Certain Children with Special Health Care Needs:

An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria

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June 2000

This report represents information that was available during six state site visits, as reported by key informants and documented in state policies. Policies may have changed since the site visits, and the view of informants may not always reflect the opinions of the constituencies they represent.

ACKNOWLEDGMENTS

This paper would not have been possible without the support of our funders. We would especially like to thank the following for their insight and encouragement:

- Christy Schmidt, Jack Hoadley, Jennifer Tolbert, Claudia Williams, and Hunter McKay of the Office of the Assistant Secretary for Planning and Evaluation;
- Trish MacTaggart, Deirde Duzor, Mike Fiore, Kathleen Blume, Clarke Cagey, Theresa Pratt, David Greenberg, and Tanya Ehrmann of the Health Care Financing Administration; and
- Sara Rosenbaum and Liz Wehr of George Washington University

We wish to thank the members of the expert panel for their guidance in selecting the site visit states, developing the interview protocols, and drafting this report. They are: Louise Bannister and Ruth Ikler of Massachusetts, Kathleen Cota of Minnesota, Ian Hill of The Urban Institute, Christopher Kus of New York, Jack Meyer of New Directions for Policy, Margaret Murray of New Jersey, Margo Rosenbach of Mathematica Policy Research, Inc., Sandra Tunis of the Centene Corporation, Marina Weiss of the March of Dimes, Greg Vadner of Missouri, and Linda Wertz of Texas.

We also extend our most heartfelt thanks to the staff members of many state agencies and managed care organizations as well as to the consumers, providers, and advocates who participated in the site visit interviews and, some of whom, reviewed a draft of this report. In particular, we thank those Medicaid agency staff who helped us organize the site visits and reviewed the draft of this report – your willingness to meet the tight timeline for the production of this report was greatly appreciated . They were: Patrick Gordon and Tracy Johnson of Colorado, Jim Gaito of Connecticut, Kay Holmes of Delaware, Louise Bannister and Ruth Ikler of Massachusetts, Jane Finn of Michigan, and Carolyn Ingram of New Mexico.

Finally, we thank NASHP's own Al Cardona for his efforts in scheduling the site visits.

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EXECUTIVE SUMMARY

The experience of children with special health care needs (CSHCN) in Medicaid managed care is of increasing interest as the number of states enrolling these children in managed care grows. Managed care offers, for the first time, accountable "systems" of health care services for CSHCN, but there are also questions about the capacity of these systems designed for healthier populations to meet the complex and highly specialized care needs of CSHCN. The U.S. Congress, the Health Care Financing Administration (HCFA) and individual states each have been adopting policies that are intended to protect Medicaid-eligible CSHCN from problematic experiences in managed care.

In the Balanced Budget Act of 1997 (BBA) Congress allowed states for the first time to require Medicaid beneficiaries to enroll in managed care, without a waiver of relevant portions of Medicaid law. But also, Congress expressly exempted CSHCN from enrollment in the non-waiver, "state plan" Medicaid managed care programs authorized by the BBA. For purposes of the exemption, Congress defined CSHCN as those children who have been determined by Medicaid or other agencies to qualify for public assistance on the basis of family income and their health condition or on the basis of their foster care status. The five categories of CSHCN in the BBA definition are listed below and described in detail in subsequent chapters of this report.

States may enroll CSHCN, as defined in the BBA, in Medicaid managed care through "waiver" managed care programs, under the authority of either Section 1915(b) or 1115 of the Social Security Act. HCFA determined that special protections for CSHCN should be incorporated in these managed care programs. Accordingly, HCFA, in June, 1999, began phasing in Draft Interim Criteria (hereafter referred to as "Interim Criteria") for evaluating state requests for new or renewed 1915(b) waiver programs and new 1115 demonstration programs. Adopting the Congressional definition of CSHCN, HCFA in the Interim Criteria asked states to show that they were able to identify these children, track the quality of their care in managed care plans and provide for other special protections. While the BBA definition will pick up broad categories of children, HCFA anticipates that states and MCOs will need other processes in place to identify CSHCN who do not fit the BBA definition.

HCFA also recognized the need to gather additional information about current practices and challenges in serving CSHCN under managed care programs that could be used to refine the Interim Criteria to better reflect critical safeguards. Many states have already developed or adapted their Medicaid managed care programs for children that the states have determined to be CSHCN. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) also became interested in examining how Medicaid beneficiaries who are CSHCN are currently served to provide states with information to help them improve their programs.

These two federal agencies combined resources and, through a contract with George Washington University, commissioned the National Academy for State Health Policy (NASHP) to examine how current state practices in the delivery of care to CSHCN relate to Congressional and HCFA policies for protecting CSHCN in Medicaid managed care. NASHP was directed by the funders and an expert panel to conduct site visits in six states (Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico) in the Fall of 1999. During each two and a half day visit, interviews were conducted with a wide variety of stakeholders, including Medicaid and other state agencies, Managed Care Organizations, parents of CSHCN, providers, and advocates.

The Interim Criteria, summarized below and set out in Appendix B, form the framework of this report. Our charge was to inform HCFA and ASPE on the "fit" between the states' activities and the Interim Criteria, for purposes of determining whether the Criteria should be adjusted as HCFA applied them to state waiver requests. It is important to understand that the Interim Criteria **did not apply to any of the six states at the time this study was conducted**. The report presents the study's findings by each major topic area addressed in the Interim Criteria. The following summarizes the key findings in each of these areas.

Definition

For purposes of exempting children about whom there was concern, Congress defined "children with special needs" as Medicaid beneficiaries under 19 years of age who[1]:

< Receive SSI
< Are eligible under 1902(e)(3)[2]
< Are in foster care[3]
< Are receiving foster care or adoption assistance (Title IV-E payments)
< Are receiving Title V-funded care coordination services.

- Medicaid agencies and other entities in the study states use various methods to define CSHCN, depending on the purpose and objectives of the initiative. They may use diagnostic criteria, presence of risk, functional status, or utilization of services to define CSHCN, and they may also use one or more of the BBA categories. For example, informants find that a categorical definition such as SSI is useful to identify a class of children that may need certain safeguards (such as those contained in HCFA's Interim Criteria), whereas they find a definition based on

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[1] In the remainder of the report these five categories of children are referred to as the BBA definition of CSHCN. The definition is based on HCFA's interpretation of the BBA, as delineated in the Interim Criteria.

[2] 1902(e)(3) is the state plan option that allows states to serve children who need an institutional level of care in the community – if the cost of serving them in the community does not exceed the cost of caring for them in the institution. This category does not include similar children who are served under a home and community based waiver.

[3] This category does not include children who are served by the Child Welfare agency but who are not in the custody of the Child Welfare agency – even if the child is living outside the home, perhaps with a relative.

diagnostic criteria and functional status is more useful to determine what types of services are necessary to care for these children. The key informants' view is that no single definition defines a special needs child for all purposes, and that the definition may need to vary, depending on how it is to be used. Informants were interested in a definition that can provide guidance to managed care program operation or evaluation activities, such as the identification of children's actual needs for the purpose of enrolling them in particular programs, coordinating and delivering care, or conducting quality of care studies.

- It was the informants' opinion that the BBA definition is suited for the primary purpose for which it was designed - to identify which groups of children for whom a state must seek a waiver and develop certain safeguards prior to enrolling them in mandatory managed care. However, many informants felt that a strict application of the BBA definition is insufficient. While it will pick up broad categories of children, it does not capture some children with the greatest need of safeguards. Specifically excluded are special needs children who qualify for Medicaid under different eligibility categories than those of the BBA definition, or receive Title V-funded services without care coordination. Further, informants were concerned that the BBA definition would be used to identify a precise number of CSHCN in each state and across states, and, thereby, create misinformation about CSHCN. They noted that the definition cannot be used to produce a consistent count of CSHCN across states, nor can it be used to get an unduplicated count of CSHCN within a state. This is because the BBA groups overlap, and, therefore, adding together the number of children in the five groups does not produce an accurate count of the number of CSHCN in each state.

Identification and Tracking

- At the time of the site visits, states reported that they were using their own definitions of children with special health care needs, all of which differed from HCFA's interpretation of the BBA definition in its Interim Criteria. In reviewing the BBA definition, informants in the six states considered it more important to define CSHCN in a way that would permit them to identify and track individual children and their care needs, as opposed to identifying aggregate groups of children.

- If required, the Medicaid agencies in site visit states reported that they could identify all children in the five BBA groups, although none were doing so at the time of the site visit. The group that poses the most difficulty is those children receiving Title V-funded care coordination because, although states can identify these children with changes to their information systems and processes, no system typically exists for communicating individual level information from the Title V agency to the Medicaid agency.

Enrollment and Disenrollment for CSHCN

- States reported that their policies for enrollment and disenrollment are generally not specific to CSHCN; they apply to all populations who are enrolling in managed care. The issues in the Interim Criteria - outreach to CSHCN and their families, training of enrollment counselors, disenrollment for cause, and auto assignment - are addressed, to some extent, by those general policies. States and MCO informants found it difficult to conduct more targeted activities, specific to CSHCN, however, because of the difficulty in identifying CSHCN prior to enrollment and insufficient information about their health status, current provider, or contact information.

- The availability and transfer of information in the enrollment process was identified as the key issue in enrollment and disenrollment by a range of stakeholders.
  - S Families wanted to know which, if any, aspect of their child's care will be disrupted by the move to managed care and how to access care in their new MCO.
  - S MCOs wanted accurate and complete contact information for new enrollees, as well as information from claims or encounter data about services the children were receiving prior to enrollment so that they may prevent disruptions in care.

  There were concerns, however, about how much detailed information at the time of enrollment would be useful to the family. Informants also questioned how much information should be made available to the MCO, and how it should be provided and collected because of confidentiality concerns. In general, these issues were of greater importance to informants in the site visit states than the particular policies and practices regarding outreach, training, auto-assignment, or disenrollment.

Provider Capacity, Access to Specialists, and Access to Benefits

- All site visit states reported contract provisions in place with their MCOs to assure sufficient provider capacity and access to specialty care. Although those polices were not identical to those described in the Interim Criteria regarding capacity standards or the identification of particular types of specialists in MCO networks, states placed considerable importance on the availability of qualified providers who can serve all enrollees in managed care, including CSHCN.

- While the Interim Criteria address several issues of importance regarding provider capacity and access, informants reported that the specification of capacity standards and certain types of providers for a managed care network are not as critical as ensuring that individual CSHCN have access to the full range of services each needs.
  - S The importance of experienced providers goes beyond primary care, specialty, and subspecialty physicians. All individuals who come in contact with the child need to have an understanding of what it means to have special needs; from personal care assistants, to child welfare agency staff, to DME suppliers, to x-ray technicians, and the MCO staff, themselves.

- The availability of those services that make a difference in the child and family's day-to-day lives; wheelchairs, in-home therapy, diapers and other supplies, private duty nursing, and pharmacy services are considered by families to be at least as important as access to appropriate physicians.
- Parents and providers want to know that there is an established and ongoing system of care, whether managed care or fee-for-service, that can respond to the chronic nature of the child's illness or disability and the ongoing needs of the family throughout the transitions from child to adolescent to adult.

Quality of Care

- Few Medicaid agencies had implemented performance measures specific to CSHCN, as envisioned in the Interim Criteria, although all had conducted qualitative studies and measured MCO performance in areas of concern to CSHCN. They have attempted to stratify those general performance measures in a few cases where the numbers are large enough to provide valid information. The states cited low enrollment numbers for CSHCN and lack of performance measures specific to the population as barriers to implementing quality programs such as are envisioned in the Criteria.

- Site visits informants emphasized the need for both retrospective, long-term assessments of quality as well as early warning and response systems to real and potential problems. While HCFA's Interim Criteria, issued in June, 1999, address retrospective assessments, they do not provide real-time identification of problems. Parents, advocates, and providers underscored the importance of using managed care complaint systems as "real time"markers of potential problems that children and families encounter in Medicaid managed care.[4]

Coordination of Care

- Informants concurred that care coordination is essential for CSHCN and that HCFA's Interim Criteria describe factors important to the care and well-being of children with special needs. The Interim Criteria, however, leave unaddressed many important elements that may ultimately affect the impact of care coordination on a beneficiary's health status and care needs. Terms used in the Criteria, such as "assessment", "treatment plan", and "case management" have multiple meanings among stakeholders, leading to confusion about who should receive care coordination, what is to be provided, and what the outcomes of care coordination should be.

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[4] HCFA recognizes the importance of "real time" warning indicators as measures of quality of care. Since its issuance of the Interim Criteria in June, 1999, HCFA has amended its terms and conditions for waiver programs to include a requirement that states monitor complaints and grievances for the five BBA groups and report them to HCFA periodically.

- Historically, a variety of providers, agencies, and programs have provided components of care coordination to CSHCN. While states and MCOs have developed strategies for coordinating the responsibilities for care of CSHCN across those agencies and programs, opinions vary as to which entity should be ultimately responsible for coordinating the child's care. Although there is no dispute that MCOs should coordinate care within the scope of their covered benefits, questions persist on the extent to which MCOs should be held accountable for coordinating care across the broader array of community and school-based services. Parent and advocate informants in particular stressed the need for neutral parties who could advocate for the child without regard to fiscal implications. Finally, parents emphasized that they, ultimately, coordinate much of their child's care and that the delivery system must recognize and support them in that role.

Payment Methodology

- All Medicaid agencies reported adjusting payments by demographic factors such as age, sex, and eligibility category. Therefore, they would not need to make any changes to meet the Interim Criteria. There was also a growing consensus among the agencies of the need to move beyond these factors to base capitation payments on enrollee health status and to use payment to provide incentives to improve MCO performance.

- The Interim Criteria address only the need for a payment mechanism that accounts for special needs populations enrolled in capitated managed care. Informants raised other issues including:
    - Concern with the adequacy of overall payments to MCOs to accommodate the needs of CSHCN, especially given the limits the Upper Payment Limit (UPL)[5] imposes on MCO payments. Some informants reported that the UPL prevented them from adjusting payment to MCOs for additional costs incurred by meeting pent-up need due to lack of providers in fee-for-service or to compensate them for the costs of fulfilling administrative requirements that do not exist in the fee-for-service system (such as quality studies and care coordination).
    - Concerns about adequate payment for providers from both MCOs and the fee-for-service system.
    - Frustration about the difficulty in establishing payment responsibility for specific services among the multiple agencies that serve CSHCN.

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[5] The Upper Payment Limit is the Federal requirement that the cost of caring for Medicaid beneficiaries under managed care can be no greater than that spent under fee-for-service.

Stakeholder Input

- All Medicaid agencies had public processes in place for the development of the managed care program, similar to that described in the Interim Criteria. States typically involved in those processes those responsible for caring for CSHCN, including families, advocacy groups, providers, MCOs, and Medicaid and other state agencies.

- Informants, including Medicaid agencies, emphasized the importance of involving stakeholders in all aspects of managed care program operation and evaluation, not just program development, and of measuring the results of stakeholder input by assessing the changes that result from that involvement.

Key informants among the six states generally felt that HCFA's Interim Criteria for waiver applications address in general terms the primary topics of importance to CSHCN and their families. However, they expressed concerns with some of the specific requirements and standards, and noted that certain issues, such as access to services and care coordination, warrant increased emphasis because of their critical importance to CSHCN and their families. Further, many of the identification and delivery of care issues that are identified in the Interim Criteria are of equal importance in the fee-for-service system.

Much of the interest about the impact of Medicaid managed care on children with special health care needs reflects concerns about possible cutbacks in services that would have been provided in fee-for-service or restrictions on access to specialist providers. Unfortunately, in attempting to collect data for purposes of comparing Medicaid managed care with fee-for-service systems, we found that little had been done to identify CSHCN specifically in fee-for-service, or to assess how care is delivered to them. Consequently, we are unable to include any meaningful comparisons of the impact of managed care, as opposed to fee-for-service reimbursement, on these children.

Stakeholders emphasized that no one definition or single model of care can address the needs of all children with special health care needs. The needs of CSHCN are complex and, therefore, require multiple approaches and systems to adequately serve them. Further, factors in the larger health care marketplace impact the delivery of care to CSHCN, regardless of the delivery system. It is important that the Criteria that are developed to provide safeguards to CSHCN reflect the diversity of these children and their care needs, and recognize the multiple components of their care, including medical, social, educational, and environmental factors.

I. INTRODUCTION

The 1997 Balanced Budget Act (BBA) allows states to require most Medicaid beneficiaries to enroll in managed care without seeking a waiver of Federal Medicaid law. With the exception of three populations, states may require mandatory enrollment in a managed care organization (MCO), Prepaid Health Plan (PHP), or a primary care case management program (PCCM) by amending the Medicaid state plan. Congress specifically excluded three populations from the state plan option:

- certain children with special needs;
- beneficiaries dually eligible for Medicare and Medicaid; and
- American Indians.

A state must still seek a waiver before enrolling any of these populations into mandatory Medicaid managed care. Congress intended the continuing waiver requirement to ensure that these vulnerable populations receive satisfactory care under managed care arrangements. National advocacy groups as well argued the need for the higher level of federal scrutiny and public input afforded through the waiver process to assure sufficient safeguards and protections as a condition of mandating enrollment of these populations.

This report, prepared by the National Academy for State Health Policy (NASHP), focuses on one of the exempt populations, certain children with special health care needs. The report describes the experiences of six states that, under various pre-BBA arrangements, have been enrolling children with special health care needs (CSHCN) in comprehensive or specialized managed care arrangements on a mandatory or voluntary basis. The framework for this study is a Health Care Financing Administration (HCFA) guidance document, entitled Interim Draft Review Criteria (Interim Criteria), which was published in June, 1999. The Interim Criteria address areas for use in HCFA review of states' waiver proposals to enroll any one or more of the groups of children specified as CSHCN in the BBA into mandatory Medicaid managed care.

NASHP undertook this study at the request of HCFA and the Office of the Assistant Secretary for Planning and Evaluation (ASPE), both of which wished to understand current state experiences with regard to CSHCN and Medicaid managed care and the appropriateness of the HCFA Interim Criteria. The study was carried out under a contract between the agencies and the George Washington University Center for Health Services Research and Policy, for which NASHP served as a subcontractor.

The study had two key purposes. First, the study examined whether the Interim Criteria address factors deemed critical by stakeholders to meet the needs of CSHCN under Medicaid managed care. Second, it assessed the issues that may be faced by states and others in satisfying the Interim Criteria.

The report reflects extensive on-site interviews with stakeholders (Medicaid, other state agencies, MCOs serving CSHCN, and the children's parents, providers and advocates) as well as a review of relevant documents (e.g., managed care contract documents, screening tools for identifying CSHCN). The experiences of six states are reflected in this study: Colorado, Connecticut, Delaware, Massachusetts, Michigan, and New Mexico. The interviews and document analysis took place during the fall and winter of 1999-2000.

The report is organized in chapters corresponding to the topics addressed by the Interim Criteria:

- Definition of CSHCN
- Early identification and continuous tracking of CSHCN
- Informed enrollment and disenrollment options and protections
- Adequate provider capacity and access to services
- Quality of care
- Coordination of care across providers and agencies serving CSHCN
- Adequate payment
- Stakeholder input

Each chapter closes with a summary of findings about current state practices in the particular topic area being discussed. These summaries are designed to respond to study questions posed by the Contractor for this report. The questions addressed in each chapter summary are:

1. Can states meet the Interim Criteria?
2. How do states monitor and evaluate Managed Care Organization (MCO) performance in areas addressed by the Interim Criteria?
3. How do states address areas identified by the Interim Criteria in their fee-for-service systems?
4. How do state practices vary according to state characteristics?
5. Do the Interim Criteria address the most significant issues faced by children and their families?

Study Methods

The study was guided by an expert panel representing a number of stakeholders. (Appendix A provides the list of those who served on the expert panel.) This panel selected the site visit states, reviewed the site visit protocol, and reviewed the draft report.

To help the expert panel select site visit states, NASHP staff produced a background paper identifying a number of aspects of states' managed care programs.[6] Based on the following criteria, the expert panel selected ten states that were not yet subject to the requirements of the Interim Criteria:

- Each state enrolled some or all of the BBA-defined subsets of children with special needs on a mandatory basis.
- Each state enrolled at least two of the BBA-defined subsets of children with special needs.
- Each state used at least one strategy for assuring access to care pertinent to special needs populations (e.g., allowing the use of specialists as Primary Care Providers).
- The selected states needed to vary among themselves in terms of longevity/experience of program and number of children with special needs enrolled in the program.
- Two of the selected states had to use §1115 waivers in their managed care programs and the remainder had to use §1915(b) waivers.

In addition, methods of risk adjustment in calculating capitation payments and incorporating behavioral health benefits in managed care programs were considered in state selection. Finally, the panel strove for a geographic balance among the site visit states as well as representation of both urban and rural states. NASHP staff selected the six final site visit states based on key informant availability within the time-frame required for the study.

Table 1 identifies basic characteristics of the site visit states' managed care programs.

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[6] Data sources for site selection included findings from the Kaiser/HCFA symposium on children with special health care needs in Medicaid managed care, data from NASHP's Guidebook to Medicaid Managed Care, and findings from a survey conducted by HCFA and APHSA. This information was supplemented by information available from the participating agencies on the current status of certain waiver initiatives.

Table 1: Site visit state Medicaid managed care program characteristics

State	**CO**	**CT**	**DE**	**MA**	**MI**	**NM**
MCO	**U**	**U**	**U**	**U**	**U**[7]	**U**
PCCM	**U**			**U**		
BH/PHP[8]	**U**			**U**		
Specialty Managed Care Programs	Safety Net Project: grant funded program in which 4 out of 5 MCOs voluntarily participate; goals are to identify CSHCN and improve care coordination. (Grant ends summer 2000.)			Special Kids **ì** Special Care serves children in foster-care with complex medical needs; pilot program started in 1999.	Children's Special Health Care Services (CSHCS): voluntary program for Title V beneficiaries, including those with Medicaid; may choose a "Special Health Plan" or fee-for-service.	
Program Start Date	MCO: 1976; PCCM: 1982; BH/PHP: 1995	1995	1995	1992	MCO: 1972; Special Health Plans:1998	1997
Waiver Type	1915(b)	1915(b)	1115	1115	1915(b)	1915(b)
# Managed Care Enrollees	MCO: 88,393 PCCM: 51,623 BH/PHP: 218,262	229,000	71,000	MCO: 141,369 PCCM: 446,062 BH/PHP: 483,515 (enrollment in Special Kids **ì** Special Care began week of site visit)	MCOs: 750,000 Specialty plans: 2,000	212,000
# MCOs	5 MCOs; 8 BH/PHP (1/geographic area)	4 MCOs (1 is FQHC-owned)	3 MCOs[9]	4 MCOs; 1 BH/PHP	27 MCOs; 2 Special Health Plans	3 MCOs

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[7] Actually, Michigan contracts with both MCOs and PHPs that deliver primary care in the "MCO" program. However, the only difference in requirements between the two is in the scope of services included in the capitation payment and the requirement for State licensure so both are referred to as MCOs in the remainder of this report.

[8] A BH/PHP is, in this report, defined to be a Prepaid Health Plan (PHP) that delivers only behavioral health services. Throughout the remainder of this report the term MCO includes PHPs unless otherwise specified.

[9] The number of MCOs was reduced to two as of January 1, 2000.

State	CO	CT	DE	MA	MI
Broad Eligibility Groups Enrolled	TANF, Poverty Level children and pregnant women, SSI, Aged	TANF, Poverty Level, SSI	TANF, Poverty Level, SSI, Aged	TANF, Poverty Level, SSI	TANF, Poverty L

One of the first methodological challenges the study confronted was in reconciling the BBA-defined subset of children with special health care needs with existing state methods for defining their enrolled population of children. According to the BBA, a child under 19 years of age is considered to have special needs if the child:

(i) is eligible for supplemental security income under title XVI, (SSI);
(ii) is described in section 501(a)(1)(D), (children receiving Title V-funded care coordination);
(iii) is described in section 1902(e)(3), (children similar to "Katie Beckett" children);
(iv) is receiving foster care or adoption assistance under part E of title IV; or
(v) is in foster care or otherwise in an out-of-home placement.[10]

HCFA reports that the choice of these five groups reflected Congress' intent that states be able to identify and track children on the basis of the types of assistance they receive. However, as will be discussed in the next chapter, states do not commonly enroll children on the basis of the BBA-defined categories. Table 2 identifies the enrollment status of the five BBA-defined subsets of children with special needs as of the Fall 1999.

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[10] As will be discussed in the **Definition** chapter of this paper, HCFA's Guidance to States dated December 27, 1999, interpreted this definition to mean: (i) children receiving SSI; (ii) children receiving Title V funded care coordination; (iii) children found eligible under §1902(e)(3), which allows states to cover children similar to Katie Beckett children as a state plan option; (iv) children receiving Title IV-E; and (v) children in the custody of the Child Welfare agency.

Table 2: Enrollment status of BBA-defined subsets of CSHCN (except those otherwise exempted/excluded from managed care enrollment)[11]

BBA Category	Managed Care (MCO, PCCM, or PHP) Enrollment Status
SSI Children	All six site visit states require these children to enroll in managed care.
1902(e)(3)	Delaware and Massachusetts require these children to enroll in managed care. Colorado, Connecticut, and New Mexico do not use this eligibility provision in their Medicaid programs so in those states no child is eligible under 1902(e)(3). In Michigan, these children may join the Title V program and be exempt from MCO enrollment.
Foster Care/Out-of-Home Placement	Connecticut and Delaware require these children to enroll in MCOs. Colorado and Massachusetts require them to enroll in their specialty behavioral health programs but allow these children to choose whether they wish to enroll in the MCO or PCCM programs, or remain in fee-for-service. New Mexico requires children in foster care who were placed in-state to enroll, but does not allow those placed out-of-state to enroll. Michigan does not allow these children to enroll in managed care.
Receiving Foster Care or Adoption Assistance	Connecticut and Delaware require these children to enroll in MCOs. Colorado and Massachusetts require them to enroll in their specialty behavioral health programs but allow these children to choose whether they wish to enroll in the MCO or PCCM programs, or remain in fee-for-service. New Mexico requires children in foster care who are placed in-state to enroll, but does not allow those placed out-of-state to enroll. Michigan does not allow these children to enroll in managed care.
Receiving Title V Funded Care Coordination	Colorado, Connecticut, Massachusetts, and New Mexico require these children (unless otherwise exempted or excluded) to enroll in managed care. Michigan does not allow any child receiving Title V services to enroll in their general MCO program but offers Title V beneficiaries who live in some parts of the State a choice between fee-for-service and two Special Health Plans that serve only Title V beneficiaries (both those that do and those that do not qualify for Medicaid). The Title V agency in Delaware does not provide care coordination services and so in this State no child belongs to this group.

