplemented by using administrative data bases (e.g. cost and utilization data, ICD-9 and other diagnostic coding) and aid code analysis to identify children with special health care needs.

5 The pediatric standard for care for children with special health care needs is that of a “medical home”. A medical home is an approach to providing care that is accessible, family-centered, comprehensive, continuous, coordinated, compassionate and culturally competent. For further information, see the American Academy for Pediatrics, Managed Care and Children with Special Needs: Medical Home Checklist; www.aap.org/advocacy/medhome/resourcesmedhomechecklist.htm). Families and caregivers of children with special health care needs should be allowed to choose as a medical home either a primary care provider or a specialist with the capacity and expertise to provide primary care services to such children.

6 State officials may want to review the technical assistance document "Optional Purchasing Specifications: Medicaid Managed Care for Children with Special Health Care Needs to develop contract provisions on behalf of these children. These specifications provide illustrative language on covered benefits and delivery of services to children with special health care needs. The specifications were prepared by George Washington University Center for Health Services Research and Policy (CHSRP) with funding from the Health Resources and Services Administration (HRSA) and the March of Dimes Birth Defects Foundation, in collaboration with the Health Care Financing Administration (HCFA), the Substance Abuse and Mental Health Services Administration (SAMSHA) and the Department of Education (DOE). They were reviewed through a series of vetting meetings involving State Medicaid and public health officials, health care providers, managed care organization representatives, consumers and other outside experts. The specifications can be found at the following website: www.gwu.edu/~chsrp.

7 Title V agencies can assist in monitoring the quality of care for CSCCN. Therefore, we recommend that the Single State Agency responsible for administering Medicaid contact the Title V agency to coordinate performance measures for children with special health care needs.