All site visits were conducted in the Fall of 1999. During each two and a half day visit, NASHP staff interviewed state Medicaid agency staff and a wide variety of stakeholders. The exact groups interviewed varied by state depending on the state's managed care program structure and other state-specific characteristics. Informants generally included:

- state Medicaid agency staff, including contractors such as the EQRO and enrollment broker;

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[11] Site visit states reported that they do not generally define their managed care program exemptions and exclusions in terms of the BBA-defined groups. Therefore, the status shown in Table 2 applies only to those children in these groups who are not excluded or exempted due to membership in another group. For example, Colorado, Massachusetts, and Michigan excluded (did not allow to enroll) all Medicaid beneficiaries with private comprehensive health insurance. Therefore members of the BBA groups, such as most members of the 1902(e)(3) group, who had comprehensive health insurance could not enroll into managed care. However others, such as SSI children, who did not have other comprehensive health insurance were required to enroll.

- MCO staff;
- parents of children with special health care needs;
- child advocates (including Family Voices, among others);
- other state agencies that serve CSHCN, such as the Maternal and Child Health (MCH) agency, Early Intervention and Special Education Programs' administrative agency, Developmental Disabilities Agency, Mental Health/Substance Abuse agency, and the Child Welfare agency; and
- medical providers who deliver care to CSHCN, including primary care providers (PCPs), specialists, and specialty hospitals.

The expert panel was also instrumental in the development of the interview protocol. Separate but similar protocols were developed for the state Medicaid agency and all other informants (both are included as Appendix B). These protocols used HCFA's Interim Criteria as a framework for the interview protocols.

NASHP staff provided site visit informants with a copy of the protocol in advance of the interview and, when possible, informants supplied NASHP staff with relevant documents for review before the visit. To encourage frank interchange Medicaid staff were not present in interviews with other informants. Sources of individual comments are not identified in this report, nor is the report intended to provide a case study of any one state.

NASHP faced an ambitious schedule in completing the study. In the five months from the date of the initial Expert Panel meeting on October 14, 1999, to preparation of a draft report, states were selected, site visits scheduled and conducted, and findings analyzed. In addition, numerous efforts were made to ensure the accuracy of the information contained in this report. As part of that effort, NASHP staff prepared a summary matrix identifying site visit state policies in the areas identified by the Interim Criteria. Medicaid agency staff in the site visit states reviewed this matrix before NASHP staff drafted the report. Medicaid agency staff and other key informants also reviewed the draft report for accuracy before publication. The expert panel also reviewed the draft report before publication.

The report presents information that was available during the site visits, as reported by key informants and documented in state policies. The authors wish to caution readers that policies may have changed and that the views of informants may not always reflect the opinions of the constituencies they represent.

II. DEFINITION

Interim Criteria

The Interim Criteria, developed in response to the 1997 Balanced Budget Act (BBA), are designed to assist the Health Care Financing Administration (HCFA) in its review of states' waiver proposals to enroll one or more of the five groups of CSHCN in mandatory Medicaid managed care. To ensure consistency among the states, the Interim Criteria establish the following definition of CSHCN:

The State has a definition of children with special needs that includes at least these five subsets:

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. *In foster care or other out-of-home placement;*
4. *Receiving foster care or adoption assistance; or*
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 is defined by the State in terms of either program participant or special health care needs.*

Introduction

As noted earlier, the BBA, which was enacted in 1997, allowed states to require most Medicaid beneficiaries to enroll in managed care (managed care organizations, pre-paid health plan, and primary care case management) by amending the Medicaid agency's state plan rather than by having to obtain a waiver from the Federal government. National advocacy groups were concerned that eliminating the need for a waiver would reduce Federal scrutiny of Medicaid managed care programs. These groups had also used the waiver process as a vehicle for ensuring that state agencies heard and addressed their concerns about Medicaid managed care. In response to these concerns, as well as for other reasons, Congress continued to require states to obtain waivers before requiring certain children with special needs, among the most vulnerable of Medicaid beneficiaries, to enroll into managed care.

Within the BBA, Congress, in effect, defines CSHCN as any child who belongs to one of five categories. States may only mandate enrollment of these children after obtaining a waiver from HCFA. Congressional intent in selecting these five specific groups of children, as interpreted by HCFA, was to make sure that members of these groups would be readily identifiable so that states could easily determine when they needed to obtain a waiver for mandatory enrollment of these children. Therefore, the BBA definition relies on factors, primarily Medicaid eligibility category, that states could reasonably be expected to be tracking already for other purposes.

In its role as oversight agency for Medicaid, HCFA responded to the BBA's designation of these five groups of children as exempt from mandatory Medicaid managed care by establishing two key priorities:

- Monitoring how these children fare under capitated managed care.[12]
- Ensuring that those states granted a waiver allowing them to mandate enrollment of these children provide appropriate safeguards.

HCFA produced the Interim Criteria in 1999 to address these issues. As a result, the definition HCFA uses for CSHCN throughout the Criteria elaborates upon the five groups specified in the BBA. HCFA reports that its intent in the development of the Interim Criteria was to ensure that states provide safeguards, at a minimum, to members of these five groups who are enrolled in mandatory managed care. HCFA's intent was not to limit states to providing safeguards only to members of these BBA groups. Because the Interim Criteria were developed to fulfill the intent of the BBA regarding CSHCN they also do not address the establishment of safeguards for members of these groups who are served in fee-for-service or in voluntary managed care. Nor does HCFA intend to examine the care provided to these children by fee-for-service or in voluntary managed care. Congress's charge to HCFA, through the BBA, was to safeguard the children served by mandatory managed care programs, not those served by other delivery systems.

Prior to 1997, the Medicaid agencies in all of the site visit states had either developed a formal written definition of CSHCN or had defined various groups of enrollees, including children, who were to receive services such as care coordination/case management. States generally developed these definitions by first determining the purpose of the definition then developing a definition to fulfill that purpose. As a result, these definitions varied depending on their ultimate purpose and were almost universally developed with input from stakeholders within the state. Among the various definitions developed by states in response to specific situations:

- "SSI children" has been used as a definition for CSHCN when stratifying survey results. Some children in the SSI category have behavioral disabilities but are physically healthy. On the other hand, some children in non-SSI categories have severe chronic diseases, such as diabetes or asthma. If "SSI children" is used as a definition to stratify children enrolled in a managed care organization (MCO) that does not provide behavioral health care it would not produce a clean division between children with special physical health needs and children without special physical health needs. However, it would divide the children into "those mostly with physical

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[12] It should be noted that these efforts represent the first time that HCFA has examined the experience of any specific special population in managed care or fee-for-service.

health needs" and "those mostly without physical health needs." These groupings could suffice for purposes of stratifying survey results to compare the general experience of CSHCN enrolled in the MCO with that of other children.

- Many quality studies require a more specific definition of CSHCN. In one state studying asthma, the state determined that clearer results could be obtained by studying the care provided to those who had an inpatient admission or emergency room visit for asthma. In this case, a definition based on a child's SSI eligibility was determined to be insufficient.

- A state seeking to determine which children need care coordination adopted the following definition: Persons having ongoing health conditions that (1) have a biological, physiological, or cognitive basis; (2) have lasted, or is virtually certain to last, for at least one year; and (3) produce one or more of the following sequella: (a) significant limitations in areas of physical, cognitive, or emotional function; (b) dependency on medical or assistive devices to minimize limitation or function of activities; (c) significant limitation in social growth or developmental function; (d) need for psychological, educational, medical, or related services above the usual for the child's age; or (e) special ongoing treatments such as medications, diets, interventions, or accommodations at home or school.

- Definitions of CSHCN for purposes of adjusting capitation payments for enrollee health status are frequently based on diagnoses, which are good predictors of expected cost. So, that in most states that adjust capitation rates for health status a child with HIV would belong to a higher cost category than a child with asthma.

- As at least one state has demonstrated, a definition used to decide which children are to be enrolled in a specialized program for CSHCN is likely to be different than one used to identify which children in a general MCO program need care coordination. For example:
  - Massachusetts *Special Care* **Ì** *Special Kids* program is specifically designed to serve very medically complex children who live in foster care homes. For this program, the definition of CSHCN addresses both the living situation and the level of care the child needs.
  - The definition of CSHCN included in Massachusetts general MCO contract addresses only the level of care the child requires.

The varied state Medicaid agency definitions were developed by states as they used the flexibility afforded in Federal Medicaid regulations to develop programs that addressed state-specific concerns, based on the eligibility and service options chosen by each state's Medicaid program.

Approaches to Defining CSHCN

The BBA definition is the latest among many definitions of CSHCN that have been developed over a number of years. These numerous definitions of CSHCN can be classified by type.

- Categorical definitions are based on the receipt of a certain type of aid, such as SSI.
- Service definitions are based on the receipt of a certain service, such as care coordination.
- Epidemiological definitions are based on the child's health status and need for care.
- Diagnostic definitions are based on the presence of certain conditions, such as AIDS.
- Functional definitions are based on the child's ability to perform the functions of daily living.
- Cost definitions are based on the cost of caring for the child.

Each of these approaches has its strengths and weaknesses. For example, a functional definition may exclude children who have a serious chronic disease but function well because the disease is under control. A service definition may exclude children who need, but are not receiving, a specific service. A categorical definition will exclude CSHCN who do not receive the specified type of aid.

Most of the definitions in use today are a combination of types. For example, the BBA definition combines categorical and service definitions. The MCH bureau definition discussed below is primarily epidemiological. The state Medicaid agencies reported using all of these approaches in various combinations depending on the purpose of the definition.

None of the definitions developed to date have been generally accepted as suitable for all purposes and most reported using multiple definitions for different specific purposes. This is true not just in Medicaid or managed care but also among other agencies that serve CSHCN. For example, the MCH bureau recommends the following definition for use in Title V agency planning and systems development:

> *Children with special health care needs are those who have or are at increased risk for 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.*[13]

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[13] This definition appears in; McPherson et al., "A New Definition of Children with Special Health Care Needs," 102 Pediatrics, No. 1 July 1998. It was endorsed in a workgroup convened by the Association of Maternal and Child Health Programs and the Maternal and Child Health Bureau on October 18, 1998.

Several of the state Title V agencies informants reported that they use the recommended definition for planning. However, none of them reported using this definition in the delivery of care. For the purpose of identifying CSHCN for delivery of care the Title V agencies reported relying primarily on a diagnostic approach and narrowing the definition to include only those children who have one of many pre-specified physical conditions.

Understanding the Definition in the Interim Criteria

The definition of CSHCN used in the Interim Criteria was based on the following language from the BBA (P. L. 105-33).

Exemption of certain children with special needs.--A State may not require under paragraph (1) the enrollment in a managed care entity of an individual under 19 years of age who--

> *(i) is eligible for supplemental security income under title XVI;*
> *(ii) is described in section 501(a)(1)(D);*
> *(iii) is described in section 1902(e)(3);*
> *(iv) is receiving foster care or adoption assistance under part E of title IV; or*
> *(v) is in foster care or otherwise in an out-of-home placement.*

This definition was designed to cast a broad net so that any state that might be enrolling any CSHCN into managed care would first be required to obtain a waiver. These five groups also were selected at least partially because Congress believed that members of these groups would be easy to identify among other Medicaid beneficiaries, thus enabling states to identify easily when they need to obtain a waiver for mandatory enrollment. These five groups would be likely to contain almost all children that state agency, provider, MCO, and consumer informants considered to be CSHCN. They are, however:

- likely to include other children who are not considered CSHCN by key informants; and
- exclude other children who are considered CSHCN.[14]

Also, there is a wide range of physical and behavioral needs among the members of these groups. Using this broad definition as the definition for CSHCN in all managed care program operations and evaluation poses challenges as the definition was not specifically designed to be used that way.

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[14] Colorado performed a study which found that 13% of children who were SSI at the time of the study were in another Medicaid eligibility category (primarily TANF) within the previous 2 ½ years. Another study found that in 1996, 10-24 percent of the adults in AFDC had a risk-adjusted diagnosis (indicating the likely presence of special needs). This State is now completing a similar study for children and anticipates similar findings.

Also, key informants in the site visits reported that the BBA definition in the Interim Criteria, which is not identical word-for-word to that included in the BBA, was not clear. For example, the definition included in the Interim Criteria does not specify an age cut-off for children, leaving unanswered whether a child becomes an adult at age 18, 19, or 21. However, the language in the BBA defined children as those under 19 years of age.

This section of the report clarifies which children must be included in each category of the BBA definition of CSHCN, as the definition appears in the Interim Criteria. States may, at their option, broaden these categories to include more children. (This chapter addresses only issues related to the BBA and state Medicaid agency definitions of CSHCN. Issues related to identifying and tracking children who meet these definitions are covered in the next chapter.)

Group 1: Blind/Disabled Children and Related Populations (Eligible for SSI Under Title XVI)

The group of blind/disabled children includes all people under 19 years of age who are receiving SSI payments. This is the most straightforward of the five BBA groups. As a result, all site visit states clearly understood which children belonged to this group. They all also reported that they could identify members of this group without undue difficulty, if required to do so. (This will be discussed in more detail in the following chapter on **Identification**.)

Group 2: Eligible Under Section 1902(e)(3) of the Social Security Act

This group includes only children who are found eligible for Medicaid through §1902(e)(3) of the Act (often referred to as the "state plan option"). This provision allows states, at their option, to provide Medicaid to a child under 18 years of age if the state has determined:

- the child needs a level of care provided in a hospital, nursing facility, or ICF/MR;
- it is appropriate to provide the care outside the institution; and
- the cost to Medicaid of caring for the child outside the institution is no greater than that of providing care to the child within the institution.

This group usually consists of children whose families have incomes that are higher than the incomes earned by other Medicaid beneficiaries. Generally, children qualifying under this provision would not otherwise qualify under other eligibility avenues due to family income. Many of these children have private insurance as well as Medicaid.

There was considerable discrepancy among site visit states about which children were included in the 1902(e)(3) group. States have great flexibility in deciding what avenues they will use to determine

Medicaid eligibility and may be serving children who are precisely like those found eligible under §1902(e)(3) through waivers or traditional venues of eligibility. The Interim Criteria definition does not include these other children as CSHCN. However, if a state Medicaid agency wished to expand the definition in the Criteria to include these other children it could do so. The site visit states used a great variety of eligibility avenues to extend Medicaid eligibility to children like those described in §1902(e)(3).

- Colorado, Connecticut, and New Mexico reported that they do not use 1902(e)(3) as an eligibility option in their Medicaid programs. Instead these states cover some children who meet these requirements through Home and Community-Based (HCB) waivers.

- Massachusetts and Delaware reported using only 1902(e)(3) to cover children who need an institutional level of care and did not otherwise qualify for Medicaid.

- Michigan reported using 1902(e)(3) and an HCB waiver to cover these children. This State used the 1902(e)(3) provision to cover a very small group of children who require care in a hospital.

Those states that preferred using the HCB waiver generally cited two advantages of a waiver over 1902(e)(3).

- a waiver allows the state to offer these children some services, such as respite care, that would not normally be provided by Medicaid.

- a waiver allows the state to limit the number of children they serve who need an institutional level of care but whose families earn too much income to otherwise qualify for Medicaid.

States that use a state plan option may not limit the number of children they serve under 1902(e)(3), nor may they offer additional services to this group of children only.

The same child, depending on which of the six states he or she lives in, can be found eligible under 1902(e)(3), an HCB waiver, or another eligibility group. Strictly interpreted, this definition results in identifying different children as CSHCN in each state. This element is a source of confusion in the states. Although few would argue that a child requiring an institutional level of care is not a CSHCN, the BBA definition in the Interim Criteria does not include all children who need an institutional level of care. Instead, it includes only those children covered under the 1902(e)(3) state plan option who need an institutional level of care, who are cared for in the community, and whose families have incomes that are too high to otherwise qualify for Medicaid. This group of children is really only a subset of those who could be designated as having special health care needs because of their need for an institutional level of care. Children with similar characteristics are not counted under this BBA definition if they are eligible through different Medicaid eligibility categories.

Groups 3 and 4: Foster Care Related

Most Medicaid eligible children in foster care belong to both foster care-related groups identified in the BBA definition in the Interim Criteria.

1. *Children in foster care or other out-of-home placement* means all children who are in the custody of the state. This group does not include children who are receiving residential care (group home; residential treatment center, etc.) but remain in the custody of their families. Nor does it include those children who are served by the Child Welfare system but have not been removed from the custody of their families – even if the child is living outside the home, perhaps with other relatives.

2. *Receiving foster care or adoption assistance* means all children who are eligible for Title IV-E payments. Title IV-E of the Social Security Act (Adoption Assistance and Child Welfare Act) provides federal funds to states for maintenance payments of most children in foster care and some other settings. Medicaid agencies must extend Medicaid eligibility to all children who qualify for IV-E payments. In order to qualify for Title IV-E a child must have been receiving (or eligible to receive) cash assistance payments (e.g., TANF, SSI) before removal from the home.[15] Almost all children in foster care meet this requirement because, after removal, the question for IV-E eligibility determination becomes: "Would the child have been eligible for cash assistance considering only the child's income and assets?" In some cases, the child remains eligible for IV-E after adoption (and leaving the foster care system). If a child continues to be eligible for IV-E after adoption, the child is said to be receiving adoption assistance. This BBA-defined group of CSHCN includes all children who are eligible for Title IV-E payments – both those in the custody of the Child Welfare agency and those who have been adopted.

The only distinctions between the two foster care-related groups are that:

- The "children in foster care" group would include the relatively few children who are in the custody of the Child Welfare agency but are not eligible for Title IV-E payments. These children would not be included in the "receiving foster care or adoption assistance" group.

- The "receiving foster care or adoption assistance" group would include the relatively few children who have been adopted but remain eligible for Title IV-E payments. These children would not be included in the "children in foster care" group.

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[15] Schneider A. and Fennel K., *Medicaid Eligibility Policy for Children in Foster Care,* March 1999: National Academy for State Health Policy, Portland, ME.

Group 5: Title V

Title V was reported as the most difficult group to understand. This difficulty starts in the specific language included in the BBA. The BBA states that a state may not require "an individual under 19 years of age who ... is described in section 501(a)(1)(D)" to enroll in managed care without a waiver. Reference to the Social Security Act (the Act) finds that this provision does not describe an individual as implied in the BBA. Specifically, 501(a)(1)(D) of the Act reads:

> *SEC. 501. [42 U.S.C. 701] (a) To improve the health of all mothers and children consistent with the applicable health status goals and national health objectives established by the Secretary under the Public Health Service Act for the year 2000, there are authorized to be appropriated $705,000,000 for fiscal year 1994 and each fiscal year thereafter-*
>
> *(1) for the purpose of enabling each State--*
>
> *(D) to provide and to promote family-centered, community-based, coordinated care (including care coordination services, as defined in subsection (b)(3)) for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families;*

Subsection (b)(3), referenced in 501(a)(1)(D), then defines care coordination services to mean "services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families."

In essence, the provisions referred to in the BBA definition authorize funds to be used to "provide and to promote" coordinated care as part of a community based system. They do not describe an individual, require a state to provide a service called care coordination to individual children, or specify who is to be considered a child with special health care needs. (However, the MCH bureau, which administers Title V, recommends the use of the specific definition[16] presented earlier in this chapter for purpose of planning and systems development.) In other words, this section of the Act (like that authorizing Medicaid) gives states great flexibility in how they use the funds, both in terms of services provided and populations served. Table 3 shows that the Title V agencies in the site visit states used this flexibility to develop greatly varying programs that best meet the needs of CSHCN and their families in each state.

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[16] As previously stated, that definition is, "Children with special health care needs are those who have or are at increased risk for 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."

In its Interim Criteria, HCFA interpreted the BBA definition to mean that “a child described in section 501(a)(1)(D)” is a child who is receiving Title V-funded care coordination services.[17] Even this is problematic. The Title V programs in two of the site visit states do not provide care coordination. These states operate Title V programs but no children served by the Title V program would belong to the Title V group in the BBA definition because no child in these states is receiving Title V-funded care coordination. Also, the number of Medicaid eligible children who receive care coordination services varies greatly among the Title V programs, from a low of 55 in Connecticut to a high of 2,824 in New Mexico. As a result the BBA definition does not identify a consistent group of children from state to state.

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[17] Please refer to the letter issued to all State Medicaid Directors on December 17, 1997 regarding §1932(a) of the SSA for more information about the basis for this interpretation.

Table 3: Site visit states Title V programs in brief

State	Brief Program Description
CO	Serves children whose families have incomes below 133% of poverty and who have specific physical diagnosis; uses MCH definition (at risk) for planning purposes; funds specialty clinics in rural areas; Title V CSHCN program is sole Medicaid provider for hearing aids, orthodontia, and some therapeutic services for children (these and other services are also provided to Title V beneficiaries who do not receive Medicaid); directly provides care coordination; served 8,272 children in FY '98 (57% were also eligible for Medicaid).
CT	Funds two contractors that provide state-wide service using satellite clinics; contractors provide medical, therapeutic, and care coordination services using an inter-disciplinary approach; serves children below 300% of poverty with disabilities; 12,723 children were served by the Title V program, 750 of those were enrolled in the Title V CSHCN program (specialized inter-disciplinary approach), 55 of the 750 were also eligible for Medicaid.
DE	Title V funds some free-standing specialty clinics (neurology, cardiology, ophthalmology) for children birth to 21 who are underinsured or not insured; other than that does not provide direct care and does not fund care coordination
MA	Does not provide or pay for direct services; has case management staff in six regional offices; provides case management to children who have multiple or complex disability requiring coordination that will last at least one year or be fatal, also the primary diagnosis cannot be mental health or developmental disability; will provide referrals and one time problem-solving assistance to all who call in; serves 697children (498 of these also receive Medicaid); responds to over 3,000 calls for assistance each year.
MI	Serves children who have one of 2,700 different qualifying physical diagnoses, if the condition has the necessary level of severity and chronicity to qualify and requires care from a physician subspecialist at least once per year; Title V-only funds medical (Physician, DME, etc.) and therapeutic services related to the disability (except Title V-only children enrolled in specialty health plans receive care coordination and a preventive care benefit); Title V participation is not based on financial need; however, families with high enough incomes are required to contribute to the care through a payment agreement; 24,000 children are served by Title V (about half of those also receive Medicaid).
NM	Title V funds special clinics to eliminate mal-distribution of special services (cleft lip/palate, pediatric endocrine, pulmonary, neurology); the program serves those below 200% of poverty; 2,730 children receive services from the specialty clinics (1,475 of those also receive Medicaid); 4,806 children receive care coordination (2,824 of these also receive Medicaid); the Title V special health care needs program also provides newborn genetic and hearing screens; IDEA case management/service coordination; and birth defects prevention.

Issues in Applying The BBA Definition

Overlap Among the Five BBA Groups

Many children belong to more than one of the five groups included in the BBA definition. For example, SSI children are likely to be receiving Title V-funded services. Title V programs in site visit states primarily served those with physical (not behavioral) disabilities and "disability" is also a requirement for receipt of SSI. Similarly, almost all of those found eligible under 1902(e)(3) also meet the requirements for receiving Title V services (although they may not be receiving Title V-funded care coordination services). Finally, the two groups of children in foster care overlap almost completely, and many of these children could also be receiving Title V services.

The overlap among the five groups may not be a major issue if the sole purpose of the definition in the Interim Criteria is to define which children should receive care coordination, have special safeguards, or cannot be mandatorily enrolled in managed care without a waiver. For those purposes it does not matter whether the child qualifies more than once. (It should be noted that if all children who belong to one of the five groups are to receive care coordination/case management then issues of resources and funding will arise. Those issues are apart from the definitional issues and will be discussed later in this paper.)

The overlap does become a major issue if one of the purposes of the BBA definition is to allow state and federal governments to count and separately track the number of CSHCN. Due to the overlap it is not possible to count the number of children who belong to each of the five groups and add these numbers to come up with the overall number of CSHCN. This number would be much higher than actual as many children would be counted two or more times. It would also be very difficult (and perhaps costly) to produce an unduplicated count of all children who belong to at least one of the groups as that would require matching information that is currently stored in different systems that were not designed to communicate with each other. These issues are discussed more in the chapter on **Identification**.

BBA Definition Does Not Include a Consistent Group of Children in All States

In addition to the overlap issues there is an issue of consistency. The same child may or may not belong to one of the five groups depending on the child's state of residence. This issue is particularly pertinent to the 1902(e)(3) and Title V groups. As previously discussed, a medically complex child who belonged to a family that had a higher income than that normally allowed under Medicaid and lived in the community could be eligible under 1902(e)(3) or under a HCB waiver. The BBA definition would only define the child as CSHCN if he or she was eligible under 1902(e)(3). Similarly, state Title V programs vary in terms of coverage and services so that a child who receives Title V services in one state may not do so in another. Some states do not have any children that belong to the Title V BBA group.

Federal laws encourage states to develop Medicaid and Title V programs that best meet the needs of each state. The definition of CSHCN used in the Interim Criteria depends on each state's choice to implement a certain provision of Title XIX or use of funding supplied in Title V. This impacts the definition's usefulness as both an indicator of a child's need for special safeguards and for determining how many CSHCN are served by Medicaid. Using the Interim Criteria definition the same child would be provided with safeguards in one state and not in another. Also, the same child would be counted in one state and not in another. If the Criteria is intended for either of these purposes it might be better to base the definition of CSHCN in the Criteria on elements that do not vary as much among states.

BBA Definition Does Not Include All CSHCN and Includes Some Who Are Not CSHCN

Many informants felt that a strict application of the BBA definition would not result in identifying all CSHCN. For example, one Title V agency representative noted that there are a number of children in the TANF population who have special needs related to asthma or behavioral health who do not meet the definition. An MCO conducted provider focus groups to determine who providers would consider to be CSHCN. The children identified by the providers were those who had behavioral health needs (ADHD) or failure to thrive. Many children with these diagnoses would not be picked up in the BBA definition.

MCOs, providers, and advocates also pointed out that diagnoses alone should not be used to identify CSHCN as there can be vastly different needs within each diagnosis. At the same time, social factors can also impact the child's level of need. For example, a mild asthmatic with a difficult family situation might need more assistance than a severe asthmatic who has strong family support or is already receiving care coordination from the Public Health agency. Social factors are not generally captured by the BBA definition.

Key informants also felt that the BBA definition includes children who are, in the informants' opinion, not CSHCN. For example, one advocate pointed out that not every child in foster care has special needs, although many do. These children may need special treatment in an MCO, but the need for such treatment is more due to the living situation of the child than the child's physical or behavioral health needs. Almost all informants recommended an approach to defining and identifying CSHCN that was based on each child's individual needs rather than the child's category of Medicaid eligibility or receipt of particular services.

Current Medicaid Agency Definitions of CSHCN

As discussed earlier in this chapter, all site visit states use different definitions of CSHCN to fulfill different functions in managed care program operation and evaluation. Examples of definitions that states use for different purposes include:

- Using the definition “SSI children” to stratify survey results to show the responses for CSHCN versus other children enrolled in an MCO.

- For a quality study on care provided to CSHCN: using the definition “SSI eligible children who had at least five visits to a provider in a year and had a claim showing one of a number of diagnosis (diabetes, ventilator dependent, etc.).”

- For identifying children who need care coordination: using the definition “Enrollees with HIV/AIDS, or other conditions with a cognitive, biologic, or psychologic basis resulting in sequella which include but are not limited to (1) need for medical care or special service(s) at home, place of employment, or school; (2) dependency on daily medical care, special diet, medical technology assistive device, or personal assistance in order to function; and (3) persistent limitation of function.”

- For qualifying children who wish to enroll in a specialized managed care program: using the definition “children in the custody of the Child Welfare agency and living in a foster home who need complex medical management over a prolonged time; and need one of the following on a regular basis for a prolonged time (1) skilled nursing care requiring complex nursing procedures or skilled assessment, or (2) monitoring related to an unstable medical condition.”

Clearly, these definitions are not interchangeable. For example, the definition for stratifying consumer survey results would not be appropriate for qualifying children for enrollment in a specialized managed care program. Some of these definitions have been developed for “one-time” use, such as those developed for quality studies. Others have been developed for ongoing use in managed care program operations, such as those used to qualify children for enrollment into a special managed care program.

Table 4 provides further information about the formal written definitions of CSHCN used in four of the six site visit states. (Other definitions developed for a specific programmatic function are discussed in the chapters that discuss the other aspects of that function.)

- Two states established separate written definitions for use in different managed care programs. For example, Massachusetts uses one definition in its general MCO program and another in its program for children living in foster care homes who have complex medical needs.
- Both Colorado’s and Massachusetts’ general MCO definition are meant to capture children and adults with special needs.
- The written definitions for Delaware’s MCO program, Colorado’s Safety Net Project, Massachusetts’ *Special Kids* Ì *Special Care* program, and Michigan’s Special Health Plans were developed specifically for identification of certain groups of CSHCN.
- Both of the specialized managed care programs for CSHCN used formal definitions of CSHCN
- Neither of the BH/PHPs used a formal definition

- Three of the six general MCO programs used a formal definition

All of these definitions were developed for ongoing use in managed care program operations and most were intended to result in the provision of care coordination/case management to CSHCN (and sometimes adults with special needs). Medicaid agency, MCO, advocate, and consumer informants in three of these states reported strong stakeholder involvement in developing these definitions. No state Medicaid agency reported using a formal written definition of CSHCN in their PHP, PCCM, or fee-for-service programs.

Table 4: Formal (written) state definitions of CSHCN

State	Definition (source)
CO	*MCO*: Persons having ongoing health conditions that (1) have a biological, physiological or cognitive basis; (2) have lasted, or is virtually certain to last for at least one year; and (3) produce one or more of the following sequella: (a) significant limitations in areas of physical, cognitive, or emotional function; (b) dependency on medical or assistive devices to minimize limitation or function of activities; (c) significant limitation in social growth or developmental function; (d) need for psychological, educational, medical, or related services above the usual for the child's age; or (e) special ongoing treatments such as medications, diets, interventions, or accommodations at home or school. (1999 MCO contract; edited; does not apply to PHP or PCCM program)
	Safety Net Project: 4 of 5 plans voluntarily participate in the Safety Net Project, a grant-funded project, coordinated by the Medicaid agency. These plans have voluntarily agreed to use a broader definition of CSHCN for Safety Net Project Activities including "Children, 21 years and under with multiple, chronic, or complex health needs or risk factors which includes social and support services as well as medical needs." (State comments on draft report)
CT	None currently, adopting BBA definition.
DE	"Those who have or are suspected of having a serious or 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." (1998 contract)
MA	*MCO*: Enrollees with HIV/AIDS, or other conditions with a cognitive, biologic, or psychologic basis resulting in sequella which include but are not limited to (1) need for medical care or special service(s) at home, place of employment, or school; (2) dependency on daily medical care, special diet, medical technology assistive device, or personal assistance in order to function; and (3) persistent limitation of function. (People w/disabilities definition in MCO contract; edited; does not apply to PHP or PCCM program)
	Special Kids Ì Special Care program: All participants are CSHCN; defined as children in the custody of Child Welfare agency and living in a foster home who need complex medical management over a prolonged time; and need one of the following on a regular basis for a prolonged time (1) skilled nursing care requiring complex nursing procedures or skilled assessment, or (2) monitoring related to an unstable medical condition. (Informing material; edited)
MI	*MCO*: None
	Special Health Plans: State Title V definition which is based on a physical diagnosis, severity, chronicity, and need for care by a physician subspecialist at least once per year. (Interview)
NM	None currently; the State is working on a definition of CSHCN and MCOs are required to provide case management and other services to this population.

Comparison of State Medicaid Agency and BBA Definitions

The formal, written, state Medicaid agency definitions of CSHCN are radically different from the BBA definition. These definitions use different approaches to defining CSHCN.

- The BBA definition uses the *categorical* and *service* approaches; it defines CSHCN based on the source of the individual's Medicaid eligibility or receipt of certain services.

- The written Medicaid agency definitions use *epidemiological*, *diagnoses*, and *functional* approaches; essentially they define CSHCN based on the individual's health and/or functional status.

Although preferring epidemiological, diagnoses, and functional approaches for written definitions of CSHCN, all site visit states reported also using a categorical approach in some aspects of program operation and evaluation. However, different approaches are used in different situations.

State Medicaid agencies only use a categorical approach when it is *not* necessary to make sure that all CSHCN are identified as such and that no child who does not have special needs is identified as a CSHCN. In addition, states only use a categorical approach when it is deemed impractical to contact individual children to determine their individual needs.

- Colorado uses a categorical approach to stratify the results of consumer surveys into two groups: adults mostly with disabilities (SSI adults) and adults mostly without disabilities (all other adults).

- Several states rely on a categorical approach for different aspects of the enrollment process:
    - Michigan excludes children in foster care from their managed care program; and
    - Massachusetts only assigns SSI beneficiaries (children and adults) who do not select a managed care option to PCCM providers (other beneficiaries in mandatory enrollment groups are assigned to MCOs or PCCM providers).

- States often combine category of eligibility and service information from claims or encounter data to select beneficiaries to include in quality study samples. For example, Colorado selected all SSI beneficiaries (adult and children) who had a hospital stay for its study of discharge planning for people with disabilities in MCOs, PCCM, and fee-for-service.

Epidemiological and functional approaches depend on an individual's health and functional status. Determining who meets these types of definitions, therefore, requires contacting the individual (or the individual's family) to gather that information. Medicaid agencies reported using these approaches when the additional certainty that all and only CSHCN were identified justified the additional resources needed to contact each child's family. Without exception, states reported using an epidemiological or functional approach to specify which children should receive care coordination/case management services.

As mentioned earlier in this chapter, these approaches are not mutually exclusive. For example Massachusetts' definition for qualifying children for participation in its *Special Kids* Ì *Special Care* program combines categorical and epidemiological approaches. This definition limits participation in the program to children in foster care homes (categorical) and who need complex medical management (epidemiological).

Site visit states reported they will have difficulty implementing the Interim Criteria as written due to the wide range of purposes the BBA definition is expected to serve in the Criteria, including enrollment, quality, care coordination, and payment. Before the BBA no state used a single definition to meet all of these purposes. Their experience had shown that it was more effective to develop specific definitions to fulfill specific purposes. Further their experience indicated that although a categorical approach, such as that used by the BBA, worked for some purposes, other approaches were necessary for other purposes. Several key informants recommended that the Federal government approach developing a CSHCN definition (or definitions) in the same way that many states approached the issue. First, determine the purpose the definition will serve, then develop a definition that suits that purpose. These informants also recommended that the Federal government involve stakeholders in the process of developing a definition for CSHCN. Finally, some informants recommended that this effort build on work done by other Federal agencies such as those of the Maternal and Child Health Bureau.

Definition of CSHCN: Summary of Study Question Findings

How do current state managed care definitions match the BBA definition?

No site visit state used the BBA definition in managed care program operation and evaluation. Instead they all reported using a variety of definitions developed to meet specific one-time and ongoing MCO program purposes. Many key informants, based on their experience, expressed doubt that any single definition of CSHCN could serve all the purposes identified in the Interim Criteria. The greatest differences were observed between the BBA definition and those used by the states to decide which children need care coordination. For this purpose the states preferred the use of an epidemiological or functional definition over the mostly categorical approach used by the BBA. Finally, no PCCM or PHP program in the site visit states reported the use of any formal Medicaid agency definition of CSHCN.

How do states define CSHCN in the fee-for-service system?

No site visit state reported the use of any formal Medicaid agency definition of CSHCN in fee-for-service Medicaid.

How do state definitions vary according to state characteristics?

The use of formal state definitions varied by program type, not state characteristic.

- Both of the specialized programs for CSHCN used formal definitions of CSHCN.
- Neither of the BH/PHPs used a formal definition.
- Three of the six general MCO programs used a formal definition.
- Neither of the PCCM programs used a formal definition.

The specific definitions used in the states varied according to the purpose the definition was designed to serve. However, states tended to use:

- a categorical definition, as exemplified by the BBA definition, when it was impractical to contact individual children to determine their individual needs and when it was not necessary to identify all CSHCN and only CSHCN.

- an epidemiological or functional definition when the additional certainty that all and only CSHCN were identified justified the additional resources needed to contact each child's family.

Does the BBA definition meet the most significant issues faced by children and their families?

The BBA definition did not meet all of the most significant issues faced by CSHCN and their families. It was generally felt that the BBA definition suited the primary purpose for which it was developed – deciding whether a state Medicaid agency needs to obtain a waiver before requiring enrollment into managed care. Because Congress wanted to ensure that no state enrolled a child with special needs without first obtaining a waiver, the definition they developed was very broad. Also, because they wanted to make it easy for a Medicaid agency to determine whether they enrolled CSHCN, Congress chose a categorical approach that made use of information Medicaid agencies were likely to be already tracking for other purposes.

All informants felt this single definition did not (and should not be expected to) meet other purposes that were important to CSHCN and their families, such as enrollment in specialized programs, quality studies, and provision of care coordination. They felt that other definitions, using other approaches, were better suited to these purposes. Most of the state Medicaid agencies reported extensive involvement by parents, advocates, and others who care for CSHCN in the development of the multiple definitions they use for various purposes. None of those definitions matched the BBA definition. The BBA definition is also radically different from that proposed by the MCH bureau and several advocacy organizations. This definition, like the state definitions, was developed with input from those familiar with the needs of CSHCN and their families.

Many consumers were not familiar with all of the groupings included in the BBA definition and so were unable to fully assess its adequacy. Even Medicaid informants were not clear on which children belonged to the five groups in the BBA definition. Informants familiar with the various BBA groups felt that the BBA definition would both include children who were not CSHCN and exclude children who were CSHCN. There was consensus among most key informants that a definition based on the health and functional status of individual children was better suited to determining the need for care coordination than the primarily categorical approach used in the BBA.

There was also consensus that states needed the flexibility to use different definitions of CSHCN for different programmatic purposes and that a similar approach might be needed at the Federal level. The BBA language was developed to determine whether or not a state needed to obtain a waiver and may not be appropriate for studying quality or determining which children need care coordination. Some informants recommended that the federal government first determine why they need a definition, then develop a definition to meet that need. Finally, it was pointed out that if the purpose of the BBA definition is to produce a national count of CSHCN, it will not fulfill that purpose. Many children belong to more than one of the five groups and would thus be counted more than one time. Also this definition would not identify a consistent group in all states. Medicaid beneficiaries under age 19 with similar levels of medical need were included or excluded from the definition based on: family income, eligibility options selected by the state Medicaid program, and service and population options selected by the state Title V programs.

III. IDENTIFICATION AND TRACKING

Interim Criteria

Concerning the identification and tracking of CSHCN, the Interim Criteria require that:

The State identifies and/or requires MCOs/PHPs to identify children with special needs. The State collects, or requires MCOs/PHPs to collect, specific data on children with special needs. The State explains the processes it has for identifying each of the special needs groups described above [the five populations in the BBA definition].

Introduction

A system to identify CSHCN is important to a state's ability to ensure that all CSHCN are cared for in the way the Medicaid agency intends. And states must also have in place a means of tracking those children over time, if the MCO and Medicaid agency are to assess the care delivered to CSHCN.

Most informants interviewed reported that the need to identify the child as a CSHCN is less important then the need to serve the child. For example, most felt it was important to care delivery to identify whether a child had asthma or was technology dependent; few felt it was important to label that child as a CSHCN. One informant from a behavioral health agency even reported that labeling the child as CSHCN could prove harmful as such a label could prevent the child from reaching his or her full potential by creating the impression that the child had limited abilities.

Almost all Medicaid agency and MCO informants agreed that identifying individual needs was a necessary first step in serving CSHCN and desired to do a better job of identifying those needs. Many MCOs identified a lack of accurate enrollee contact information as an issue in identification; if they couldn't contact the enrollee, by telephone, mail, or in-person, they couldn't determine the enrollee's needs. As will be discussed in more detail in the next chapter on **Enrollment**, state Medicaid agencies' perennial problems with obtaining current contact information have become an issue for MCOs. All MCOs included in the site visits send packets of information to new enrollees at the addresses supplied by the Medicaid agency. One MCO estimated that half of these packets are returned to the MCO as undeliverable. All MCOs also reported that they receive few telephone numbers from the Medicaid agency. The Medicaid agencies provide the contact information they have available, but that information, for a variety of reasons, is never totally accurate or complete.

Most MCOs voiced a desire for a better understanding of the Medicaid agency's expectations regarding which children should be identified and for what purpose. Other informants also wanted a better understanding so that they would know what to expect the MCO to provide to different children. Particular concern was raised regarding which children should receive case management/care coordination.

At the time of the site visits, none of the site visit states had developed a means of identifying all state-defined CSHCN that was satisfactory to the state, although each reported being able to identify some of these children. All Medicaid agencies and most MCOs were also making efforts to improve their existing means of identifying CSHCN. Few informants outside the Medicaid agency or the MCOs reported awareness of any efforts on the part of the agencies and the MCOs to identify CSHCN.

The first part of this chapter discusses how Medicaid agencies and MCOs would identify all children who meet the BBA definition of CSHCN, if required to do so. The second part of this chapter discusses how states currently identify CSHCN. It may be helpful throughout this chapter to keep in mind that the systems developed for identifying CSHCN directly relate to the approach used to define CSHCN.

- A categorical approach relies on a child belonging to a certain group that has been established for other purposes. Therefore, a state that chooses this approach to define CSHCN bases its identification system on a source of that information, such as the Medicaid agency's eligibility system.

- A service approach relies on the delivery of a certain service or set of services to a child. States adopting this approach base their identification system on a source of that information, such as claims or encounter processing systems.

- A diagnoses approach relies on a child having a certain diagnosis. Identification systems based on this approach rely on information gathered from such sources as claims or encounter processing systems.

- A functional approach relies on a child being able to perform at a certain level. Therefore, states taking this approach will base their identification system on a source of that information. Unfortunately Medicaid agencies have no ready source of that information and so each potential CSHCN would need to be assessed.

- A health status approach relies on a child's overall health. Again, Medicaid agencies have no ready source for that information.

It also follows from the use of multiple approaches to defining CSHCN discussed in the previous chapter that many states combine multiple sources and types of information to identify CSHCN. Finally, when thinking about systems of identification it is important to remember that identification is not the end of a process but simply the first step in a larger process to ensure the delivery of care to CSHCN.

How State Medicaid Agencies Could Identify BBA Defined Children with Special Needs

Prior to the BBA, state Medicaid agencies had not defined CSHCN as all children belonging to the five groups specified in the BBA because they and almost all other informants do not, as discussed in the previous chapter, find this definition useful for program operation or evaluation. As a result, no site visit state reported – at the time of the site visits – regularly identifying and tracking information about all of these children. Each state Medicaid agency reported that if required, they could identify some or all members of the five groups specified in the BBA definition. Further, they reported that they could develop systems that would identify all of the children included in the BBA definition. Most expressed a reluctance to make major changes to their managed care programs to identify and track (count) BBA-defined CSHCN because they still did not see this as a useful definition for program operations and evaluation. Rather, they would prefer to keep building on the existing efforts to monitor and safeguard the care of CSHCN that each had developed with input from other stakeholders in the state.

Most agencies were planning to identify and track the experience of BBA-defined CSHCN in managed care to the extent required under the Interim Criteria. However, they were struggling to reconcile the Criteria requirements with existing efforts to identify and track children who meet definitions developed by state Medicaid agencies and MCOs for specific programmatic purposes. Some informants expressed concern that efforts to identify and track the experience of BBA-defined CSHCN would draw resources from the state and MCO efforts and were not clear what benefit would be derived from identifying and tracking BBA-defined CSHCN.

Table 5 identifies the sources of information state Medicaid agencies reported that they could use to identify BBA-defined CSHCN, at the time of the site visit. Several states were in the process of developing different means to identify these children, but these methods are not displayed in the table. For example, Connecticut is working with the Title V agency to develop a system for exchanging information about the specific individuals that are receiving Title V services and developing a system to identify SSI eligibles in their eligibility system.[18]

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[18] Connecticut, unlike the other site visit states, did not have an existing eligibility code for SSI beneficiaries because this state is a “1634 state.” 1634 states are a small group of states that do not automatically provide Medicaid to those receiving SSI payments. In Connecticut these children may be found eligible for Medicaid through the same State-administered process as all other Medicaid beneficiaries. Therefore this State did not, previous to the BBA, need to track SSI beneficiaries as a separate eligibility category in its Medicaid program. However, to meet the requirements of the BBA, this State plans to begin accepting information from the Social Security Administration identifying SSI beneficiaries.

Table 5: Existing sources of information Medicaid agencies could use to identify BBA-defined CSHCN

	Medicaid Eligibility System	Information from Non-Medicaid Agency	Information from Medical Providers
SSI Children	CO, DE, MA, MI, NM		CT
1902(e)(3)[19]	DE, MA, MI		
In Foster Care	CO, CT, MA, MI, NM		DE
Receiving Title IV-E	CO, CT, MA, MI, NM		
Receiving Title V Funded Care Coordination		MI	CO, CT, DE, MA, NM

It is clear from Table 5 that states would rely heavily on their Medicaid eligibility systems to identify four of the BBA-defined CSHCN groups. This follows directly from the categorical nature of the BBA definition. The only BBA group states would not identify by Medicaid eligibility category are those receiving Title V-funded care coordination because a child's receipt of any Title V service has no bearing on his or her eligibility for Medicaid. Information from another agency, such as the Title V agency, was the least reported existing source of identification in most of the site visit states. However, several states were considering moving in that direction, as the Title V agency is the only source that could reliably identify all Medicaid beneficiaries under age 19 who are receiving Title V-funded care coordination services. Each of these sources is discussed in more detail below. The use of medical providers to identify CSHCN was cited only when the Medicaid agency currently had no other source of more reliable and easily obtainable information.

Medicaid Eligibility System

Not surprisingly, state Medicaid eligibility systems track Medicaid beneficiaries' current and historical Medicaid eligibility information, usually including the basis (e.g., receipt of SSI payments) of each individual's eligibility. The information about the basis of Medicaid eligibility is often referred to as the individual beneficiary's eligibility category. When a child's membership in one of the five BBA groups is defined by eligibility category (SSI, 1902(e)(3), and foster care) there is an existing information system that tracks **all** Medicaid beneficiaries who belong to the group over time. All site visit states also have existing mechanisms to pass eligibility category information to MCOs and PHPs, but not on a regular basis to PCCM or fee-for-service providers. All site visit state Medicaid agencies and MCOs

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[19] As discussed in the **Definition** chapter, Colorado, Connecticut, and New Mexico do not use §1902(e)(3) and, therefore, no child in these states belongs to this category of the BBA definition.

reported they would use this source of information whenever possible to identify BBA-defined children with special needs.

Sometimes there are delays in changing a child's eligibility category, which can be problematic in the identification process. For example:

- a child may appear to belong to the TANF eligibility category during February,
- then be found eligible for SSI in June, and
- have that eligibility change made retro-active to February.

In this example the child is ultimately identified as SSI (special needs), rather than TANF (not special needs) as of February. Site visit states reported that changing an existing Medicaid beneficiary's eligibility category to SSI or foster care may take up to a year, and the change may be back-dated so that it appears that the child was identified as SSI or foster care during that year. This means that some children that are not identified as belonging to a BBA-defined group when services are provided or studies conducted may be found to belong to that group once the activity is completed. It is not known how many children this effects, but anecdotal reports suggest that the lag time between application and approval for SSI is growing. Colorado studied this issue and found that 13 percent of children who were receiving SSI at the time of their study had been in another eligibility group (primarily TANF) within the 2 ½ years previous to the study.

Information from Other Agencies

Information from agencies other than the Medicaid agency has the potential to identify all children belonging to the "foster care related" and "receiving Title V-funded care coordination" services groups. All children in foster care are known to the Child Welfare agency and all children receiving Title V services are known to the Title V agency. In all but one site visit state, the Child Welfare agency routinely identifies individual children in foster care to the Medicaid agency. The Medicaid agency then uses this information to assign a specific eligibility category to these children indicating their foster care status.

As will be discussed shortly, most site visit states did not report the existence of similar systems to transfer information from the Title V agency to the Medicaid agency because, prior to the BBA, neither agency saw the need to exchange that information. Connecticut, however, reported that it was working to establish such a system for identifying Title V children in order to meet Interim Criteria requirements. This State's Medicaid agency is working to establish a marker on its eligibility system that would, based on electronic information provided by the Title V agency, identify all Medicaid beneficiaries served by the Title V agency. This information would then be passed to the MCOs so that they could also identify all children receiving Title V services. However, this process is still in the discussion stage and, as currently envisioned, would identify all children served by Title V, not just the 55 Medicaid eligible children who were receiving Title V-funded care coordination services.

Although information from other agencies could potentially identify all of the children belonging to two of the BBA-defined groups, it can be extremely difficult to establish a means of exchanging information. The difficulty of exchanging information varies among states (and agencies) based on several factors.

Historical Need to Exchange Information

By federal statute, all children receiving Title IV-E payments are automatically eligible for Medicaid. As a result, in five of the site visit states, the Medicaid and Child Welfare agencies had established ways of exchanging information and tracking these children to determine Medicaid eligibility **before** the BBA defined this group as children with special needs. Qualifying for receipt of Title V services, on the other hand, was never pertinent to obtaining Medicaid eligibility or paying claims for services. As a result, Title V and Medicaid agencies in five of the site visit states reported no existing means of exchanging information identifying Medicaid eligible children receiving Title V care coordination services because, prior to the BBA, there was no reason to do so. Most reported that even after the BBA, it would serve no purpose to the Title V agency to identify these children to the Medicaid agency.

Confidentiality Concerns

In addition to Federal confidentiality requirements each state and each program has its own confidentiality requirements. Further, each is likely to have its own interpretation of what those requirements allow. The impact of these concerns varies widely among the site visit states from no impact to, in one instance, preventing exchange of any information identifying the children each agency serves. Some informants reported that the impact of confidentiality on their ability to gather information identifying CSHCN also varies according to the knowledge about confidentiality requirements of the individual case workers within the agencies.

Compatibility of Systems

Typically, each agency has independently developed its own system for identifying and tracking the children it serves. These systems are not generally designed to communicate with each other. Not only is it possible that the agencies are using incompatible hardware, but it is very likely that the agencies developed different ways of identifying the children. As a result, any efforts to identify children served by both agencies are likely to need an algorithm to match the children by factors such as name, birth date, and social security number. Finally, tracking a child's eligibility for Title V services is almost certain to require the Medicaid agency to modify its eligibility subsystem so that it can carry that information and track changes in an individual's Title V eligibility over time. MCOs would need to make similar changes to their management information systems if they were required to provide additional information on children with special needs that were identified by this method.

These are complex systems and any change would require planning and extensive testing to make sure it works correctly, all requiring resources in terms of money and staff time from the Medicaid and Title

V agencies, as well as the MCOs. The exact cost of establishing these systems will vary among states but is likely to be significant. Implementing these changes can also take more time than apparently needed due to competing priorities and limited resources.

It is clear that these issues can be addressed and that the involved agencies can share information identifying the children they serve; five of the site visit states currently exchange information with either the Child Welfare or Title V agency identifying the children each serves. However, where these systems are not in place (mostly with Title V agencies) addressing confidentiality concerns and establishing systems that are capable of exchanging and tracking information will take time and effort by both agencies, not just the Medicaid agency. It was not always clear in the site visit states that both agencies were willing and able to put forth the effort and absorb the costs of establishing these systems.

Provider Information

Site visit states also reported identifying BBA-defined CSHCN through the provider during provision of service. The states tended to rely on provider information only when no other source of information was available because, for reasons discussed below, provider information was not considered to be complete or reliable.

Some states now require MCOs to provide physician visits to new enrollees within a specified time (usually 90 days) and more reported planning to do so, especially if the final BBA regulations require that. This is an obvious opportunity for identifying CSHCN (BBA, state, and MCO defined). However, no MCO reported being able to provide an initial visit to all new enrollees within a specified time for the following reasons:

- The problems discussed earlier in contacting new enrollees will affect MCOs' ability to provide these visits to all new enrollees. Again, if the MCO cannot contact the enrollee, it cannot inform them of the need to make an appointment with their physician. In some cases, all the MCO can do is wait for the enrollee to seek care.
- Other enrollees will be new to the MCO, but continuing with their current physician. In these cases, it may be difficult for the MCO to convince either the enrollee to obtain or the physician to provide an "initial" office visit, since neither party views the visit as initial.
- Even if the enrollee changes physicians upon enrollment, he or she may simply not wish to see the physician without a specific reason, such as an illness or annual check-up.

Even when the enrollee does visit his or her provider it is unlikely that the provider would, without specific training, identify BBA-defined CSHCN. Providers are not accustomed to asking patients whether they receive Title V-funded care coordination or SSI benefits. This practice would be difficult to implement as a patient's SSI or Title V status is not usually germane to medical treatment, and the physician would not ask these questions of any patients who were not Medicaid beneficiaries.

However, as will be discussed in the next section of this chapter physicians would be more likely to identify state-defined CSHCN, since those definitions are generally based on health or functional status.

Also, agencies serving children with special needs (e.g., some Title V agencies, Early Intervention agencies, etc.) may require the development of a plan of care for each child. Many of these agencies require or encourage the physician to sign the plan of care. As a result, MCO-contracted physicians approached for signature would know that their patient is receiving services from another agency or program. Home health agencies or physical and speech therapists are also likely to know when a child is eligible for services from another program, as the other program may be paying for a portion of the agency's services. Finally, children in foster care are frequently identified when the child's foster care provider brings the child in for care.

Despite signature requirements in some states, physicians in all site visit states reported that they were rarely involved in the development of a plan of care. They also frequently did not receive a copy of a completed plan of care for the child's records. As a result, providers are unable to identify many of their patients who belong to the groups specified in the BBA. Only one physician interviewed for this report spoke of routine involvement in the development of a plan of care prepared by **any** agency.

It is possible for a Medicaid agency or MCO to identify some children meeting the BBA definition through provider information. It is extremely unlikely that this method could be relied on to identify all children who belong to any BBA-defined group. In addition to the issues discussed above, no Medicaid agency or MCO reported an existing system that routinely collects information about children identified by providers as belonging to one of the BBA-defined groups. Establishing such a system could take a considerable investment of resources on the part of MCOs and Medicaid agencies and would likely result in little increase in the number of children identified as meeting the BBA definition.

Both Medicaid agencies and MCOs reported using providers as a source of identification for some groups specified in the BBA. However, as discussed in the next section of this chapter, both reported that the use of that information was primarily by the provider as one of several "flags" that might identify a child who could benefit from MCO case management/care coordination.

Identification and Tracking of State Medicaid Agency-Defined CSHCN

As discussed in the chapter on **Definition**, the Medicaid agencies in four site visit states have, in their contracts with MCOs, a definition of CSHCN that differs from that included in the BBA. (The other two states did not have formal written definitions of CSHCN at the time of the site visits although both are developing or implementing one.) None of the site visit states defined CSHCN in their fee-for-service, PHP, or PCCM programs. This section focuses solely on state practices in identifying and tracking the children who meet the state Medicaid agency definitions in use in the MCO (not PHP) programs in those four states.

Definitions used in these four states are not dependent on the child's enrollment in a specific non-Medicaid program or on the basis for the child's eligibility for Medicaid. Instead, they are based on the health and functional status of the individual. In some ways, these health-based definitions are more difficult to put into practice than the categorical definition found in the BBA. For most of the groups identified in the BBA definition, no need exists for anyone (Medicaid agency, MCO, or PCCM provider) to interview the child and family to determine whether or not the child belongs to that group. The MCO or PCCM provider may, however, interview the child and family to determine services the child needs or what help the child needs to access those services.

On the other hand, the Medicaid agency or the MCO/PCCM provider must interview the child and family to determine whether the child meets a needs or functional based definition. (Usually a pre-established script or screening tool is used for these interviews.) This approach creates different issues in identification and tracking. Each of these will be discussed in this section.

- How and when are potential CSHCN identified?
- Who makes the final decision as to whether a child meets the Medicaid agency's definition and what information is this decision based on?
- How is the child's identification as a CSHCN tracked and used by the MCO, PCCM program, and Medicaid agency?

As discussed in the previous section, the site visit states with non-BBA definitions established these definitions primarily for the purpose of identifying Medicaid enrollees, including children, who need extra help in accessing appropriate care. They were not intended to be used in areas such as enrollment, MCO performance assessment, or network adequacy. As a result none of these Medicaid agencies had systems in place for the MCOs to report to them which children were identified as CSHCN. (One state, however, reported that some MCOs voluntarily used the Medicaid agency definition for internal monitoring purposes in areas such as network adequacy.)

Finally, it should be noted that the MCOs in the two states where the Medicaid agency had not established a definition of CSHCN at the time of the site visit (Connecticut and New Mexico)[20] reported using strategies similar to those used in the other four states to identify Medicaid beneficiaries, including children, that might benefit from case management (as do the MCO's in Michigan's general program). Also, even though these Medicaid agencies' contracts do not specify a definition of CSHCN, they do specify that contracted MCOs must provide case management/care coordination. Further, Connecticut plans to study the services delivered to CSHCN. In addition, Connecticut and

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[20] Connecticut was in the process of adopting the BBA definition at the time of the site visit.

New Mexico have facilitated working relationships with some of the agencies that provide care coordination to CSHCN. (These issues will be discussed in the chapter on **Coordination of Care**.)

Special Programs and Their Impact on Identifying and Tracking CSHCN

Michigan's *Children's Special Health Care Services* (*CSHCS*)[21] and Massachusetts's *Special Kids* **ì** *Special Care* programs are both unusual in that they serve only children who the state considers to have special needs. Specifically,

- the Michigan program enrolls only children who participate in the State's Title V program; and
- the Massachusetts program enrolls only children living in foster homes who have complex medical needs.

The MCOs involved in these programs do not need to make any efforts to identify which children among their enrollees meet the formal definition of CSHCN developed for these programs, for meeting the definition is a condition of enrollment. This also means that membership in the MCO is a reliable way for both the MCO and the Medicaid agency to track an individual's CSHCN status over time. Enrollment and disenrollment from the program is governed mostly by the child's CSHCN status. However, the issue of identifying CSHCN is still pertinent to these programs in the sense that these children need to be identified within the general Medicaid population in order to be found eligible for enrollment into the specialized program. Therefore, these programs are also discussed here and readers should bear these differences in mind when reading this section.

When CSHCN are Identified

Children's health needs and functional status are not static. Single events, such as a car accident or the development or flare-up of a chronic disease can cause a healthy child to become one with special health needs. Children can also recover from such incidents. These realities mean that:

- The number of CSHCN is not static, and any count simply represents a point in time.
- Efforts to identify CSHCN as part of the enrollment process are not sufficient to identify all CSHCN as their health care needs may change while they are enrolled in an MCO.

As a result, Medicaid agency and MCO informants all specified that their efforts to identify potential CSHCN are ongoing, not limited to the time of enrollment (often a one time event). However, the ongoing identification efforts reported in Michigan are the efforts of the general MCOs, not the Special

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[21] The CSHCS program also serves persons over 21 with cystic fibrosis and certain coagulation disorders.

Health Plans. The general MCOs are identifying children that could apply to the CSHCS program and be disenrolled from the general MCO. Similarly, the ongoing efforts reported by Massachusetts are performed by the Child Welfare and Medicaid agencies, not the MCO contracted to provide services for the *Special Kids* **Ì** *Special Care* program.

Although children's needs change, the time of enrollment is also an important time to identify CSHCN. During enrollment an enrollment broker or the MCO are likely to make direct contact (via phone or mail) with the enrollee to determine the enrollee's MCO or PCCM provider choices. Given that Medicaid beneficiaries, especially those with special needs, frequently select their managed care provider based on their health needs, enrollment is an opportune time to ask the enrollee to identify those needs. Key informants in the three site visit states with general MCO programs (Colorado, Delaware, and Massachusetts MCO program) reported that CSHCN are identified by the MCO at the time of enrollment. Neither of the special programs that serve only CSHCN reported doing so because CSHCN are identified as part of the enrollment process which occurs *before* enrollment in the MCO.

Who Decides if a Potential CSHCN Meets the State Medicaid Agency Definition

Who decides whether a child has special needs is an important consideration. In Colorado's, Delaware's, and Massachusetts' MCO programs, the Medicaid agency established the definition and then delegated most identification tasks to the MCOs. However, Colorado's MCO contract specifies that the Medicaid agency may make the final determination. Except in Michigan's and Massachusetts' special programs, the role of other state agencies, providers, and consumers is limited to referral of potential CSHCN to the MCO.

Both Michigan and Massachusetts reported that, for their specialized programs, the state agency makes the determination of the child's special needs status as a condition of enrollment. In the Massachusetts program, the Medicaid agency's clinical staff makes the determination. In Michigan, the Department of Community Health, which includes both the Medicaid and Title V agencies, makes the determination, then passes that information on to the enrollment broker. In both cases, the determination is made after review of the potential CSHCN's medical records and other information. Also, both states pass the information collected during enrollment to the child's new MCO.

MCO informants reported that their emphasis is to identify those people, including children:

- who have immediate needs at the time of enrollment (such as an operation that was scheduled prior to enrollment in the MCO); or
- who should be served by the MCOs case management/care coordination program.

MCOs do not generally focus on identifying all children who meet the state Medicaid agency's definition of a CSHCN. As previously mentioned, most MCOs felt that identification as a CSHCN was not important to serving the child; it was more important to determine what the child’s needs were and how to meet them. Most Medicaid agencies also placed greater emphasis on identifying individual needs than identifying a group of children who were defined as CSHCN. During initial implementation of its waiver program Delaware, (which did not at that time have a definition of CSHCN in its contract) provided information to all MCOs identifying the services that the 400 children who were receiving case management in fee-for-service were getting from the fee-for-service program. This information was intended to help the MCOs provide continuity of care for these children and identify children who might potentially need case management from the MCO.

How CSHCN Are Identified

The first step in identifying CSHCN using a definition based on the needs of the child is to identify a larger group of children who are likely to meet that definition. The MCO then performs a more detailed assessment for these potential CSHCN to determine who among them actually meets the definition.

Table 6 specifies the sources of information MCOs and Medicaid agencies in the four states with Medicaid agency definitions that differ from the BBA use to identify CSHCN. Essentially, each of these is intended to identify enrollees that may have immediate or complex health needs. In each case, the Medicaid agency or MCO needs to get more complete information from the parent or child before deciding whether or not the child meets the definition of CSHCN.

Table 6: Sources of information used to identify potential CSHCN

	Colorado	Delaware	Massachusetts/ MCO	Massachusetts/ Special Kids Ì Special Care	Michigan/ CSHCS Program
Screening Tool by Enrollment Broker	U		U		
Screening Tool by MCO	U	U	U		
New Member Outreach	U	U	U		
Client Surveys	U		U		
MCO Claims Data	U	U	U		U
Medicaid Claims Data	U	U[22]		U	
Eligibility Category	U		U		

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[22] This occurred only during program implementation in 1996. This information is not currently passed to MCOs because children are normally enrolled in the MCO before obtaining enough services on fee-for-service Medicaid to create a claims history.

Referrals	**U**	**U**	**U**	**U**	**U**

This table indicates that referrals from others that serve the child are most frequently used to identify potential CSHCN. MCO claims data is the next most frequently reported source of information, followed by new member outreach, screening tools completed by the MCO, and Medicaid claims data. Eligibility category and screening tools completed by the enrollment broker were the least frequently reported sources of information. (It is important to note here that for reasons that will be discussed in the **Enrollment** chapter, neither the enrollment broker nor MCO is able to locate and screen a high percentage of enrollees.)

Referrals

Referrals are notifications from someone familiar with the child's needs that the child may need additional help in accessing care or is having difficulty doing so. Referrals can come from anyone who serves the child including: providers, enrollment staff, family members, the Medicaid agency, and other state agencies. However, when asked to cite the source of most referrals, many MCOs mentioned contracted hospitals because the child's complex health needs are likely to be discovered during, or result in, a hospital stay.

MCO informants cited referrals as a good source of identification of potential CSHCN. However, referrals cannot be relied on to identify all potential CSHCN. Almost all informants other than the Medicaid agency and MCOs, including MCO subcontracted providers and MCO enrollees with special needs, were unaware of the case management/care coordination programs offered by most general MCOs. They were also unaware of any efforts to identify CSHCN. As a result, many potential referral sources are unaware of who takes referrals or that there is someone at the MCO to do so. Even if they were aware of the MCO's programs, only those who saw the program as a benefit and had the time to make the referral would do so. Michigan's special program for Title V children was the exception. Almost all interviewed in that State were aware of the program and would make referrals to the agency that administers the program.

MCO Claims and Utilization Data

MCOs reported using data from claims to identify potential CSHCN but in different ways. Some produce reports to identify high-cost or high-utilization children. Some produce reports indicating which children are frequently seen in the emergency room or have a prescription or other indication of a specific chronic illness such as asthma or diabetes. Many of the MCOs interviewed for this report also cited claims from home health agencies or durable medical equipment (DME) providers as a potential source for identifying CSHCN. The advantage cited by the MCOs of using these reports is that they can identify all children who might be CSHCN and for whom services have been billed. Also, this source does not rely on those outside the MCO to identify potential CSHCN except insofar as they must submit a claim in order to receive payment. The drawback is that none of these reports can identify a child until that child has received services that are in some cases very specific.

One staff-model MCO uses utilization information it has about the services its provider employees delivered to the child before the child was enrolled in the MCO to identify CSHCN. This same MCO uses utilization information from children's previous enrollment into the MCO to identify CSHCN who are returning to the MCO. This model, although interesting, has limited applicability as most MCOs are not staff model and so would not have information about services subcontracted providers delivered to children before they became enrollees.

New Enrollee Outreach

New enrollee outreach refers to the efforts MCOs make to contact new enrollees to: obtain or confirm PCP choice, explain how to access care through the MCO, answer any questions the new enrollee may have about the MCO, and identify any immediate needs the enrollee may have. In the four site visit states with Medicaid agency definitions of CSHCN, all those that used general MCOs (Colorado, Delaware, and Massachusetts) to deliver care to CSHCN also used new enrollee outreach as an opportunity to identify potential CSHCN. The two specialized programs did not use new enrollee outreach as a source of information for identifying potential CSHCN because the child had already been found to meet the Medicaid agency definition before enrolling in the program.

MCOs in several states reported a similar process for new enrollee outreach. Typically, they reported, such outreach is usually conducted over the phone or through the mail. However, MCOs occasionally visit the new enrollee's home to perform the new enrollee orientation. Most MCOs reported making attempts to contact new enrollees by phone, followed by mail if they could not contact the person by phone. Phone efforts usually include scripted questions designed to elicit information about the enrollee's health needs. Mail efforts usually include a request for the enrollee to call the MCO. In some cases the mailed information includes a form that the enrollee can complete and return to the MCO identifying medical needs. If the information collected indicates that the child might have complex health needs, the child is referred to case management/care coordination staff within the MCO. This staff performs a further assessment (usually over the telephone but sometimes during a home visit) to determine, among other things, if the child meets the CSHCN definition.

Most MCOs reported that the information they receive from the Medicaid agency is frequently missing the telephone number or has an incorrect number. They also reported that some of the addresses are incorrect. (These issues and efforts to address them will be discussed more completely in the **Enrollment** chapter.) As a result, new enrollee outreach does not reach all new enrollees and cannot be relied upon as a sole source for identifying potential CSHCN. The accuracy of the address and telephone number has a direct impact on the success of efforts to contact potential CSHCN.

Eligibility Category

Several MCOs in Colorado and in Massachusetts' general MCO program reported that they used the eligibility category as a factor in helping them identify potential CSHCN. These MCOs reported making extra efforts in their attempts to contact new enrollees who were SSI eligible.

Screening Tools

Many in the field believe that a screening tool is the preferred method for identifying potential CSHCN. Ideally, such a tool could be administered to all children upon entry to the MCO and on a regular basis thereafter. Doing so would enable the MCO to identify all children who were CSHCN. However, for a number of reasons (see **Enrollment** chapter for more details) neither the enrollment brokers nor the MCOs reported success in contacting all potential CSHCN for screening. As a result, screening cannot be relied on as a sole source for identifying CSHCN.

Use of a standardized screening tool was among the least frequently reported means to identify CSHCN, at least partially because it was not pertinent to the specialized programs that serve only CSHCN.

- State efforts for both of the special programs go beyond the use of a simple screening tool. Both states reported extensive efforts to identify each child's specific needs and current providers (including obtaining the child's medical records) prior to enrollment.

- Among the three site visit states with formal written definitions of CSHCN in their general MCO contracts, two use a screening form administered by the Medicaid agency-contracted enrollment broker.

- At least one MCO in all three site visit states with a definition of CSHCN in their general MCO contracts reported the use of a standardized screening tool or health risk assessment upon enrollment into the MCO.

A number of research organizations have developed and continue to refine screening tools to identify CSHCN. Some expressed optimism that as the state of the art in screening tools continues to evolve, such tools will become more useful. However, at the time of the site visits, those Medicaid agencies and MCOs that reported using a screen did not use those developed by these organizations. Most MCOs and Medicaid agencies did examine those produced by research organizations as they developed their own tools. Most also reported consulting other stakeholders in the development of the tool. As will be discussed in the **Enrollment** and **Care Coordination** chapters, one of the reasons that Medicaid agencies and MCOs do not use the tools developed by research organizations is the length of many of the tools. Among the shortest are the QuICCC-er and PRA+ with 16 and 9 questions respectively. One state reported that its experience using a 12-question tool was that even 12 questions were too many to expect many enrollees to answer during the enrollment process. Both states that require their enrollment brokers to complete screening tools share a copy of the completed tool with the MCOs. MCOs generally view the information from the enrollment broker as an initial screen, indicating which children need follow-up. Their follow-up process typically includes the use of a more detailed MCO-developed screening tool.

One of the MCOs in each of the three states where the MCO(s) administer an assessment tool supplied a copy of that tool. These tools tended to be longer than those administered by the enrollment broker, although still brief : 1 page (18 questions), 2 pages (15 questions), and 3 ½ pages (16 questions).

- All three tools asked questions to identify specific health conditions the child might have.
- Two asked about services the child was currently receiving (e.g., medical supplies and equipment, specialists, therapy, home health).
- One tool asked about the caregiver’s needs (including the need for help in coordinating the child’s care) and understanding of the child’s medical condition.
- One tool asked for demographic information such as sex, race, and age.
- One tool was designed primarily for administration over the telephone.
- Two tools were designed primarily as mail-out surveys.
- All three tools are used to identify CSHCN at the time of enrollment and ongoing.

Medicaid Claims and Utilization Data

MCOs and Medicaid agencies can use Medicaid claims and utilization data to identify CSHCN in the same way that the MCOs use their own claims and utilization data (previously described). Massachusetts and Colorado have done so. During program start-up, Massachusetts’ Medicaid agency used claims information to identify children who might be eligible for participation in their *Special Kids* **Ì** *Special Care* program. Also, Colorado is now implementing a pilot project with two MCOs to share fee-for-service histories of children who are assigned to the MCO. The MCOs plan to use this information to facilitate their identification of children with special needs. Confidentiality has been an issue in the development of this process. For some time the Medicaid agency was not sure if it could share this information with the MCOs. Other site visit states do not use utilization to specifically identify CSHCN.

However, Medicaid claims and utilization data is not available for many CSHCN after the initial implementation of the managed care program. After implementation, new beneficiaries are quickly enrolled into MCOs and, therefore, do not develop a claims history in fee-for-service Medicaid. The only information that remains consistently available from the Medicaid agency is for those children that are enrolled with a PCCM provider and for other services that are excluded from the MCO’s benefit package. As a result, Delaware (which uses only MCOs and excludes few services from the managed care program) only provided utilization information about new enrollees during program implementation; it no longer has any information to provide from claims. Also, Colorado (which uses both PCCM, MCO, and PHP models and excludes several services from managed care) finds that only 50 percent of the children in their State have any fee-for-service history.

Theoretically, encounter data from another MCO that served the child would be able to provide similar information for some children, but none of the site visit states were providing encounter data information about the services delivered to new enrollees at the time of the site visit (two were considering doing so). Of course, encounter data would only be available for children that were changing MCOs, not for children who were new to the Medicaid program. Also, until recently, most considered the encounter data to be too incomplete and inaccurate to provide much useful information. However, now that these reporting issues are being worked out, more states reported considering providing this information to MCOs.

Tracking Medicaid Agency-Defined CSHCN

HCFA's Interim Criteria for identification requires that "the State collects, or requires MCOs/PHPs to collect specific data on children with special needs." States or MCOs need to be able to track CSHCN over time if they are to collect information about the care provided to CSHCN, during the time they are CSHCN.

Only one of the general MCOs reported establishing systems that enable them to track CSHCN as a group over time. All MCOs reported systems that enable them to identify which children are receiving case management/care coordination services. However, those systems are not generally integrated into the claims processing or enrollment systems so that it would be difficult to produce reports showing the experience of these children in the MCO. One staff-model MCO was the exception. This MCO has an electronic medical record that tracks appointment and service information. Some information in this system now goes back to 1996. The Clinical Information System incorporates information from the MCO's appointment booking software, communications between nurse and physician, and has a direct link to another database that shows emergency room usage.

None of the Medicaid agencies have established means for general MCOs to report the number of children they have identified as CSHCN or which children are so identified to the Medicaid agency. As previously mentioned, most of the Medicaid agencies instead rely on:

- eligibility group to identify CSHCN for performance assessment purposes;
- site visits to ensure that appropriate policies are in place for identification of CSHCN; and
- complaints and grievances to identify day-to-day issues related to the delivery of care to CSHCN.

In each of the four states, neither the Medicaid agency nor any of the MCOs could reliably provide the number of children who met the state definition of a CSHCN or was confident that they had identified all CSHCN. The MCOs could identify the individuals and number of children receiving case management services from the MCO, but each acknowledged that not all CSHCN were in case management. Nor were there mechanisms in place to identify these children to the Medicaid agency. Only in Delaware were there any provisions to pass on the information about a child's participation in case management to the new MCO, and in that State the MCOs said that such information was not generally passed to them from the previous MCO.

Identification and Tracking: Summary of Study Question Findings

Can states meet the Interim Criteria for identifying CSHCN?

Identifying BBA groups

State Medicaid agencies and MCOs reported that, when required, they could ultimately identify all members of the five BBA-defined groups of CSHCN, although none reported doing so on a regular basis at the time of the site visits.[23] Most Medicaid agencies reported a reluctance to identify and track the BBA-defined CSHCN because they, and almost all other informants, did not consider the definition to be useful for program operation and evaluation. Instead they would prefer to continue to devote their resources to building upon the systems each had established with input from stakeholders to safeguard and monitor the care delivered to CSHCN.

Medicaid agencies reported that using their existing eligibility systems they could identify all BBA-defined children for whom they had established an eligibility category (usually SSI, foster care, and 1902(e)(3)) in fee-for-service and in PCCM programs, as well as in MCOs. However, issues with retroactive changes of eligibility category would likely result in a few children being incorrectly identified.

At the time of the site visits, most Medicaid agencies could only identify some of the Title V group. However, to prepare for the implementation of the Interim Criteria, most were establishing means of identifying all members of BBA defined groups. Title V was described as the toughest group to identify as, unlike foster care, no system typically exists for communicating individual level information from the Title V agency to the Medicaid agency as such a system was not needed prior to the BBA. Developing such a system will take time and money from both agencies and may prove challenging since some informants reported uncertainty about the benefits of establishing such a system.

Collecting Specific Data on Children with Special Needs

States reported collecting data from MCOs for all enrollees, such as encounter data, complaint/grievance, and consumer survey information that can be used to judge the care provided to enrollees, including CSHCN. Much of this information could be analyzed by the Medicaid agency to

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[23] Again it is important to remember that none of these states was required, at the time of the site visit, to meet the Interim Criteria because they had not sought or obtained a waiver since passage of the BBA.

produce special reports for CSHCN and the various children who meet that definition. Some, however, reported concern that groups identified in the BBA definition may not always be the best groupings for analysis of data. For example, analyzing the care of all SSI children as a group may not be an effective method to analyze the care provided to children who had specific health conditions such as asthma or autism. A sample consisting only of children with those conditions would yield more pertinent information.

No state reported that its general managed care program collects information for CSHCN that is different than that collected for other enrollees or other enrollees with special needs. Both states with specialty programs for a subgroup of CSHCN collect different information from the MCOs participating in those programs than from other MCOs. The additional information collected from the specialty programs is mostly collected in order to assess MCO performance in care coordination. (These are all discussed in more detail in the **Coordination of Care** chapter.)

Medicaid agencies do not collect any information from PCCM providers that serve CSHCN. Also, only one of the site visit states had done any analysis to examine the experience of CSHCN in PCCM and fee-for-service systems.

How do states monitor and evaluate MCO performance in identifying CSHCN?

At the time of the site visits, Medicaid agencies reported that they anticipate identifying four of the five BBA-defined groups (all except those receiving Title V funded care coordination) by eligibility category. At least two anticipate being able to identify the Title V group through information from the Title V agency. In these cases the MCO has no role in identifying the BBA-defined CSHCN and, therefore, there is no need for the Medicaid agency to monitor and evaluate MCO performance in this area. There is also no need for the Medicaid agency to monitor MCO performance in identifying CSHCN enrolled in the two specialty programs that serve only children with special needs All program participants must be CSHCN and, therefore, no further efforts are needed to identify them as CSHCN.

At the time of the site visits, several Medicaid agencies reported that they monitor and evaluate the identification of state-defined CSHCN. However, most state efforts are not directed specifically at identifying CSHCN. Instead these efforts are focused on discovering if the MCO fulfilled the purpose for which it was supposed to identify the children. For example, many efforts were directed at determining whether the MCO provided appropriate case management/care coordination services and whether the MCO identified enrollee's individual health needs. Some states ensure that written policies regarding identification of enrollees who may need care coordination/case management services are in place during annual site visits to each MCO. Some take the further step of interviewing MCO staff to make sure that they are aware of the policies. Massachusetts is working with its contracted MCOs to develop screening tools that each could use to identify enrollees with immediate or complex needs.

Finally, most site visit states look to complaints and grievances and stakeholder input to help them determine whether MCOs are identifying and meeting the needs of CSHCN.

How do States identify CSHCN in the fee-for-service system?

Medicaid agencies did not report any efforts to identify BBA-defined CSHCN in their fee-for-service systems, nor is there any "push" for them to do so. Most attention at both the national and state level has been focused on examining how well CSHCN fare under managed care, not how well they fare under fee-for-service.

Do the Interim Criteria on identification address the most significant issues faced by children and their families?

Because informants reported that the BBA definition, as used in the Interim Criteria, generally does not meet the needs of CSHCN and their families it follows that identification of these groups also does not meet their needs. In particular, the Interim Criteria do not address the identification issue most often raised by MCOs, consumers, and state agencies. Informants from these groups most frequently cited the importance of identifying an individual child's needs, including the need for case management/care coordination rather than identifying all children who belonged to a group labeled CSHCN. (Issues such as care coordination are addressed by other sections of the Interim Criteria and will be discussed in later chapters.) MCOs also frequently cited their inability to contact many new enrollees by telephone due to missing or incorrect information from the Medicaid agency as a significant challenge in identifying the individual needs of CSHCN and other enrollees.

Informants reported that identifying CSHCN and their individual needs is the most important factor in serving CSHCN, and that these efforts could not be one-time events because children's health status and needs change over time. Informants also believe that tracking these children's experience could yield valuable information. But they reported that the BBA definition is often not the right definition to use in these efforts. For example, many reported that evaluation of the care provided to various subgroups of CSHCN defined by health condition (autism, asthma, cerebral palsy, etc.) would often yield more useful information then evaluation of the care provided to SSI children as a whole. This preferred approach requires a finer definition and more specific identification than that used in the BBA.

Although they prefer a needs-based definition, key informants in the site visit states generally reported that they are still struggling with effective ways to identify children who meet such a definition. Four major unresolved issues were reported by a range of informants (Medicaid agency, MCO, consumers, and providers). They are:

- The difficulty of obtaining and maintaining correct contact information for enrollees, since contacting enrollees to determine their needs is a necessary first step in serving CSHCN. (This issue will be discussed more in the next chapter on **Enrollment**.)

- The lack of service history (either claims or encounter data based) for new Medicaid beneficiaries. Also, some expressed concern that state and federal confidentiality requirements might prevent transmission of service history information, when it exists, to the MCO.

- Lack of coordination among the various programs and agencies that serve CSHCN (Medicaid, Title V, Child Welfare, Education, etc.)

- The lack of clarity about the criteria children needed to meet in order to be provided certain services, such as care coordination/case management and therapies.

Some informants expressed concern that the resources needed to establish a system that would identify and report on a regular basis on the experience of children who met the BBA definition would draw from resources that might otherwise be used to resolve these outstanding issues.

IV. ENROLLMENT AND DISENROLLMENT FOR CSHCN

Interim Criteria

Concerning issues of enrollment and disenrollment for CSHCN, the Interim Criteria require that:

The State performs functions in the enrollment/disenrollment process for children with special needs, including:

- *Outreach activities to reach potential children with special needs and their families, providers, and other interested parties regarding the managed care program.*

- *Enrollment selection counselors have information and training to assist special populations and children with special health care needs in selecting appropriate MCO/PHPs and providers based on their medical needs.*

- *Auto-assignment process assigns children with special health care needs to an MCO/PHP that includes their current provider or to an MCO/PHP that is capable of serving their particular needs.*

- *A child with special needs can disenroll and re-enroll in another MCO/PHP for good cause.*

- *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 for individuals with mental health and substance abuse diagnoses -- against the enrollee.*

Introduction

HCFA's Interim Criteria address certain elements of enrollment and disenrollment in managed care. They attempt to identify issues that may be of particular importance when conducting mandatory enrollment of a special needs child into managed care, among them outreach regarding program options, appropriate training of enrollment staff, the methods by which a child is assigned to a managed care plan, and disenrollment options and protections.

This study identified other components of the enrollment process that may also impact children with special health care needs and their families. These emerged during our interviews with the various stakeholders and our review of the relevant materials. They include:

- the extent of interaction between the family and the enrollment counselor;
- the availability of information on provider networks;
- the availability of medical information about the enrollee;
- and what information is provided to the MCO.

In addition, the state's standard enrollment policies on issues such as enrollment lock-in, guaranteed eligibility and enrollment continuity after a break in eligibility may have an effect on the enrollment of CSHCN in managed care. Finally, significant differences exist between the enrollment practices of mainstream managed care plans, which enroll the majority of the special needs populations, and those of special managed care programs that target a specific group of children with special needs.

This chapter discusses our findings and observations regarding the Interim Criteria on enrollment and disenrollment as well as other enrollment practices that have a bearing on children with special health care needs. For discussion purposes in this Chapter, the term "MCO" refers to those organizations that provide a comprehensive set of services; it does not include PHPs.

Current Practice in Enrollment and Disenrollment of CSHCN in Medicaid Managed Care

The enrollment process for managed care was fairly similar in all site visit states, and, in general, applied to all enrollees in managed care. There were few practices in mainstream managed care enrollment targeted specifically to Medicaid beneficiaries with special care needs. In fact, one of the characteristics of a mainstream managed care system is to facilitate enrollment among managed care organizations without regard to the particular health status of individual enrollees. The role of the enrollment counselor, whether based at a contracted enrollment broker or housed within state or local government, is to provide sufficient information to prospective enrollees so that they can voluntarily select a managed care option. It is expected that the activities and interventions of the enrollment counselor will facilitate the family's choice of a managed care plan. At the same time, the enrollment counselor is expected to be impartial to any particular option and to not unduly influence an enrollee's decision. A certain tension exists between these two expectations, and it becomes particularly apparent when discussing enrollment options for special needs beneficiaries. Though a family with a special needs child could benefit from more intensive intervention when selecting a managed care option that can meet their needs, enrollment counselors must make sure that their communication does not result in biased selection of a particular MCO.

Selection, or “assignment,” bias is also of concern in the auto-assignment process for general managed care programs. Safeguards are often put in place in the auto-assignment process to prevent a disproportionate number of any group of beneficiaries from being assigned to any one MCO. Generally, states use a variety of factors to conduct auto-assignment in their mandatory managed care programs, though very few have included the provision of matching enrollees to their current provider or to one who can meet their needs.

Five of the site visit states reported using an enrollment broker to conduct enrollment activities. New Mexico alone retains the enrollment function within the Medicaid agency. The broker or state agency mails an enrollment packet to the family that generally includes a letter and brochure informing them about the managed care program, an enrollment form, and comparative information about the managed care options available in their geographic area. Delaware also includes actual marketing materials from the MCOs. The letter instructs the family to enroll within a certain period of time, and they can do so by phone or by mail. The enrollment counselor generally conducts some follow-up with the prospective enrollee, either by phone or mail, prior to the deadline for enrollment. After that date, the enrollee is assigned to a managed care plan.

Table 7: Enrollment systems in site visit states

State	CO	CT	DE	MA	MI	NM
Who Conducts Enrollment	Enrollment broker	Enrollment broker	Enrollment broker	Enrollment broker	Enrollment Broker	Medicaid agency
Enrollment Form Submission	Enrollment by phone or mail	Enrollment by phone or mail	Enrollment by phone or mail	Enrollment by phone or mail, or in-person at state service centers and selected sites	Enrollment by phone, mail, and through face-to-face contact with contracted CBOs	Enrollment by phone or mail
Time Allowed to Choose Managed Care Option	Minimum choice period is 65 days; average is 90-120 days	30 days from date of enrollment letter	30 days from date of enrollment letter	30 days from date of enrollment letter	30 days from date of enrollment letter for Medicaid MCOs, 45 days for CSHCS	At least 14 days from date of enrollment letter

Follow up Process	Letter #2 sent if no response after 45 days; beneficiary notified of MCO they will be assigned to if no response within 20 days. The letter that notifies enrollees of their default assignment also tells them that, if they have been on Medicaid before, some of their medical history may be shared with the assigned MCO to help them identify special needs.	Three phone calls made by enrollment broker. If no response w/in 30 days assigned to MCO; MCO assignment notification letter sent.	If enrollee's choice information is not received within 20 days, enrollment broker contacts enrollee to remind him or her to select MCO.	Reminder card sent 15 days after initial enrollment letter.	Attempt phon after 10 days; reminder lette 15th day, conta field counsel (200 contract CBO staff) for personal follo on 20th day; p assigned an confirmation l sent on 30th d enrollment in Medicaid MC

Outreach Activities

HCFA identified outreach to potential children with special needs, as well as their families and providers, as an important component of serving CSHCN in managed care. According to current interpretation of the Interim Criteria, a state could satisfy this portion of the Criteria by conducting general outreach efforts that could be expected to reach CSHCN as well as more targeted activities. State Medicaid agencies in the six site visit states reported various outreach activities regarding managed care enrollment, though few conduct outreach directed specifically to CSHCN. Generally, prospective enrollees for managed care are alerted to the fact that they will have to enroll (if a mandatory program) when they are determined eligible for Medicaid. In most instances, they do not receive any additional information about the program until the enrollment process begins. Several states did hold educational sessions and provided information targeted to various constituencies during the initial development and implementation phases of their managed care programs. (See Chapter on **Stakeholder Input** for further discussion.)

The outreach that states reported conducting was usually a general initiative, of benefit to the entire universe of potential managed care enrollees, including CSHCN. For example, Delaware and Connecticut include outreach as a component in their contracts with their respective enrollment brokers. In both instances, the broker conducts periodic outreach activities in the community to inform prospective beneficiaries about the managed care programs. They target provider sites familiar to the Medicaid population, such as hospitals, FQHCs, and public health clinics. The New Mexico Medicaid agency contracts with community-based organizations (CBOs) to inform their respective constituencies about the managed care program and their managed care choices. The State has found that this practice has been very effective because the CBOs are generally trusted by consumers to convey accurate information. Some of New Mexico’s contracts are with those CBOs that serve CSHCN. Colorado also implemented some outreach activities in its mainstream managed care program that target CSHCN. Through its grant-funded initiative, the “Safety Net Project,” it hired Parent Advocates who conduct Medicaid education sessions for parents and other community members. These sessions focus on EPSDT and how to access benefits, specifically for children with special needs.

Some agencies and organizations outside of the Medicaid agency reported conducting more targeted outreach to specific populations. Public Health agencies sometimes take an active role in explaining managed care and the enrollment requirement to the families it sees through its maternal and child health initiatives, WIC, or Title V programs. During program start up, advocacy agencies took the lead in informing their constituencies about the state Medicaid agency’s transition to managed care. *Health Care for All,* in Massachusetts, conducted consumer education during the implementation of the State’s Medicaid initiatives, as did *Delawareans with Special Needs* during Delaware’s implementation of the Diamond State Health Plan in 1996.

Targeted outreach was more often reported when a state develops a specific initiative for a certain identifiable population. Massachusetts initiated the *Special Kids* **Ì** *Special Care* program for children in foster care with intensive medical needs. It targets a subgroup of foster care children who meet specific medical criteria. In this case, the Child Welfare agency can identify the potential enrollees without too much difficulty. It contacts the foster parents to explain the program and the option for their foster child to enroll. In Michigan, Title V children who are eligible for the *Children's Special Health Care Services (CSHCS)* program and live in a county with a Special Health Plan option are contacted by the enrollment broker or one of its contracted community-based organizations. The family learns about the health plan options and is given the choice of enrolling in one of two Special Health Plans or in fee-for-service.

Outreach specific to providers who serve special needs children about the managed care program was reported even less frequently. Most of the providers with whom we met reported receiving limited information about the managed care program in which their patients enrolled. Provider informants found themselves unfamiliar with how the children for whom they care will now receive services. In many instances, they reported that it is much more difficult to access services for the child in managed care than it was in the fee-for-service system. Several of the physicians with whom we spoke were also concerned with the lack of knowledge on the part of their colleagues who do not treat children with special health care needs. They voiced concern about the limited awareness and education that other physicians have about serving children with special health care needs. That translates into a reluctance on the part of those providers to take them as their patients. In turn, it puts a greater burden on a small group of providers who are willing to serve these children.

This particular aspect of the criteria and the practices among the states related to it highlights one of the major recurring themes of this report: there needs to be agreement on which children are potential CSHCN. For enrollment, that agreement is important so that Medicaid agencies and MCOs may better target their outreach efforts. And, as discussed above, it may be that agencies and organizations other than Medicaid agencies and MCOs are better able to reach potential CSHCN because of the services that those entities have provided historically.

Training and Information Available to Enrollment Counselors about CSHCN

Though HCFA identified training and information about special needs as particularly important in the ability of enrollment counselors to serve children with special needs, it is an area that does not appear to receive much attention among the states. In general, Medicaid agencies reported that enrollment staff were prepared to provide information about provider availability and networks if they have the information. One state reported that the enrollment counselors have the information necessary to assist special populations in selecting an MCO or PCP that can meet their needs. Another state explained that the enrollment counselors are not medical experts and, therefore, cannot be asked to help with the selection of appropriate medical providers. Most enrollment staff have not received specific training about special needs populations or medical conditions. In some instances, however, they have received training on the interview process with enrollees so that they are prepared to ask questions that may identify particular health needs. They also have information on resources and services available to the Medicaid population that may be helpful to enrollees with special needs.

The two site visit states with specific managed care initiatives for children with special health care needs did report particular training or expertise in enrollment staff. The enrollment broker in Michigan is responsible for enrollment in both the general managed care program and the program for Title V children. The broker has a full-time staff person with extensive background in assisting people with disabilities. She is responsible for training, in-service, and consultation with all enrollment staff. This individual also participates in home visits, if necessary during the enrollment process. In Massachusetts, staff for the enrollment broker receive training on any new special programs, such as the *Special Kids* **Ì** *Special Care* program so that they are aware of the options available to enrollees with special needs. The actual enrollment for this particular program is facilitated by an RN within the Medicaid agency who has specific training and an understanding of the children's medical conditions.

Interaction with the Family and Prospective Enrollee During the Enrollment Process

The amount of interaction between enrollment counselors and the prospective enrollee and family varied among the site visit states. In most instances, site visit states reported that it is largely dependent on the family contacting the enrollment staff to ask a question or to complete the enrollment process. These contacts provide the opportunity to assist families with the choice of a plan and/or provider that can meet the particular needs of the enrollee. In all site visit states, the enrollment counselor is prepared to help the family with their selection by providing them with additional information about the MCOs' provider networks and/or the availability of individual PCPs.

These contacts also provide an opportunity to learn more about the prospective enrollee. Two site visit states, Colorado and Massachusetts, incorporate specific screening in the enrollment process, the results of which they then pass along to the selected MCO. In neither instance is the assessment a specific screen for children with special needs.

- Colorado uses the "expedited appointment screen," consisting of three questions: 1) does the enrollee have any medication or health care needs within the next two months, 2) is the enrollee pregnant, and 3) what is the current address and phone number. The enrollee or family member may give this information to the enrollment broker during a phone enrollment process or, alternatively, may answer the questions on the enrollment form if they choose to enroll by mail. This information is transferred electronically to the MCO with the other enrollment data. It is not transferred to the PCCM or PHP provider.

- In Massachusetts the enrollment broker conducts a health needs assessment over the phone, using a standardized form, if the beneficiary is willing to participate in the interview as part of the managed care selection process. The *Health Needs Referral Form* contains four sections: 1) case information, 2) selection of a plan, 3) member consent to inform plan of their medical condition, and 4) medical condition, which includes a list of 21 possible conditions that may be checked off. The assessment information is sent to the MCO in which the beneficiary has enrolled, if the member consents to having the information on medical conditions shared with the MCO. The information is not sent to the PCCM or PHP provider.

As noted above, key informants reported that contact with the family is largely dependent upon the family's initiation and, therefore, the amount and type of information that is collected and conveyed is inconsistent from one family to the next. The enrollment broker in Delaware tries to make phone contact with every family who hasn't submitted its enrollment information within 20 days of the initial enrollment letter. The counselors use that opportunity to coach the family about contacting the MCO when they first enroll in the MCO. Michigan alone reported regular face-to-face contact during the enrollment process. The enrollment broker contracts with community-based organizations to conduct in-person orientation to the managed care options and to do individual follow-up with potential enrollees who have not responded to their initial enrollment letter.

Concerns of Families and Advocates about Enrollment in Managed Care

Family members and advocate informants expressed several concerns about receiving insufficient information, both during the enrollment process and throughout the child's enrollment in managed care. They expressed the need for more information and a better understanding of the Medicaid program, in general. They want to know what benefits are covered and how to access them, either through the MCO, PHP, PCCM provider, or through fee-for-service. If their child sees a particular provider, they want to know how they can continue to get care from that provider. One enrollment broker noted that they frequently hear from parents of children with special health care needs that they want more information on how the program works and lists of specialists and ancillary providers that are participating in the MCOs' networks.

From both the MCO's and the Medicaid agency's perspective, this seemingly simple request for current information about participating providers is extraordinarily problematic to provide. Even though MCOs attempt to provide updated information to the entities responsible for enrollment, the information does not stay current for long, and it is not necessarily as comprehensive as families would like. These problems are not unique to Medicaid contracts; they occur in the commercial marketplace as well. It is difficult to maintain a current roster of providers who are taking new patients, and there is also considerable fluctuation in an MCO's provider network.

Parent informants were particularly concerned with understanding how various therapies are provided under managed care, and how this may differ from what their children were receiving under fee-for-service. Several told of how they had to appeal a decision made by the MCO to terminate services and, further, that they were not adequately informed of their rights to continued services for their child, pending a decision on their appeal.

Several families and advocates with whom we spoke expressed concern about how much medical information should be shared with enrollment staff during the enrollment process. Although they want to make sure that their child gets appropriate and comprehensive care in managed care, they are reluctant to give specific details about their child's medical condition, the extent and types of services that they have been using, or the providers they have been seeing. They question whether the enrollment broker is the appropriate entity with whom to share this information. They are also concerned about completing a postcard that details their medical care needs when it is unclear who may see that information.

The Selection of a Managed Care Option

Enrollees, in general, choose their managed care provider based on the availability of certain providers and the recommendations of their friends and family. Strong networks of families with special needs children play a pivotal role in helping new families determine how they can access the best care for their child. Word-of-mouth recommendations and personal experiences were reported as far more influential than MCO report cards or the results of satisfaction surveys. Families of children with special health care needs were often more interested in learning whether a certain specialist, DME provider, or home health agency was in a network than they were in knowing if a particular primary care provider was included. They wanted to be able to maintain the network of providers that had been taking care of their child. In those states that have a PCCM option, families often reported preferring this managed care arrangement to that of an MCO. They believe that their child will have better access to the care that he or she needs under the flexibility of the PCCM system. They are more confident that within a PCCM system they can put together a system of care that works for their child, even if they have to do the care coordination themselves.

The Information that the MCOs Receive

One of the major issues for both the state Medicaid agencies and the MCOs was what information about the individual enrollee is conveyed to the MCO at the time of enrollment. Beyond the usual and universal concerns about the accuracy of the contact information (address, phone number), there is considerable variation in practice and opinion as to what additional information is, and should be, transferred to the MCO.

As discussed above, the enrollment brokers in both Colorado and Massachusetts attempt to collect health-related information from enrollees with whom they have contact. Although this information is intended to assist the MCO in identifying those new enrollees who may have immediate or complex special care needs, the MCOs interviewed reported that it is of limited use. The data is only available for a small subset of enrollees since it is only collected from those who have contact with the enrollment counselor and are willing to share the information. Further, the data that is collected tends to be very incomplete. MCOs in Massachusetts noted that there can be a lag period in correlating it with the new enrollee's membership information, because it is transmitted separately from the enrollment data. As noted above, neither of these states transmit the screening data to the PCCM provider, though, in both instances, the majority of the state's children with special health care needs are enrolled in this managed care option.

New Mexico reported two activities that increase the knowledge an MCO has about a new enrollee. First, it provides information on approved prior authorization requests from fee-for-service to the MCOs. In addition, the Medically Fragile Waiver (MFW) program provides a paper roster of the children who are to be enrolled in the MCO. The case manager for the child will then contact the MCO to coordinate services. This communication between the two entities facilitates a relationship between service coordination and delivery, which benefits the child's care.

Two of the site visit states made a particular effort to transfer health-related information about new enrollees to the MCOs during the initial implementation of their managed care programs.

- In 1996, the Delaware Medicaid agency identified those fee-for-service beneficiaries who were receiving case management services. They identified 400 children and provided that information to the MCOs upon their enrollment for follow-up by the MCO and possible identification as a child with special needs.

- During the transition to managed care in 1997, the New Mexico Medicaid agency provided fee-for-service claims and prior authorization information on all new enrollees, identifying services and providers, to the MCOs through a secure Internet connection. The information was posted after the MCO was chosen but before the enrollment effective date. There were twenty eligibility categories for which the agency provided data, including high DME costs and the receipt of case management services. The information is still being provided to the MCOs when it is available. Many new enrollees, however, have no fee-for-service claims history with Medicaid.

The majority of MCOs with whom we met would like to have more information about the new enrollee so that they can initiate appropriate care sooner. Although five site visit states reported transferring information about PCP selection to the MCO, several of the MCOs interviewed said that they did not receive that information. This issue, among others, contributes to the sentiment on the part of the MCOs that they have to "start over" with the enrollee during their welcome/ membership process.

Some of the MCOs also expressed interest in getting information about the enrollee's language and cultural background.

Most of the MCOs want the state to provide utilization data and/or diagnosis information that can help them identify those enrollees with special care needs. They believe that, in most instances, there is some amount of fee-for-service experience or encounter data that can be transferred to the MCO. Several of the MCOs expressed frustration, knowing that the enrollment broker asks the enrollee's family about significant medical issues or conditions in order to assist their choice of a plan and provider, but does not pass the information to the MCO. They are concerned that families have to go through multiple interviews and screenings in order to initiate care.

MCOs identified a similar problem when an enrollee transfers from one MCO to another. Although Delaware requires the MCO to transfer the medical records when the enrollee changes membership from one MCO to another, this area appears to be much less defined in other states. Several MCOs indicated that they did not routinely receive clinical information from the previous MCO without the intervention of the enrollment broker or Medicaid agency.

Some of the MCOs, on the other hand, prefer to receive no health-related information from the state and/or enrollment broker. They just want accurate phone numbers and addresses so that they can contact the new members and initiate a thorough enrollment process for themselves. This seemingly simple request highlights one of the perennial problems in Medicaid and, now, in managed care enrollment: maintaining current demographic information for Medicaid beneficiaries. MCOs in most states have learned that, even if the enrollment broker collects up-to-date information during interaction with the new enrollee and transfers that to the selected MCO, it will be overwritten by the state's eligibility file information the next month. Federal law stipulates that state eligibility systems can update beneficiary information only when the enrollee reports the changes herself. To address this problem, Colorado's enrollment broker has created a special field to collect any new enrollee information that is not overwritten by the State's eligibility file. Both the official address field and the new contact information field are sent to the MCOs, who then use both when trying to contact new members.

Despite the host of challenges that the federal law causes, there are some good reasons for the restriction. For example, if someone other than the beneficiary can change the address, the cash assistance check may not end up in the right beneficiary's hands. Or a child may visit a grandparent for a short time, causing the MCO to believe that the child's permanent address has changed, when it hasn't. In some instances, a beneficiary may be using a particular address that allows them to hide from an abusive partner or parent. They do not want to update their eligibility file with an actual address that might facilitate being located by their abuser.

For several reasons, state Medicaid agency representatives are either reluctant or unable to transmit the type of detailed clinical information that MCOs would like to have. Some are concerned about giving too much information about an individual enrollee to an MCO and the timing of that information transfer for fear that the MCO could attempt to derail the enrollment of an unwanted member. The MCOs emphatically rejected that notion, however. Other states, such as Colorado, expressed an interest in giving fee-for-service and encounter information to the MCO, if available, so that the enrollees' care is enhanced and more appropriate from the outset of their enrollment. As mentioned in the previous chapter, the State is initiating a pilot project with two MCOs to share fee-for-service claims histories of default-assigned children at enrollment. Although there have been concerns about the restrictions imposed by state and federal confidentiality laws, state agency staff feel that they have addressed those requirements by limiting the scope of the project. A fee-for-service report is provided only for default-assigned enrollees who are unresponsive to enrollment requests, and they are notified in writing of the disclosure of information.

The Assignment Process

Table 8: Default assignment in site visit states

State	Default Assignment Policies	Selection Rate
CO	Default assignment protocol defined in State statute 1. If previous enrollment in MCO, assigned to previous MCO 2. If other family member in MCO, assigned to same MCO 3. If two or more choices available, random assignment to an MCO 4. PCCM is not included in default assignment protocol	Approximately 60% select; 40% assigned (estimates represent MCO enrollment only; not PCCM).
CT	If two or more plan choices are available in an area the beneficiary is assigned randomly to a plan; efforts are made to ensure that all plans receive relatively the same number of assigned beneficiaries	Approximately 86% select; 14% assigned.
DE	All enrollees pre-assigned to a participating MCO, using random assignment. If enrollee does not complete enrollment process with enrollment broker within 30 days, default assignment will become effective.	All enrollees auto-assigned with initial letter; have 30 days to voluntarily select MCO. Approximately 75% select, either confirming preassignment or choosing another MCO.
MA	• Default assignment based on geography and provider affiliation • For SSI eligibles, look at diagnosis information from Social Security Administration; determine which providers treat disabling condition. Send information to enrollment broker, who makes manual assignment • SSI beneficiaries who do not choose a managed care option are assigned to PCCM, all others are assigned to a MCO or PCCM provider	Approximately 80% select; 20% assigned.

MI	• If enrolled in MCO w/in last three months assigned to previous MCO • Weighted random assignment – best performing MCOs get most assignments (best based on performance in HEDIS measures and EQRO evaluation)	Approximately 60% select; 40% assigned (applies to Medicaid MCOs only).
NM	• If enrolled in MCO w/in last 6 mos; assigned to previous MCO • If other family member in MCO, assigned to same MCO • Weighted random assignment – best performing MCOs get most assignments (best is defined each year and may be based on a variety of factors (e.g., external quality review score, specific HEDIS indicator, such as childhood immunizations and number of EPSDT screens)	*Overall:* Approximately 60% select; 40% assigned *SSI:* 80% select; 20% assigned.

In mandatory managed care programs the opportunity to choose an MCO or PCCM provider is time-limited. In the site visit states; the enrollment choice period is between 30 and 120 days. In all six states, the enrollment entity follows the initial enrollment letter with either a reminder letter, phone call, or personal contact. Once the choice period expires, the enrollee is assigned to an MCO or PCCM provider. In Delaware, the enrollee is actually "preassigned" to an MCO at the time of the initial letter, and it is up to the enrollee to change or confirm that assignment. As illustrated in Table 8, the percent of enrollees that are auto-assigned ranges from 14% to 40%, according to states' enrollment figures. New Mexico reported that, though the auto-assignment rate is 40% for all enrollees in managed care, the SSI population appears to be more likely to choose an MCO than to be auto-assigned. Data on SSI enrollment in New Mexico's managed care program indicates that 80% select an MCO and only 20% are auto-assigned.

HCFA's Interim Criteria in this area stipulate that the state's auto-assignment process for CSHCN should result in the enrollee being assigned to an MCO/PHP with their current provider or to one that can meet their particular needs. States' policies and procedures for auto assignment vary and are, in part, dependent on the particular managed care choices available in the state or a specific geographic area. For example, if only one MCO is available in a given area and there is also a PCCM option, the state may elect to default assign to the MCO. Colorado and New Mexico use other family members' membership in a particular MCO as one of the criteria for assignment. Michigan's general MCO program and New Mexico also weight the random assignments based on the MCOs' performance in certain quality measures, such as HEDIS and EQRO evaluations. These states felt that it is important to be able to reward those MCOs that perform well with a greater number of auto assignments. Three of the states (Colorado, Michigan, and New Mexico) look at previous enrollment in an MCO as a criteria for making an assignment, but only Massachusetts reviews previous provider affiliation through their claims data, independent of an enrollee interview.

Massachusetts also reported a separate auto-assignment process for SSI eligibles. The state eligibility unit develops a list of unenrolled disabled beneficiaries who are managed care eligible. It then translates the disability diagnosis code that is used by SSI (ICD9) for each beneficiary into a specialty experience code. This information is then transferred to the enrollment broker, which uses the specialty experience code in the provider data base to match the member to a PCCM provider in the enrollee's geographic area who has experience in treating the enrollee's disabling condition. The assignment is done manually. SSI enrollees who are auto-assigned are only assigned to a provider in the PCCM program, not to an MCO.

HCFA's proposed Criteria poses certain challenges to Medicaid agencies in the level of detail that it suggests. By definition, auto assignment means that there has been little, if any, contact with the prospective enrollees. Therefore, there may be little information available as to their previous use of providers or which providers are most appropriate for their condition. This is particularly true if the enrollee is new to Medicaid and has no fee-for-service claims history. Although the state Medicaid agency or its enrollment broker can try to reach the enrollee for this information, these attempts are unlikely to be successful, given their lack of response to the enrollment solicitation.

In general, state Medicaid agency informants did not feel that they could make an informed assignment based on the child's medical need because of the incomplete medical utilization history. Even when a previous claims history exists, one has to determine which providers are more important when making auto assignments. One informant noted that children with special health care needs often have multiple providers, which makes the identification and assignment process even more difficult. It is difficult to construct a computer algorithm for such individualized preferences. As a result, most states reported that instead of assigning children to MCOs based on the child's need they instead, through the contractor selection process, made certain to contract only with MCOs that can meet all Medicaid enrollees needs. Thus ensuring that assignment to any MCO would be assignment to an MCO that meets the child's needs. Several state Medicaid agency staff felt that HCFA's requirement of allowing disenrollment to another managed care entity within 90 days after enrollment affords some protection for the family and enrollee, if the original assignment is inappropriate.

Disenrollment

HCFA's Interim Criteria require that a child with special needs can disenroll and re-enroll in another MCO/PHP for good cause. This was consistent with existing policies on disenrollment[24] for Medicaid managed care members in all of the site visit states. Four of the site visit states allow disenrollment without cause only for a specified time after enrollment. After that time, good cause is required, which is determined by the Medicaid agency. At the time of the site visits, Delaware's policy required a determination of good cause for disenrollment at any time except their annual open enrollment period. Massachusetts did not require a determination of good cause; one can change MCOs or PCCM provider at any time.

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[24] The term "disenrollment" can refer to one of several situations in managed care. In this instance, disenrollment means changing enrollment from one managed care entity to another. The other situations, disenrolling to fee for service, or disenrolling from Medicaid are not discussed in this section.

Although this study did not ascertain specific rates of disenrollment in the six site visit states, we know from previous studies of general managed care programs that rates for disenrollment without cause (often tied to an open enrollment period) can range from less than 2% to about 8% of the enrolled population.[25] Disenrollment for cause is even less, usually less than 1% of the managed care population. Both state Medicaid agency staff and MCO staff stress that problem solving is preferable to disenrollment and that mechanisms are in place at the MCO, enrollment broker and state agency, to assist the enrollee with their complaints and concerns. The informants felt that the policies and procedures that have been adopted for the general enrolled population can also meet the needs of children with special needs.

HCFA's second criteria for disenrollment seeks to ensure that an MCO/PCP does not discriminate against the enrollee if it requests the disenrollment or transfer of that enrollee. Again, contract policies in all site visit states were consistent with this criteria. States have been very careful to address this issue and, in many instances, have worked with consumers and advocacy groups to develop strict guidelines for an MCO's request for disenrollment. In all cases, the Medicaid agency reviews MCO disenrollment requests to ensure that they are not discriminatory and/or related to the enrollee's medical condition. If necessary, Medicaid staff conduct an investigation into the reasons for the request.

Other Enrollment Policies That May Affect CSHCN

There are several other enrollment policies that pertain to the entire enrolled population in Medicaid managed care but that may be of particular importance to CSHCN. These are discussed below.

Enrollment Lock-in

A lock-in is when an enrollee must remain in his or her chosen or assigned MCO for a certain period of time, usually 6 or 12 months, unless permitted to disenroll for cause. The lock-in becomes effective after an initial enrollment period in which the enrollee may change enrollment to another managed care option. With the passage of the BBA, HCFA requires that enrollees have 90 days after enrollment in the MCO (not including the open enrollment period) to change their managed care enrollment, without cause, before the enrollment lock-in begins.

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[25] Further information on this subject can be found in the following NASHP publications: *Enrollment and Disenrollment in Medicaid Managed Care Program Management*, by Jane Horvath and Neva Kaye, December 1996; *Outreach, Marketing, Enrollment and Disenrollment Policies in Medicaid Managed Care: Report from a 1996 Survey*, by Neva Kaye, Jane Horvath, and Cynthia Pernice, December 1997; *A Snapshot of Seven State Medicaid Managed Care Enrollment and Disenrollment Systems*, by Neva Kaye and Cynthia Pernice, October 1998; and *Medicaid Managed Care Enrollment and Disenrollment: The Experience of Four States*, by Deborah Curtis, July 1999.

Although consumers resist the notion of being locked in to a particular MCO, the MCOs welcome this policy because they feel that they can develop a plan of care and a relationship with the enrollee during that time. It affords some stability for both enrollee and provider that can be particularly beneficial to children with special needs. Four site visit states reported a lock-in policy: Colorado and New Mexico use a six-month period, and Delaware and Michigan use 12 months. The policy is not fool-proof, however. Several MCOs expressed frustration with allowing enrollees to change their enrollment before the lock-in begins. Some Medicaid agency informants also believe that this period is a disincentive to completing a thorough assessment of the new enrollee because the MCOs do not want to devote the resources if the enrollee doesn't stay with the MCO.

Disenrollment prior to lock-in seemed to be a particular issue in Colorado, where families who begin their enrollment in an MCO decided that they want the PCCM system for their child instead. Although data on disenrollment is unavailable to support these perceptions, some state agency representatives, MCOs, providers, advocates, and consumers in Colorado have the sense that the majority of families with children with special health care needs disenroll from the MCO and enroll in PCCM as soon as it becomes clear to them that the care delivery for their child has changed.[26]

Guaranteed Eligibility

Guaranteed eligibility means that an enrollee of an MCO or a PCCM is guaranteed a minimum period during which he or she remains eligible for services from the MCO or PCCM provider, regardless of whether he or she loses Medicaid eligibility. Although less common among states' Medicaid managed care programs than in their SCHIP programs, this policy can be particularly helpful in the continuity of care for CSHCN. Colorado, Connecticut, Delaware, and New Mexico adopted a guaranteed eligibility provision. Colorado and Connecticut guarantee six months of covered benefits within the MCO even if the enrollee has lost his or her Medicaid eligibility prior to the end of the six-month period. Delaware guarantees both MCO benefits and Medicaid covered services outside of the contracted benefits for six months. Finally, New Mexico grants a minimum enrollment of twelve months for children.

Enrollment Continuity

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[26] It is difficult to determine how many children with special needs in Colorado ultimately choose the PCCM over the MCO program. Data at the time of this study showed that 40% of SSI children were enrolled in HMOs. This information, however, is not adjusted for disenrollment trends.

If an enrollee loses and regains Medicaid eligibility within a two-month period, he or she can be automatically re-enrolled in the same MCO, per federal law.[27] All site visit states have adopted this policy and have established additional continuity policies for those beneficiaries returning to Medicaid who fail to select an MCO within a certain period of time. In these cases, an enrollee who does not respond to the enrollment materials is reassigned to the same MCO in which he or she was enrolled previously. States' re-enrollment periods range from 70 days to one year. Both the Medicaid agencies and the MCOs agree that this policy is helpful in maintaining some continuity of care, although there is considerable frustration on the part of the MCOs with the overall episodic nature of Medicaid eligibility. Children who have special care needs and who require special services and coordination can particularly benefit from this policy since they can be re-linked with their previous MCO and the disruption in care can be minimized. Some states felt that this policy answers, in part, HCFA's Criteria that auto-assignment be based on prior affiliation with a provider since enrollees who have been enrolled previously are automatically reconnected with their MCO (and the MCO's subcontracted providers).

Enrollment for Behavioral Health Services

Among the site visit states, considerable variation exists in how behavioral health services are provided. The following briefly summarizes the programs in the six states.

- Colorado: Mental health services are carved out of the MCO benefits and delivered by county-level BH/PHPs. Enrollment is mandatory and automatic when the beneficiary is found eligible for Medicaid; the individual is assigned to a BH/PHP based on geographic location.
- Connecticut: Behavioral health services are included in the MCO benefit.
- Delaware: MCOs cover 30 units of outpatient services and the Children's Department provide all other behavioral health services, functioning as a BH/PHP.
- Massachusetts: If enrolled in an MCO, the MCO provides all behavioral health benefits. If enrolled in the PCCM Program, the enrollee is enrolled in the Behavioral Health Partnership, a BH/PHP. Enrollment in the BH/PHP is mandatory and automatic when the beneficiary is determined eligible for MassHealth, even prior to the member choosing a MCO or PCCM provider.
- Michigan: Provision of behavioral health benefits is delegated to the Mental Health agency, which, at the time of the site visit, was transitioning to a BH/PHP.
- New Mexico: The MCO is responsible for behavioral health benefits, but must contract with an experienced Behavioral Health Organization (BHO) to deliver those benefits.

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[27] 1902 (m)(2)(H).

Beneficiaries in site visit states that use MCOs to deliver behavioral health care are informed of how they will access behavioral health benefits through the general enrollment process or by their new MCO. Many of the enrollment and disenrollment policies that apply to MCO and PCCM programs are not relevant to BH/PHPs since, in most programs of this type, only one contractor serves a geographic area, and sometimes the entire state. In this case there is no other MCO for an enrollee to choose or disenroll to.

One state with a BH/PHP relies solely on the Medicaid eligibility determination agency to notify beneficiaries of their enrollment into the BH/PHP and the inclusion of the phone number of the local BH/PHP on the back of the Medicaid ID card to provide ongoing informing about how to access these services. A consumer survey conducted by the MCH agency in this state indicated little knowledge of mental health benefits offered by the BH/PHP and how they could be accessed. This finding was corroborated by other key informants including consumers and providers.

Special Programs for CSHCN

Various aspects of Massachusetts' *Special Kids* **Ì** *Special Care* program and Michigan's *Children's Special Health Care Services* program are discussed throughout this report. In this discussion on enrollment practices, it is important to note that both of these programs are voluntary; eligible children may choose to enroll or remain in fee-for-service. Therefore, much of the concern and tension that surround mandatory managed care are irrelevant. Further, HCFA's Interim Criteria do not apply to these initiatives, except as they fit into the over-all structure of the site visit state's mandatory managed care program. However, we look to these special programs for promising practices in identifying and caring for CSHCN that may be applicable to the general managed care programs.

By design, the intent of both of these programs is to be particularly responsive to the health care needs of special needs children. In Massachusetts, the focus is on foster care children with complex medical needs, and in Michigan, on children who are eligible for Title V. The enrollment process, as noted above, is tailored to the population and eligible children are invited to enroll. There is no auto-assignment, nor are there any restrictions on the enrollee's desire to disenroll.

But, even with this lack of restrictive policies, there are still concerns on the part of families, advocates, and other agencies about enrolling children in special managed care programs. In Massachusetts, the Medical Foster Care Advisory Committee, composed of the Child Welfare agency, Medicaid agency, parents, legislators, and advocacy organizations, spent many hours working together to develop mutually agreeable protocols for enrolling children in the new program. Child Welfare staff have worked individually with foster parents to determine enrollment preferences for their child.

Michigan has faced certain obstacles in trying to enroll Title V children in the Special Health Plans. Even after an extensive development process for the program that involved parents, providers, and consumer organizations, they have found that some families are resistant to enrolling their child in one of the Special Health Plans. The families are suspicious of change and concerned that their child's care system will be disrupted. Many families with Medicaid eligible children who are also served by the Title V agency opt for Medicaid and Title V fee-for-service over the Special Health Plans. MCOs reported that some families prefer to remain in the general Medicaid MCO program rather than join the Title V program and receive Title V and Medicaid fee-for-service or enroll in the Special Health Plan to receive these services, even though that decision means that they will not be able to access Title V services.

A general Medicaid MCO reported that some families say they are comfortable with the arrangements that they have made to access care within the MCO and fear that any change would jeopardize that access. Further, some family informants reported worrying that the Special Health Plan, with headquarters in another area of the State, may not have a comprehensive network or a thorough understanding of their local service area. Consequently, it has been difficult for the State agency to assemble a critical mass of membership in either of the two Special Health Plans. Families who have enrolled their child in the Special Health Plan reported being initially comfortable in doing so because they knew they could return to fee-for-service at any time. The parents we spoke to who had enrolled their children into the Special Health Plan were very enthusiastic about the benefits of the MCO after having experienced them firsthand. The Special Health Plans anticipate that as word of these parents' positive experiences spreads, more families will choose to enroll their child into the program.

Enrollment and Disenrollment: Summary of Study Question Findings

Can states meet the Interim Criteria for enrolling CSHCN?[28]

Although the two criteria on disenrollment do not pose particular problems, in general, it is difficult for states that are administering mainstream managed care plans to meet the Interim Criteria, as currently drafted. That difficulty hinges largely on the challenge of identifying potential children with special health care needs to begin with, so that specific enrollment activities can be targeted to them.

States were conducting outreach to all Medicaid beneficiaries. This general outreach could satisfy HCFA's interpretation of the outreach requirement in the Interim Criteria, if the outreach can be shown to adequately address the needs of CSHCN and their families. However, states were not conducting much outreach about managed care targeted specifically to children with special health care needs, their families, or their providers. This is very difficult to do in a general managed care program. It was more likely to be reported to occur in special programs whose eligible populations can be easily identified prior to enrollment.

Enrollment selection counselors could probably be provided with additional information and resources that would be helpful in assisting special populations to enroll. However, this was not current practice in the general managed care programs. The criteria raise other questions about the enrollment process, such as, the extent of the contact between the enrollment counselor and family, the resources available to the enrollment broker to conduct a thorough interview with the enrollee, and the appropriateness of the enrollment counselor assisting with decisions that may be medical in nature. There appears to be a constant tension, though not specific to enrollment of CSHCN, between the potential to inform and assist the enrollee during the enrollment process, and the reality of resources, limited opportunity for contact, and the availability of up-to-date and adequate information.

As discussed in the section on auto-assignment, HCFA's proposed criteria could be difficult for states to meet because there may be little, if any, information regarding previous use of providers for a new Medicaid beneficiary. And, since auto-assignment means that there has been limited contact with the enrollee prior to enrollment, few opportunities exist for the enrollment entity to gain the necessary information to make such an assignment. States did have certain enrollment and assignment policies in place that attempt to match the enrollee with the appropriate MCO and previous providers, such as reassignment to the same MCO if there was a break in eligibility and assignment to the same plan as

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[28] None of the site visit states were required to meet the Interim Criteria at the time of the site visits because they had not yet renewed a waiver that would be subject to the BBA or the Interim Criteria.

other family members. Some state agencies reported that as part of the contractor selection process they determined that every contracted MCO was able to serve all Medicaid enrollees and, therefore, they met the Interim Criteria on auto-assignment because all assignments are to MCOs that can meet the child's needs.

Finally, the two criteria related to disenrollment were, in fact, current practice of the site visit states and MCOs and are applicable to all enrollees.

How do states monitor and evaluate MCO performance in enrolling CSHCN?

The criteria regarding enrollment largely pertain to Medicaid agency activities, or those of their contracted enrollment broker. Contracts with the enrollment broker customarily included performance measurements for outreach and education activities, the timeliness of the enrollment process, and rates of auto-assignment. The agencies' contracts with MCOs included requirements regarding orientation of new members and linkage with a primary care provider, ongoing member services, open enrollment procedures, and disenrollment. Medicaid agencies usually reported monitoring MCOs' compliance with contract specifications through site visits, periodic reports, and investigation of any complaints. With respect to disenrollment, Medicaid agencies closely monitored all MCO requests for the disenrollment of a member and have final approval of such requests.

How do states enroll CSHCN in the fee-for-service system?

There is no fee-for-service equivalent for enrollment in managed care. When individuals were found eligible for Medicaid, they generally received a brochure describing program benefits and resources, and a card, indicating their eligibility. Depending on the state, they also received more detailed information regarding the benefits that are covered under the EPSDT program. In general, the fee-for-service system offers no assistance in identifying providers that can meet the particular needs of the enrollee. It leaves Medicaid beneficiaries on their own to find a provider who will accept Medicaid and treat them. For those families who have established relationships with providers that accept Medicaid, fee-for-service can work quite well. But, for those who have not developed those relationships or who are dependent on providers who do not accept Medicaid reimbursement, enrollment in fee-for-service Medicaid can be very disruptive and the care can be very episodic.

How do state practices in enrollment vary according to state characteristics?

This study identified few, if any, differences in enrollment practices based on state characteristics. The differences in enrollment practices lie, largely, in the type of managed care program. Mandatory managed care programs have policies and requirements for program elements that include enrollment choice periods, auto-assignment, lock-in, open enrollment, and disenrollment that are not pertinent to BH/PHPs. Also special managed care programs for CSHCN may have enrollment procedures, specific to the program. The special programs operated by the site visit states are voluntary and, therefore, not subject to some of the standard enrollment requirements.

Do the Interim Criteria on enrollment address the most significant issues for children and their families?

The underlying issue in meeting the Interim Criteria on enrollment is the ambiguity surrounding exactly who is a member of the special needs population. Without a means of identifying these children, both Medicaid agencies and MCOs are uncertain as to who they should target for special enrollment efforts and who should be flagged in the general enrollment population as needing particular interventions. Targeted outreach and specific training to assist special populations are irrelevant if the special needs populations can't be identified.

The availability and transfer of information emerged as a key issue in the enrollment process for CSHCN. From the MCOs' perspective, they would like to know who they are supposed to identify as CSHCN in their membership and then to receive as much information as possible about them so that they can facilitate their care. Families want to know whether their child will be able to get the care that they need in managed care or whether it is going to be disrupted. They want more information about how managed care is going to work for their child and what their resources are. Yet, they are also concerned about providing extensive medical information about their child during the enrollment process. Given the current enrollment practice in most mainstream MCOs, there are considerable obstacles to a more detailed exchange of information, both to and from the family, and to the MCO. Regardless of those obstacles, however, there is a certain tension and sensitivity about how much information should be made available to the family, how much should be made available to the MCO, and how it should be provided and collected. In general, these concerns were of greater interest to informants in the site visit states than the particular policies and practices regarding outreach, training, auto-assignment, or disenrollment.

V. PROVIDER CAPACITY, ACCESS TO SPECIALISTS, AND ACCESS TO BENEFITS

Interim Criteria

Concerning issues of provider capacity and access to specialists, the Interim Criteria require that:

- **Provider Capacity**

  -- *The State ensures that the MCOs/PHPs in a geographic area have sufficient experienced providers to serve the enrolled children with special needs (e.g., providers experienced in serving foster care children, children with mental health care needs, children with HIV/AIDS, etc.).*

  -- *The State monitors experienced providers' capacity.*

- **Specialists**

  -- *The State has set capacity standards for specialists.*

  -- *The State monitors access to specialists.*

  -- *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.*

  -- *The State requires particular specialist types to be included in the MCO/PHP network. If specialists types are not involved in the MCO/PHP network, arrangements are made for enrollees to access these services (for waiver covered services only).*

Introduction

Provider capacity and access to specialists are essential components of managed care for all enrollees. Knowing that a particular provider will be responsible for ensuring that an individual gets the care he or she needs and that he or she will be able to see a specialist, if necessary, can be one of the real benefits of enrolling in managed care. They are particularly important criteria for those enrollees who have special health care needs. HCFA's Interim Criteria on provider capacity and specialist access seek to assure that an MCO/PHP that serves children with special health care needs has the ability to provide adequate and appropriate care to that population.

Managed care policies and practice in all site visit states address these issues, although they are not necessarily consistent with HCFA's proposed Criteria. There was universal agreement among all stakeholders, however, that managed care must be responsive to the particular care needs of its special needs enrollees through its network of providers and access to specialty care. Additionally, our interviews identified a host of other concerns for families, providers, and other stakeholders in accessing appropriate care in a managed care system. As an example, some families were more worried about getting the ancillary support services they need to make day-to-day living possible for their child than they were with primary and specialty care. Others were more interested in the MCO's experience and knowledge about caring for special needs children than they were with the experience of a particular provider.

This chapter reviews current practice of the site visit states in the areas identified by the Interim Criteria and discusses other related issues of importance to CSHCN in accessing care. Again, in this Chapter the term "MCO" refers to those organizations that provide a comprehensive set of services; it does not include PHPs.

Provider Capacity

Primary Care Providers

All site visit states include requirements for adequate network capacity in their contracts with MCOs. The specifics of those requirements vary from state to state. Five states identify the maximum number of patients that a PCP can have on his or her panel in order for the MCO to maintain sufficient PCP capacity. That ratio varies from one PCP for 1200 to one PCP for 2500 Medicaid patients. Connecticut also includes dentists and mental health practitioners in its provider/patient ratios to determine an MCO's enrollment capacity. Colorado is the only state among the six that does not designate a specific number of patients per panel but, rather, instructs the MCO to determine the number of providers necessary to serve the enrollee population. The State does not set a panel size for its PCCM program either.

Table 9: Primary care provider capacity standards in site visit states

State	Primary Care Provider Capacity
CO	*MCO* networks must include providers of sufficient numbers and types to comply with standards of access to care specified in contract. MCO sets specific numbers and types of providers (reviewed as part of annual on-site review). Medicaid agency does not establish primary care provider capacity for *PCCM*.
CT	• Must maintain a network capable of delivering covered services • No PCP may serve > 1200 Medicaid enrollees; Medicaid agency aggregates monthly report from MCOs to determine each PCP's total panel size across all MCOs and notifies MCO when exceeds 1200 • 98% of MCO's members must be within 15 miles of PCP • MCO enrollment capacity base on specific ratios of member to primary care providers, dentists, and mental health practitioners
DE	MCO must maintain sufficient primary care provider capacity in network so that there is at least 1 full time equivalent PCP for every 2,500 patients.
MA	*MCO* must maintain a network of primary care providers that ensures PCP coverage and availability throughout service area. Enrollee must have choice of at least 2 appropriate PCPs with open panels who are located within 15 miles or 30 minutes from enrollee's residence, have expertise to meet the needs of the enrollee and have the ability to communicate with the enrollee. No individual PCP may have more than 1500 enrollees on panel. Medicaid agency sets PCP/enrollee ratios for *PCCM* program.
MI	• *MCO*: must maintain provider network sufficient to provide appropriate access to covered services; at least 1 full time equivalent PCP for every 2,000 members; max travel time 30 minutes; some PCPs must offer evening and weekend hours • *Special Health Plans* – PCP (referred to in this program as the PCD or Principal Coordinating Doctor) will be a specialist or subspecialist with acknowledged expertise and current experience in management of the condition as it manifests in children
NM	• Networks must include sufficient providers to make all benefits available in accordance w/access standards • Must contract w/full array of providers to deliver level of care greater than or equal to community and Medicaid fee-for-service norms • 1 PCP for every 1,500 patients. • max travel time to PCP for 90% of enrollees that vary urban/rural/frontier (30/45/60 minutes) • MCOs submit monthly provider roster which is reviewed by Medicaid agency clinicians familiar w/provider availability in various specialty/service areas for sufficiency

Most of the site visit states' contracts with the MCOs include other directives and standards for them to follow in maintaining an adequate and accessible provider network. These standards apply to all enrollees, not just CSHCN, and include:

- maximum travel time or distance for the enrollee to reach his or her PCP
- maximum waiting times for appointments or care. These specifications include, routine visits, urgent care, specialty referrals, behavioral health services, dental care, and emergency services

- sufficient numbers and types of providers so that all benefits within the contract are accessible

States reported monitoring MCOs' compliance with these contract specifications through a variety of activities, including reporting requirements, site visits, enrollee surveys, and investigation of complaints. For example, Colorado's contract with the MCOs requires them to provide, periodically, a detailed description of their networks, including a "list of network providers and an analysis of how the numbers and types of providers are sufficient to ensure accessibility and availability of all Covered Services in a manner that promotes coordination of care, continuity of care and Independent Living, as required under (the) Contract." New Mexico requires the MCOs to submit a monthly roster of providers that is reviewed by Medicaid agency clinical staff who are familiar with provider availability in various specialty and geographic service areas. Connecticut also requires monthly reports from the MCOs, which the Medicaid agency then aggregates to determine each PCP's total panel size across all MCOs.

All states incorporated a review of provider network capacity and access during their annual on-site reviews. During these visits, Medicaid agency staff, or their designees, may look at the composition of providers in the network for representation of specialties and individual provider lists to review the size of the patient panel. They also review credentialing records, complaints and grievance reports, and waiting times for appointments. In some states, the enrollment broker periodically checks providers' ability to take new patients and the availability of appointments. MCOs are, in general, required to report any changes in their provider networks that affect access to timely and appropriate care.

Although multiple mechanisms, including provider ratios, appointment waiting times, and travel time/distance standards are in place to establish provider capacity and to monitor compliance, state agency staff voiced concern that some of the methods aren't effective. In general, Medicaid agencies felt that patient/provider ratios have limited, if any, utility. Though most have specified ratios in their contracts, they have done so because of HCFA's waiver requirements to determine PCP/patient ratios. There was considerable agreement that while a ratio analysis may be a place to start to identify numbers of providers, it does not determine provider access. In one state, a pediatrician who has particular expertise in treating HIV and AIDS is a PCP. Although the number of patients on his panel exceeded the limit, he was allowed to add more because there is no other physician who is willing to take these patients. And, even though states have the authority to freeze enrollment if panel size exceeds specified capacity, several agency staff expressed their doubts about either the accuracy or the effectiveness of this action. Many of the MCOs concurred; they feel that a ratio is a "primitive" means of determining network adequacy.

In some instances, both states and MCOs use enrollee complaints and requests for disenrollment to monitor provider networks for access and capacity.[29] From the MCOs' perspective, they find that

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[29] Since June 1999, HCFA has included the tracking and reporting of complaints, grievances, and disenrollment requests as a term and condition of states' waiver renewals, if BBA-defined CSHCN are included in the waiver. At the time of the site visits, however, none of the six states were bound by HCFA's terms and conditions

consumer surveys and complaints are the best indicator of whether their networks are adequate and appropriate to serve the enrolled population. If they receive a complaint about access to a particular provider or service, they will look more closely at their network capacity. Consumer and advocate informants frequently cited "measuring how easy it is to enter the system" as the best way to determine adequate access.

Experienced Providers for CSHCN

HCFA's Interim Criteria requires the state to ensure. "...sufficient **experienced** providers to serve the enrolled children with special needs...." Although difficult to respond to this criteria without a definition of "experienced", all constituencies agreed that the concept of experienced providers for CSHCN is extremely important. It is an issue that was raised repeatedly with many informants during our site visits.

Three of the site visit states reported addressing the issue of experienced providers through general language in their MCO contracts. Massachusetts stipulates in its contracts that the MCO's provider network "shall be responsive to the linguistic, cultural, and other unique needs of any minority, homeless person, disabled individuals, or other special population." Delaware's contract with MCOs suggests that the MCOs contract with providers of essential community services, emphasizing their expertise and importance in maintaining continuity of care, particularly for CSHCN. As noted above, Colorado directs its MCOs to have a network of providers that can provide a full range of primary, specialty, and ancillary services that meet the needs of all enrollees.

The other three states included more specific instructions in their MCO and Special Health Plan contracts regarding the experience of providers.

- Connecticut requires the MCOs to contract with certain behavioral health providers that specialize in serving children or to demonstrate that equal or better services are provided by another contracted provider.

- Providers in Michigan's Special Health Plans must have demonstrated experience in providing services to CSHCN and a subspecialist must have completed training and be certified, when available, as a pediatric subspecialist.

- MCOs in New Mexico must contract with specific hospitals and medical centers in the State that have specialized pediatric services and offer certain pediatric subspecialty services. The MCOs' subcontracts with Behavioral Health Organizations (BHOs) must be with those entities

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for CSHCN since they had not sought approval for any waiver application or renewal since June 1999.

that have a sufficient network with demonstrated capacity to serve seriously emotionally disturbed (SED) children and adolescents.

During the development of New Mexico's managed care program, the State contracted with six community-based organizations to assist in identifying appropriate providers for their constituencies, ones who should be part of the MCOs' networks. They identified potential access issues by geographic region, based on their knowledge of the available providers in the area. The CBOs continue to serve as an important "early warning system" about potential access to care issues and other problems that their constituents might face in their managed care plans.

What Providers Need to Serve CSHCN

Our interviews in the site visit states led us to discussions about what is meant by "experienced" and what do providers need to know to serve CSHCN. The physicians with whom we spoke identified several concerns in providing appropriate care for these children. Some felt that few PCPs are either prepared or willing to serve children with special health care needs. They may not have sufficient knowledge of a child's individual disability or health issue, and they are reluctant to develop that expertise because of the lack of support to provide more extensive care. For many physicians, it is partly an issue of adequate reimbursement. (See Chapter on **Payment Methodology** for a more detailed discussion.) Some physicians felt that they aren't given enough time to care for a relatively healthy patient, let alone one with complex needs. They also felt that no entity or provider is available to provide ongoing care coordination to the child and his or her family. Physicians, in general, do not want to take on that role themselves.

Several PCPs who do take care of CSHCN noted that most of their colleagues are very unprepared to see children with special needs on a regular basis. They do not understand the extenuating circumstances for such a child and the impact that it has on their family. Unfortunately, many of these unprepared physicians are also unwilling to participate in any training or education that might improve their knowledge and skills.

A critical issue that emerged when discussing the ability of physicians and other providers to treat CSHCN was that of the child's transition to adolescence and, ultimately, adulthood. According to our informants, physicians, in general, don't know how to transition the care as the child ages and becomes an adolescent, then an adult. Further, they don't know how to assist families with this transition. And, as more and more children with special needs survive to adulthood, a glaring need exists for their physicians to learn how to prepare the child and the family for the transition to adult medicine.

A demonstration project in Massachusetts is attempting to address this issue. Through a Special Projects of Regional and National Significance (SPRANS) grant from the federal Bureau of Maternal and Child Health, the Massachusetts Department of Public Health has developed the Massachusetts Partnership for Transition, which has three major components.

1. A mentoring program for adolescents and their families, consisting of eight weeks of meetings to discuss how these teenagers can learn to take responsibility for their health care needs. Separate sessions are held with the children and the parents.

2. Physical activity, adapted to the adolescents' needs and abilities, that provides empowering opportunities.

3. A nurse located at Children's Hospital who works with four of the pediatric specialty clinics (AIDS, cystic fibrosis, spina bifida, and sickle cell) to develop transition plans for adolescent patients. This individual works with both the clinic providers and the individual families to map out a plan for when the teenager transitions to adult medicine. Adult providers are also included in this process.

Those physicians who do provide care for CSHCN reported feeling the weight of that responsibility. Not only do they provide medical services, but they coordinate the child's care and petition the MCO and/or the state Medicaid agency when services that they believe the child needs are denied. According to one physician, the limited number of PCPs who are willing and able to care for CSHCN results in diminished access to care for those children who need it most. This situation, in turn, can compromise the medical outcomes for these children.

Provider and family informants noted that the notion of experienced providers goes beyond the availability of physicians who can treat CSHCN. All providers who come in contact with a child with special needs should have an understanding of their medical condition and be prepared to treat them appropriately. For example, does the wheelchair vendor understand the nature of cerebral palsy so that an appropriate wheelchair can be provided? Or does the x-ray technician know how to get a readable x-ray of a child who has curvature of the spine or lacks the muscle control to lie still?

Informants in several states also emphasized that social services staff and other agency personnel who have responsibility for arranging care need to understand the particular needs of CSHCN. Child Welfare and Juvenile Justice workers, for example, should have sufficient knowledge and training so that they can assist families in identifying resources and getting the services they need for their child. Too often, some informants noted, these individuals obstruct rather than facilitate because of their lack of understanding of the complexities of the child's medical and other needs.

The Tension Between PCP and Specialist

Specialists with whom we spoke corroborated some of the concerns of their primary care colleagues. According to one specialist, children with special needs don't seem to have PCPs, or they don't want to get their care from them. They seem to feel more comfortable coming to him for all of their care needs because he is the "constant" in their lives, whereas PCPs come and go. Some specialists would prefer that these children stay away from their PCP, while others wish that the PCP would own the responsibility for the child's care. As described above, many of the PCPs are not adequately prepared to give appropriate care to children with special needs. In one instance, a specialist found that a PCP was writing a prescription for certain durable medical equipment (DME) when he had little familiarity with the child's disease or her specific care needs.

From the family's perspective, they often reported being overwhelmed by the chronic and crisis-oriented nature of their child's health and very accustomed to going to the specialist for most needs. After multiple trips to the specialist, the lab, the x-ray technician, and the DME supplier they have little time or energy to seek a PCP for their child's routine care. If their child seems well, why make yet another appointment to see the doctor? For those parents who are cognizant of their child's primary care needs, it is much easier to get immunizations and other well-child services from the specialist if he or she is willing to provide them. According to several physicians, many special needs children fail to get preventive and maintenance care if there is no relationship with a PCP.

This situation highlights the importance of a 'medical home' for children with special health care needs, care that is accessible, comprehensive and coordinated among the many providers who may care for the child. Managed care has the capacity to implement a medical home for CSHCN because it provides the opportunity to link the child with a primary care provider. But this concept and its practice require cooperation and communication among those providers who have historically provided care to the child.

Both PCPs and specialists noted the need for coordination between them and acknowledged that the child's quality of care could be compromised because of this void. PCPs commented that specialists don't do very well in getting back to the PCP about the outcome of a referral, which makes it difficult for the PCP to coordinate the child's care. They both voiced a desire to understand each other's role in the care of the child and to improve the communication between them.

Specialists

Capacity Standards

States' policies regarding access to specialists were fairly consistent among site visit states. Each included some reference to an adequate number or availability of specialists in the MCO contract, but no Medicaid agency identifies a specific number that would demonstrate capacity. There was consensus among state agency staff that there is no magic number of specialists and that it would be particularly difficult to determine such a designation for a general contract that serves all Medicaid enrollees.

In most instances, the contract language described previously in this chapter serves to direct the MCO regarding specialist capacity. Colorado's requirement of the MCOs to provide an analysis of network capacity also instructs them to include "geographic accessibility; arrangements to provide services and equipment to members requiring technologically advanced or specialty care; and provisions for accessibility of specialty, subspecialty, and all ancillary providers and services, including those members living in rural areas and other undeserved areas." Delaware directs the MCOs to use specialists with pediatric expertise for children where pediatric specialty care is significantly different from adult care. In Massachusetts' contract requirement of case management for special populations, including people with disabilities, it directs the MCO to ensure access to providers with special expertise in treating the enrollee's needs.

Types of Specialists

Five of the site visit states do not designate particular specialist types to be included in the MCO network, as the Interim Criteria require. According to the Medicaid agencies, this requirement would be rather unwieldy for a general contract serving all Medicaid enrollees. The CSHCS Special Health Plan contracts in Michigan do require access to identified types of pediatric subspecialists. The Special Health Plans are required to contract with the Children's Multi-disciplinary Specialty Clinics, or their equivalents, and to incorporate a multi-disciplinary team approach for the most medically complex cases. New Mexico, as described above, requires the MCOs to contract with specific hospitals and medical centers in the state that have certain clinical expertise and specialties.

While the expectation among the Medicaid agencies is that the MCOs will assemble sufficient and varied specialists to meet all medical needs of the enrolled population, all contracts required the MCO to refer out-of-network if the appropriate provider is not available in network. All MCOs reported occasionally exercising this option when their enrollees have needed very specialized services or when a specialist is not available in a particular geographic area. Among the reasons cited for out-of-network referrals: speech therapy for specific conditions, training for learning how to walk again, and dental care for children with cleft palate.

The epidemiology of childhood disorders suggests that states need to pay close attention to the availability and appropriateness of specialists and subspecialists for special needs children. Although there may be only one child with a particular disorder or disease enrolled in an MCO, it does not preclude the need for a specialist who has experience with that condition as it manifests itself in children. An adult cardiologist, for example, is not the right specialist for a newborn with a cardiac abnormality.

Access to Specialists

All site visit states reported provisions in their contracts with the MCOs to facilitate access to specialists for those children who use them frequently. Colorado, Delaware, Massachusetts, and New Mexico include specific language in the MCO contracts that permits specialists to be PCPs, when appropriate. Delaware requires approval by the state Medicaid agency. Massachusetts allows specialists to be PCPs in its PCCM Program, but Colorado prohibits specialists from being PCPs in its PCCM program. Both Connecticut and Michigan have much less explicit language in their MCO contracts, but there is nothing to prohibit a specialist from serving as a PCP, if warranted. In Michigan's contracts with the Special Health Plans, the PCP is usually a specialist or subspecialist with expertise and experience in management of the child's condition, as it manifests itself in children, although a pediatrician may serve in this role, when appropriate.

According to key informants in the states, the use of a specialist as a PCP is rare. Both the states and the MCOs seem cautious about encouraging this practice because they want to make sure that specialists coordinate their care more with the PCP. They are also concerned about the specialists' ability to address the child's overall needs. The general MCOs interviewed also noted that specialists do not act as PCPs very often and that, from a systems perspective, it is a difficult linkage to make.

Table 10: Access to specialists in site visit states

State	Specialist as PCP	Standing Referral to Specialist
CO	*MCO*: Allowed but not required *PCCM*: PCPs may not be specialists	Allowed; not required
CT	No guidelines on the types of providers that may serve as PCPs are in contract, so specialist could serve as PCP. However, only certain categories or practitioners are counted as PCPs for determining the county enrollment capacity.	Allowed, but not required except all enrollees may self-refer for initial behavioral health visit
DE	Specialist may act as PCP in special circumstances, subject to approval by the State.	Allowed, but not required
MA	*MCO*: Allowed, but not required *PCCM program*: Specialist may be PCP	Allowed, but not required
MI	*MCO*: No guidelines on the types of providers that may serve as PCPs are in contract, so specialist could serve as PCP although there is no requirement to allow it *Special Health Plans:* PCP is usually a specialist or subspecialist w/acknowledged expertise/experience in management of the condition as it manifests in children. A pediatrician may also serve in this role, when appropriate.	Allowed, but not required

NM	Specialist may act as PCP, when appropriate	Allowed, but not required except all enrollees may self-refer for behavioral health, vision exams, dental, and family planning services.

A standing referral to a specialist was a more frequently reported scenario than identifying the specialist as the PCP. Again, all site visit states have provisions in their MCO contracts to allow this practice, although they do not require it. The specialist may, indeed, serve as the child's PCP for the duration of the standing referral while he, or she, is attending to the particular needs of the child.

Michigan took the concept of standing referral to a specialist one step further in its Special Health Plans. This State requires that a plan of care be developed for each new enrollee. The plans are generally developed by a community level care coordinator who is not MCO staff but rather contracts with the MCO to fulfill the care coordination function for a specific child. The care coordinator develops the plan of care in conjunction with the parents and often in consultation with the providers who are currently serving the child. The MCO then reviews the completed plan. Once the MCO approves the completed plan, it serves as a standing authorization for all services identified in the plan. Any disagreements about the need for a particular service are negotiated before the plan of care is approved. Both families and providers are very pleased with this policy and find it a vast improvement over the traditional authorization procedures in general managed care plans or the fee-for-service Title V program. Families have found that they get the child's supplies quicker and all of the child's needs are covered. They don't have to wait for services to be approved and initiated. Providers appreciate the greater ease and swiftness in obtaining services and medications for their patients.

In examining various access issues for children with special health care needs, striking differences became apparent among urban, rural and underserved areas. Though not a problem specific to special needs populations (or even to Medicaid), geography can pose special and significant challenges for these individuals because of their dependence on specialists, behavioral health providers, and ancillary providers such as home health services, various therapies, and DME suppliers. Enrollees in urban areas usually have access to a range of specialists and subspecialists. In rural and medically underserved areas it may be difficult to sustain an adequate number of PCPs, let alone specialists and ancillary services. All informants corroborated these challenges. For a particularly rural state like New Mexico there are only so many providers in the entire State and even the more urban areas may not have sufficient supply or diversity.

Access Issues of Particular Importance to CSHCN

There are several issues beyond those identified in the Interim Criteria that pertain to access to appropriate care for children with special health care needs and their families. The following section discusses some of those issues, particularly from the perspective of families, providers, and other stakeholders.

Transition from Fee-for-Service to Managed Care

Family informants often reported the transition from fee-for-service to managed care as extremely difficult and confusing. Although most states require the MCO to continue existing treatment plans with current providers for a period of time after the initial enrollment, that provision is time-limited. And, even though Medicaid requires an initial period of continuity of care, the state agency doesn't necessarily provide information to the MCO about the new enrollee's current services. Therefore, the MCO may have difficulty maintaining the same services and providers for the new enrollee. Families enrolled in Michigan's *CSHCS* program that serves Title V children reported that their transition to managed care was smooth. However, in these cases the state provides the MCO with extensive information about the child's current package of care before enrollment.

Once the MCO takes the responsibility for determining care plans and levels of service, the family frequently reported experiencing significant changes in the type and amount of care that is available for their special needs child. The MCO may place limits on the amount of in-home therapy that their child can receive or on the nursing or aide care available. The services that were provided within the fee-for-service system do not always match precisely the covered benefits under managed care.

Some families also spoke of an abrupt change in their service providers. The DME supplier that fixed their son's wheelchair over the years may not be the vendor with whom the managed care organization contracts. Or the home health agency that has been providing daily nursing and aide services for years through fee-for-service may not be the same organization under the managed care contract. These changes are not insignificant to either the child or the family. They may have established relationships with the individual employees of these providers and have developed a trust and a reliance on their service. New faces, and staff with little knowledge of their particular circumstances can be very disconcerting to families, regardless of the particular expertise and good intentions of the individual staff.

Most families of CSHCN report that they have carefully choreographed every hour of every day with a system of family, caretaker, and health care supports so that the child and the family can function. Changes to that delicate structure, whether in level or type of service or in care provider, can be extremely disruptive. Service reductions, in particular, can put a family in crisis. If they have been dependent on daily in-home services to care for their child, they cannot easily switch to a plan of care that does not include that level of care.

Family informants felt that the difficulties they face in dealing with changes to their children's care are exacerbated by a lack of information available to them and by inconsistencies in policy and practice. Medicaid agencies reported efforts to inform enrollees of their rights through enrollment material and member handbooks and by requiring MCOs to print standard messages on all notices of denial or reduction of services. Despite these efforts, some family informants reported that the changes that were made in levels of service or service providers occurred prior to being informed about these changes by the MCO. Many reported that they were not aware of their appeal rights or the fact that once they initiated an appeal that the previous level of service was to be maintained by the MCO, pending the outcome of the appeal process. One parent said that she found the grievance form to be "scary."

Providers echoed this concern about the lack of information provided to families and expressed their own frustration in the inconsistencies between Medicaid and the MCOs as to what benefits are covered. As one provider commented, "MCOs have taken the Bible (Medicaid rules) and developed their own religion." And each plan seems to interpret Medicaid requirements differently. They found it very difficult to maintain certain benefit levels for special needs children, particularly in nursing services and the therapies (physical, speech, and occupational), once they enroll in managed care.

For their part, state agency informants noted how difficult it is to provide adequate and detailed information about how managed care works to enrollees and their families. As was noted in the **Enrollment** chapter, there is only so much information that can be imparted at one time, and specific details on how services will be delivered in managed care are not necessarily relevant until a particular need arises. Further, the differences that families and providers experience between fee-for-service practice and service delivery under managed care are not necessarily due to changes in policy. Rather, managed care has provided an opportunity to monitor service delivery more closely and to adhere to Medicaid coverage policies that existed before managed care but that were not adequately enforced in fee-for-service.

MCOs and Providers Who Understand CSHCN

The issue of identifying experienced providers for CSHCN starts with the MCO itself. If the MCO doesn't understand the particular conditions and complexities of caring for children with special needs, it will be unable to recognize whether the care that these children receive is appropriate or not. Provider, advocate, and family informants reported that MCO staff who determine whether a service should be approved or not don't always know the nature of the medical condition and what that means in terms of care needs for the child and family.

Child Welfare advocates in most site visit states reported that foster children often have a long wait to access appropriate services. Several also reported that MCOs did not seem to appreciate the urgency of care and need for continuity for these children. There were also clear differences of opinion among informants from Child Welfare agencies, Medicaid agencies, and MCOs about what care was appropriate for different children. Some prefer an outpatient approach to treatment, while others prefer an inpatient approach; either may be acceptable. In the case of children in foster care, this issue is complicated because Child Welfare agencies may have difficulty finding appropriate placements for some children. These children may remain in an institutional or inpatient setting longer than strictly necessary to treat a covered condition because they have no place else to go.

Connecticut was the exception. In this State the Child Welfare agency reported that having an MCO to work with on the medical and behavioral health issues of children in foster care was a real benefit. As is discussed in the **Public Input** chapter, the Child Welfare agency in this State attributes its positive experience to the close working relationships that Child Welfare staff established with MCOs early in managed care program development

In New Mexico one of the community-based organizations that contracts with the State took the initiative to address this issue of lack of understanding of CSHCN. It invited staff of the MCO, including the Medical Director, into the homes of children with special needs so that they could see, first hand, the complexities of their medical condition and need for care. This activity achieved the intended result; it improved the understanding and responsiveness of the MCO to CSHCN.

This is also a contracting issue. Are the MCOs contracting with those providers who have experience in serving and treating children with special needs? According to several providers and families with whom we spoke, the answer is no. As one physician described the situation, the MCOs have a "K Mart Special" philosophy of contracting with any provider at the lowest cost, instead of including those providers who have the appropriate experience to care for the enrolled population in their networks. Consequently, the DME supplier for the MCO may not have any experience in fitting a child who has cerebral palsy with a wheelchair. Or the x-ray provider may not have the appropriate training to take an x-ray of a child with a degenerative muscle condition.

This lack of experienced providers can also be attributed to the unwillingness of providers to contract with MCOs. In one example, an MCO attempted to get a particular hospital to participate in the network so that children with special needs could access their care. Since the hospital refused the terms of the contract (or even to negotiate with the MCO), the MCO was forced to recommend to one family that they change their child's enrollment from the MCO to the PCCM program so that the child could see a particular specialist at the hospital.

Specialized programs for CSHCN may find it easier to address this issue as MCOs and providers participating in these programs are selected, at least partially, for their knowledge of the needs of CSHCN. However, there is no reason to believe that general MCOs cannot also address this issue. Indeed the MCOs participating in both of the specialized programs for CSHCN also participated in the general MCO program in those states.

Ease of Access

Everyone appreciates the convenience of being able to take care of his or her multiple needs in one location or through one provider. Families with a special needs child, particularly one who has difficulty with ambulation and transport, emphasized the special importance of "one stop shopping" to their ability to care for their child. A physician informant described the situation of a 14 year-old boy in a wheelchair who has an appointment with his specialist at the medical center and then has to go to different locations around the city for his lab work, x-rays, and physical therapy. What used to be one afternoon of appointments, when all of those services could be obtained at the same site, is now four different appointments and multiple trips. It is not only exhausting for the boy and his family to get in and out of a vehicle with the wheelchair, it is a scheduling nightmare for both the child who attends school and the parent who may be juggling his or her work responsibilities. Further, the lack of continuity and convenience creates a very disjointed care system for the child.

Families and providers reported that getting approvals for certain services and equipment can be much more difficult under managed care than it was in fee-for-service. Many of those interviewed cited particular obstacles to authorizations for a variety of DME and medical supplies. According to one provider, it is difficult to get a wheelchair upgrade approved for a child, even though the child has outgrown his current equipment. MCOs seem to adhere to the 5-year replacement standard that was established for adult needs, regardless of the age of the enrollee. Children grow and need replacements more frequently. Another provider described the difficulty and inordinate length of time that it took to get a strap for a wheelchair approved for a child who has no muscle control, so that he wouldn't fall out of the chair. At a price of forty dollars, this provider couldn't understand what the obstacle was to approving the request or why the child's medical condition didn't warrant the use of a strap for the chair.

Both families and providers noted their frustration and fatigue in fighting to get certain services — such as DME, therapies, home health, and private duty nursing — approved for the special needs child. Many felt that their access to care had, in fact, deteriorated under managed care and had certainly not become easier. They believe that MCOs that are accustomed to serving the general population do not understand chronic care issues or the family stresses and dynamics that result from a family member having special needs. They have not paid attention to what can facilitate their access to services and, consequently, reduce some of those stress factors. In those states that have a PCCM option as well as the MCOs, many providers reported recommending that their patients choose PCCM so that they will be able to access services more easily.

Access to Certain Services

Our interviews resulted in the identification of a number of benefits that have been difficult for CSHCN to obtain. Our informants, including both state Medicaid agency staff and other stakeholders, observed that certain benefits can be difficult to access, due to several reasons: limited provider availability, confusion about the extent of covered benefits, and disagreement among providers and/or agencies as to who is responsible for coverage. Though not necessarily unique to children with special needs, these issues may pose particular problems for these enrollees because of their complex medical needs. They include:

- Dental care: a continuous challenge for most Medicaid programs, in both fee-for-service and managed care, and exacerbated for some CSHCN because of their medical condition

- MCO formularies: they often do not include specific drugs that CSHCN need and the process to get approval can be daunting. Drugs for behavioral health diagnoses can be particularly difficult to obtain.

- Transportation: another challenge for many Medicaid programs, and a benefit that informants reported is not understood or provided very well by some MCOs. CSHCN may have particular accessibility requirements.

- Durable medical equipment (DME): as described earlier in this chapter, CSHCN face several obstacles in obtaining and maintaining their equipment and supplies. For example, it is very difficult to replace a wheelchair that has been outgrown, or to get one repaired in a timely manner.

- Home health services: the extent of service available was reported to change dramatically for a Medicaid beneficiary, once enrolled in managed care. Families and providers reported that it is difficult to justify ongoing services to the MCO if the child’s condition is not acute or his needs are not short-term. In addition, several states reported a critical shortage of private duty nurses, particularly those with training in pediatric care. Consequently, children end up staying in the hospital longer than they need to because there are not sufficient staff to care for them safely at home. (The shortage was not reported as limited to Medicaid but was rather an issue impacting all in the state.)

- Services provided in the schools: considerable tension and confusion exist as to what services the school should provide (through the Individuals with Disabilities Education Act (IDEA)) and what should be the MCO’s responsibility. Consequently, some informants were concerned that the child’s needs for services such as speech and physical therapy might go unmet while the state agency, MCO, and the school are determining which entity is responsible. (See Chapter on **Quality** for further discussion on most of these issues.)

Access to Behavioral Health

Informants in every site visit state identified behavioral health as a benefit that can be very problematic to provide and to access, both under managed care and in fee-for-service. While many acknowledge that managed care has brought improvements in behavioral health services, concern still exists that these services are not being provided effectively. Contract arrangements vary from state to state, but there appears to be considerable disagreement and confusion among the various parties as to what benefits are covered and who is responsible for providing them. Among the problems identified:

- lack of communication between the MCO and the behavioral health contractor;
- lack of involvement of other appropriate players, such as juvenile justice and child welfare agencies;
- concerns about the confidentiality of enrollee information and what information can be exchanged among providers, plans, and agencies;
- distinction between acute and chronic care, and who is responsible for providing; and
- availability of appropriate outpatient services and residential placements (particularly for foster care children) so that the child does not have to stay in an inpatient setting.

Because of these issues, families often don't know where or how to access services for their child. They may also need mental health services for themselves but don't know how to access them. Medicaid and other state agencies are all trying to address these issues, recognizing that the solutions are complex. There is little clinical agreement as to appropriate treatment protocols, and settings for treatment. Therefore, it can be extremely difficult to craft a coordinated system that meets the needs of both the enrollee and the family.

Respite Care

Many informants in site visit states identified respite care as an important service for families with special needs children. Families take on an enormous responsibility in caring for their special needs children at home. Even with in-home supports, they are on call 24 hours a day, seven days a week, and maintaining that availability often means being unable to attend to other children in the family, family outings, employment commitments, or simply a trip to the grocery store.

Informants reported that parents and other family members need a break from this demanding routine in order to preserve the health and well-being of the entire family. Respite care is a critical component in providing comprehensive care to children with special needs and their families, but, unless provided as part of a home and community based waiver, respite care is not a benefit under Federal Medicaid law. New Mexico's Medicaid agency, however, reported that MCOs were offering respite care as an enhanced benefit to their Medicaid enrollees. Those interviewed emphasized the need to recognize respite care as a reimbursable benefit and to provide the necessary services and placement options so that families have the opportunity to take a brief break from their full-time care responsibilities.

Provider Capacity and Access to Specialists: Summary of Study Question Findings

Can states meet the Interim Criteria for provider capacity and access to specialists?

All site visit states reported contract provisions in place with their MCOs to assure sufficient provider capacity and access to specialty care. Although they may not be able to meet each of the specific Interim Criteria, as currently drafted, they place considerable importance on the availability of qualified providers who can serve all enrollees in managed care. With respect to the Interim Criteria:

- State Medicaid agencies expressed concern about meeting the requirement of "sufficient **experienced** providers," without having a definition of "experienced." As discussed earlier in this chapter, states expect the MCOs to have a provider network that can serve the enrolled population, although they may not specify the particular expertise of those providers.

- None of the six states identifies a specific numerical capacity standard for specialists, though all include requirements for adequate specialist access in their MCO contracts. States felt that a specific numerical standard for specialists would not be particularly useful and would be difficult to define because of the range of specialists within a given network and the diverse medical needs of the enrolled population.

- States do have provisions in their contracts for specialists to be PCPs, if necessary, or to allow enrollees direct access to specialists for their care. This has become fairly standard policy in most general managed care programs.

- States do not routinely require particular specialist types in an MCO network in general managed care programs. Similar to the proposed requirement for specialist capacity standards, states are reluctant to identify specific specialist types because of the diverse medical needs of the enrolled population.

How do states monitor and evaluate MCO performance in capacity and access for CSHCN?

States reported employing standard methods for monitoring the performance of MCOs in meeting provider capacity and access standards. MCOs are required to submit periodic reports regarding their networks and to notify the state of any changes that occur that affect their ability to serve the enrolled population. The state agency conducts site visits to assess MCO policies and practice and reviews survey findings and complaints and grievances. In some states, the enrollment broker conducts periodic checks of a provider's availability and/or the waiting time for an appointment. Medicaid agencies all also specified maximum appointment waiting times and travel time/distance standards. Some states expressed concern that network reports and numerical standards for capacity are not sufficient to assess whether provider capacity is sufficient and appropriate.

Providers and families raised another concern, as to whether the MCO itself has sufficient internal capacity and expertise to serve CSHCN. They emphasized that children with special needs and their families need the MCO to understand their particular issues first, so that the MCO can promote access to appropriate services and providers, rather than providing barriers to care. State agencies should not only assess the adequacy of the provider networks and access policies of the MCO, but also whether the staff of the MCO appreciate the complexities and the complications of providing care to CSHCN.

How do states ensure capacity and access for CSHCN in the fee-for-service system?

There are few, if any, standards for capacity and access in the fee-for-service system. Historically, states have had no particular system for engaging a certain number or type of provider; they have been dependent on providers that are willing to accept fee-for-service reimbursement. However, the providers that have participated in Medicaid have included those traditional providers and service agencies that have particular expertise in serving CSHCN. Though the fee-for-service system may not have offered sufficient access to primary care and specialty physicians, it has typically included providers of Title V services, mental health services, early intervention services, and special education services. These same providers are not always automatically included in the network of a general managed care program.

Even though access to primary and specialty care has generally improved with Medicaid managed care because more physicians are willing to participate in managed care than in fee-for-service, many consumers would claim that access to the services needed by CSHCN is better in fee-for-service. Despite the absence of standards in the fee-for-service system, the traditional providers noted above, with experience in treating CSHCN, have been available for those populations.

How do state practices in ensuring capacity and access vary according to state characteristics?

There are several state-specific characteristics that affect state practices in ensuring capacity and access in managed care. These factors are not unique to Medicaid managed care programs for special needs populations; they have an impact on the entire health care system.

- *Rural/urban differences in the availability of providers*: This issue was a common theme among the site visit states, though a more pressing issue for those states with considerable rural areas, such as Colorado, Michigan, and New Mexico. These states and their contracted MCOs face a particular challenge in assembling an adequate network of providers for the enrolled population. They must devise policies and practices that facilitate access within and outside of a plan's network and, in some instances, outside the state.

- *Access to specialists*: In a state such as Massachusetts access to specialists is rarely a problem, due to the abundance of teaching hospitals and health care institutions in the state. Managed care enrollees, and all other state residents, can expect to get whatever specialty care they need. Another state may lack that concentration of specialty care in its general health care marketplace and, therefore, must develop alternative approaches to secure specialist care.

- *Employment issues*: Regional differences in employment have an impact on the availability of certain providers. Because of the low unemployment rate, several states reported a shortage of nurses who are willing to work for home health agencies. Many apparently prefer to work in an institutional setting where the schedule is more predictable and there is greater support. This trend has had a negative impact on the availability of private duty nurses who can provide the intensive at-home care that some special needs children require.

Do the Interim Criteria on capacity and access address the most significant issues faced by children and their families?

While the Interim Criteria address several issues of importance in serving CSHCN in managed care, our site visits revealed other concerns regarding capacity and access. There was a general sense from both state agencies and other stakeholders that the specification of capacity standards and certain types of providers for a managed care network are not as critical as being able to assure that children with special needs have access to the full range of services that they need. As discussed previously, many felt that it is equally important that the MCO, itself, understand the complexities of a child's care requirements, when he or she has special needs. Since MCO staff are in the position of making decisions about authorizations and referrals, they have as much of an impact on the child's access as the actual providers themselves.

- *Experienced providers:* Informants emphasized repeatedly how important it is that <u>all</u> providers who provide services to a child with special needs understand that child's condition and circumstances. Although the Interim Criteria focus on the notion of experienced providers, informants stressed that all individuals who come in contact with the child have an understanding of what it means to have special needs; from child welfare agency staff to DME suppliers to x-ray technicians. And, as noted above, MCO staff who are responsible for approving a child's services must also have an understanding and appreciation for the nature of the chronic illness or disorder.

- *Access to Services:* The availability of physicians, either primary care or specialty, did not seem to be of much concern for most of our informants and, therefore, may not warrant such an emphasis in the Criteria. Of greater concern was the availability of those services that make a difference in the child and family's day-to-day lives; wheelchairs, in-home therapy, diapers and other supplies, and private duty nursing. Parents want to know that they can access these services, regardless of whether they are in or out of the managed care network. They also want to know that the access will be facilitated, not hampered, by state and MCO policies and procedures.

- *System of care for CSHCN:* Although related to the above two points, it is important to highlight the need for a system of care that can respond to the chronic nature of the child's illness or disability and the ongoing needs of the child and his or her family. Both providers and families described their concerns that the managed care delivery system does not support the child's need for chronic, rather than episodic, care. Further, they are concerned that the delivery system as a whole, whether managed care or fee-for-service, is not prepared to care for a child with special health care needs as he or she matures to adolescence and then to adulthood. The providers, services, and systems are not currently in place that can meet the child's needs as he or she transitions from childhood to adolescence to adulthood.

No one model of care or set of providers exist that can meet the needs of all children with special health care needs. As has been noted repeatedly, their needs are complex and, therefore, there is no one-size-fits-all solution to their needs. There are differences, for example, in preferences as to how the care should be provided and in what setting. The criteria that are developed for provider capacity and access need to reflect this diversity and be responsive to the concerns about access to the wide range of benefits that CSHCN may need.

VI. QUALITY OF CARE

Interim Criteria

Concerning issues of quality of care for CSHCN, the Interim Criteria require that:

- *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.).*
- *The State has specific performance improvement projects that address issues for children with special health care needs.*
- *The State defines medical necessity for MCOs/PHPs and the State monitors the MCOs/PHPs to assure that it is applied by the MCOs/PHPs in their service authorization.*[30]

Introduction

The advent of Medicaid managed care has brought many advancements in the tools available for assessing the quality of care to beneficiaries. Some of these tools came from the commercial sector, such as performance measures initially designed for use by large private purchasers of managed care. In consultation with HCFA, state officials, advocacy groups, and others, the National Committee for Quality Assurance (NCQA) adapted these measures to the needs and circumstances of Medicaid beneficiaries. Today, Medicaid HEDIS is widely used by state Medicaid agencies. The 1998 survey of states conducted by NASHP indicated that 89% percent of states use all or part of Medicaid HEDIS to monitor care delivered to beneficiaries under Medicaid managed care.[31]

The design of instruments for assessing beneficiaries' experience with health care has followed a similar path. Working with the Agency for Health Research and Quality (AHRQ)[32], HCFA and other

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[30] This criterion is identified under "Plan Monitoring" in the Interim Criteria but is addressed under "Quality of Care" in this report because of its close relationship to other issues discussed in this section.

[31] Kaye N., Pernice C, Pelletier, H (editor), *Medicaid Managed Care: A Guide for States,* March 1999: National Academy for State Health Policy, Portland, ME.

[32] Formerly known as the Agency for Health Care Policy and Research.

stakeholders adapted an instrument designed for use with commercial populations for administration to Medicaid beneficiaries.   Modules were added to the core Consumer Assessment of Health Plans Survey or CAHPS to assess the more specific experience of sub-populations, such as Medicaid children with chronic conditions.   NASHP found that among the 45 states with MCO contracts in 1998, 21 states required the MCO to perform the CAHPS survey and report results, and14 Medicaid agencies directly administered the survey to beneficiaries enrolled in managed care.[33]

HEDIS and CAHPS for Medicaid make it possible to compare the experience of Medicaid managed care beneficiaries across MCOs, states, and the private sector. In that these tools are frequently required as a condition of federal waiver approval, they are now broadly adopted by states. Despite their widespread use, work continues at the federal and state levels to seek more precise instruments for evaluating the performance of MCOs and the outcome of care. Two years ago, for example, the Foundation for Accountability (FACCT) launched its Child and Adolescent Health Measurement Initiative (CAHMI) which focuses on the development of a method for identifying children with chronic conditions and a survey module that can be used with population-based surveys such as CAHPS.[34] These and other efforts are likely to create more sensitive methods in the future for monitoring performance and consumer experience relative to the needs of children with chronic conditions.

In 1997, HCFA published guidelines that sought to shift the direction of performance monitoring to a more outcomes-oriented approach. *Quality Improvement System for Managed Care* or QISMC was the result of a two-year process by state and federal officials, advocacy groups, and the managed care industry to develop standards and guidelines for assessing the impact of care.[35]   Mandatory for use by all Medicare+Choice plans, QISMC is currently published as guidelines for use by state Medicaid agencies. Demonstrated evidence of improvement is a core feature of QISMC. By undertaking rigorous projects in select areas, plans must show improved outcomes. QISMC has established a new threshold for how managed care plans will ultimately be evaluated by HCFA, state Medicaid agencies, and the public.

While the use and value of each of the above-mentioned initiatives is gaining acceptance in Medicaid managed care, more limited application of these tools has been evident for monitoring care to children with special needs. HCFA’s Interim Criteria urge the use of performance measures, satisfaction surveys, and quality improvement projects when monitoring a state's managed care program for

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[33] *Ibid.*

[34] Readers are referred to further information on The Child and Adolescent Health Measurement Initiative (CAHMI) on the FACCT web site (www:FACCT.org).

[35] Health Care Financing Administration, *Quality Improvement System for Managed Care*, September 28, 1998.

children with special needs. The following chapter reviews how prevalent their use is, as well as other strategies for monitoring and improving the quality of care.

Current Practice in Quality of Care for Children with Special Needs

When asked to describe their strategies for assuring the quality of care to children with special needs, informants focused on three key themes.

- First, informants identified specific tools to assess components or aspects of care. These tools include the use of performance measures, consumer and provider surveys or focus groups, special studies, and quality improvement projects.

- Second, informants repeatedly raised two issues that have an impact on care or monitoring efforts: criteria for determining medical necessity and the reliability and timelines of data.

- Finally, the value of "systems thinking" became evident as informants spoke of cobbling together components of a quality improvement system.

Despite frustrations, informants generally claimed that they know more about the quality of their managed care program than they do care provided on a fee-for-service basis. Aside from the activities of states' surveillance and utilization review units to monitor aberrant users and providers of care, only spotty quality oversight initiatives were identified under fee-for-service. In Colorado, Massachusetts, and Michigan, selected performance measures are used in fee-for-service, primarily related to the level of childhood immunizations and EPSDT screenings. Several states also compare care in their managed care programs to that delivered under fee-for-service or PCCM programs. Otherwise, Medicaid agencies are dependent on consumer complaints and periodic surveys to call their attention to potential quality problems. Despite the lack of oversight, parents and other informants emphasized that open access arrangements, unrestricted panels, and more generous interpretations of medical necessity found under fee-for-service provide important quality protections to children with special needs.

Collection, Verification and Use of Performance Measures

All site visit states reported collecting some or all Medicaid HEDIS as well as other performance measures from their MCOs, although only Michigan and New Mexico collect or stratify measures for children with special needs. Special Health Plans in Michigan are beginning to submit data, allowing comparison of performance to the state's general managed care program. In New Mexico, data are stratified (when sufficiently large numbers are available) by children with mental illness, severe emotional disorders, or homelessness.

Several obstacles impeded state efforts in the collection of performance measures for children with special needs:

- There is a general lack of useful measures developed specifically for children with special needs, especially in the areas of mental health and substance abuse. Efforts are underway in Colorado to develop outcome measures for persons with disabilities and mental illness. Outcome measures for behavioral health are being developed in Connecticut.

- There is a lack of data to calculate measures. Bundled rates that combined multiple services into a single global fee (such as prenatal care bundled into a single maternity rate) make calculation of some indicators impossible. Similar problems are encountered for claims from Indian Health Service clinics that traditionally have not used standard procedure codes.

- Heterogeneous populations and the lack of appropriate standards of care make outcome measures difficult to develop and interpret. MCOs in particular expressed concern about having data compared across plans or states without adjustments for variations in patient acuity. Despite reporting concerns, another MCO advocated the use of disease-specific measures to determine the types of care delivery that actually make a difference. Avoidable hospitalizations in the areas of asthma and mental illness were identified as good places to begin this analysis.

- Small numbers reduce reliability of results. This problem is particularly acute during early stages of enrollment. State Medicaid agencies and MCOs are designing collection methods to overcome small number variations, such as the collection of measures for the universe of a population rather than a sample.

- There is a lack of guidance on how best to stratify measures for children with special needs.

State Medicaid agencies and MCOs were genuinely perplexed in their efforts to develop useful and reliable stratifications. Broad stratifications fail to isolate problem areas, while controlling for specific diagnoses often produces numbers too small for meaningful analysis. One MCO plans to stratify data by children receiving case management services as a way to measure program effectiveness for children with special needs.

State Medicaid agencies and MCOs spoke of the need for improved performance measurement to monitor their programs for children with special needs. Several saw the development of new measures as an evolutionary process: having developed good and reliable measures for the general population, attention is now turning to refining those indicators for children with special needs. Meanwhile, however, states would like to see improved methods for stratifying existing measures to determine whether variations exist between MCO performance in the care of all children versus children with special needs in areas such as childhood immunization.

Verification of Performance Measures

All site visit states reported verifying performance data. Colorado requires plans to contract with an NCQA-certified auditor whereas Connecticut, Delaware, Massachusetts, Michigan, and New Mexico rely on the State's external quality review organization (EQRO) or other outside contractor for verification.

Measures Collected

All site visit states collect childhood immunization and other related EPSDT data. Only Michigan and New Mexico, however, stratify or collect measures specific to children with special needs. The remainder of these measures do not show performance for CSHCN only. Instead, these measures include CSHCN *as well as*: all other children, all other enrollees with disabilities, or all other enrollees. Table 11 summarizes requirements for the collection of performance measures within MCOs serving children with special needs. Areas shown reflect current data collection efforts. Massachusetts reported rotating performance measures on an annual basis.

Table 11: Performance measures for programs serving children with special needs in current contract year[36]

Performance Measure	CO	CT	DE	MA	MI	NM
Childhood immunization/EPSDT	**U**	**U**	**U**	**U**	**U**	**U**
Diabetes care	**U**		**U**			
Asthma	**U**	**U**				
Access to PCP	**U**					
Inpatient hospitalization	**U**	**U**				**U**
Outpatient/ER use	**U**					
No PCP/medical care visit for specified period of time		**U**				
Dental		**U**				**U**
Enrollee satisfaction levels					**U**	
Lead screening		**U**				**U**
Maternal support to women at risk					**U**	

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[36] Measures identified in Table 11 are collected for **all** children enrolled in a plan. Only Michigan and New Mexico stratify or collect measures for CSHCN.

Behavioral health re-admissions		**U**				
Otitis media			**U**			
Pharmacy						**U**
Enrollees with Plan of Care					**U**	
Enrollees with PCP					**U**	
Multi-disciplinary team visits					**U**	
Adolescent well child		**U**				**U**

In addition, all site visit states reported collecting performance measures related to special studies conducted under the federally mandated external quality review function. MCOs also collect performance data not otherwise required as part of their contracts with state Medicaid agencies.

Use of Performance Data

All site visit states use performance data to identify areas for program improvement. Three of the states (Colorado, Michigan, and New Mexico) publish MCO performance in report cards for use by consumers in selecting plans. Colorado compares MCO performance against that of its PCCM program and fee-for-service systems. For adults served in this State, 1997 data showed the PCCM program performing better in satisfaction but worse in overall quality. Other uses for performance data include:

- Calculation of penalties and incentive payments (Connecticut and Michigan)
- Calculation of capitation rates (Michigan)
- Reminders to MCOs regarding delinquent EPSDT services (Connecticut)
- Determination of need for statewide initiatives (Massachusetts and Michigan)
- Use in auto-assignment allocations (Michigan and New Mexico)

Consumer Surveys

All site visit states require the administration of the CAHPS survey, either by the Medicaid agency, its agent, or the MCO. None of the Medicaid agencies reported using the CAHPS module for children with special needs but two (Connecticut and Michigan) conduct surveys in addition to CAHPS for children with chronic conditions. These surveys tend to focus on access to specialists and non-medical support services more so than general surveys. Connecticut's survey was designed and implemented through its Children's Health Council and may be used in the future as a basis for incentive awards to MCOs. A separate consumer survey was conducted for the Special Health Plan in Michigan. Once sufficient eligibility lengths are achieved under the program, an NCQA vendor will administer the CAHPS survey to enrollees of the Special Health Plan.

No separate analyses were conducted of the CAHPS survey data for children with special health care needs. Delaware and New Mexico over-sampled SSI and medically fragile waiver populations in their survey efforts. Next year, Michigan plans to stratify survey responses from enrollees of its general managed care program by specific cultural groups and adults with disability. When questioned regarding the absence of special survey questions or analysis for children with special needs, Medicaid agencies generally mentioned the issues of small numbers and the lack of sufficient eligibility lengths.

The Medicaid agencies in all site visit states require MCOs to survey enrollees. Only Colorado specifies the use of the CAHPS survey instrument and only New Mexico requires MCOs to survey members with serious or chronic conditions.

Other Survey Initiatives

Generally, state agency and parent informants found only limited use for consumer satisfaction surveys, noting the trend for most respondents to show satisfaction. While many spoke of the limitations of existing survey techniques, nearly all site visit informants identified information from families about their experience in managed care as the leading means for assessing the success of a managed care program for children with special needs. To better assess actual experience with their managed care programs, state Medicaid agencies and MCOs reported plans to abandon or supplement general survey techniques with more targeted approaches for soliciting consumer feedback in the future. Among those plans:

- Focus group of persons with developmental disabilities (New Mexico)
- Family survey conducted by one MCO (Michigan)
- Topic-specific surveys, such as transportation, case management, mental health (Colorado, Delaware, Michigan, and New Mexico)
- Adding questions on specific topics such as transportation to a general consumer survey (New Mexico)

Many informants expressed concern that programs are not doing enough to reach out to those parents who are not inclined to complain publicly or participate in meetings. Expanding opportunities for ongoing feedback was widely advocated during interviews. An MCO in Colorado plans a parent focus group to assess the best way to exchange information on the program. A similar effort in New Mexico resulted in recommendations for the Medicaid agency to conduct multiple focus groups with parents on issues affecting the care of their children with special needs.

Provider Surveys

New Mexico required its three contracted MCOs to conduct a general survey of primary care providers, specialists, institutions, and ancillary providers to assess their experience under Medicaid. In the future, Colorado plans to survey providers for awareness of issues relating to cultural competence and disabilities. As part of its annual quality improvement goals, Massachusetts will require its MCOs to survey providers and case managers to assess their experience with care coordination services.

Primary care provider, specialist, and care manager informants spoke openly of their experiences under these programs during site visit interviews. Many reported never being approached for their feedback and had constructive suggestions for how the care system could be improved for children with special needs. While time and opportunities may be limited for soliciting their feedback, many of these informants stressed the importance of maintaining open communications to address their concerns on a regular basis.

Special Studies

As part of federally mandated external quality review, all site visit states contract with an external quality review organization (EQRO) to conduct studies. Several of these studies are specific to children with special needs. Table 12 summarizes study topics identified by state Medicaid agencies and MCOs and whether study findings were specific to children with special needs.

Table 12: Summary of past special studies related to children

Topic Area	CO	CT	DE	MA	MI	NM
Specific to CSN						
Behavioral Health	U					
Identification by MCOs of CSN/Care Coordination	U	U	U	U		
Mental health needs of kids in juvenile justice system						U
Service integration (schools, MCO, PCP, mental health)						U
Discharge planning for institutionalized children		U				
Plan of care: actual services received and outcome		U				
Access to service			U			
General Studies of Services Provided to Children That are Important to CSN						
EPSDT/childhood immunization	U	U	U	U	U	U
Discharge planning for persons with disabilities	U					

Asthma		U			U	U
Discharge planning for inpatient mental health		U				
Blood level screening		U				
Diabetes			U			
Sickle cell			U			
Behavioral health			U			
HIV					U	
Access to care					U	

State agency, parent, and advocacy group informants noted the need for broad participation in the design of studies. In New Mexico, a joint study on the mental health needs of children in the juvenile justice system is planned with participation from Child Welfare, Public Health, and Medicaid agencies as well as the MCOs. Advocacy groups in Connecticut were asked to join in the design of a second EPSDT study after complaining about methods used in the first study. The state Medicaid agency in Colorado has begun to seek consumer input into the design of its studies.

As with performance measures, many expressed concern that small numbers make special studies on children with special needs unreliable. An epidemiologist associated with an EQRO for one state suggested the value of conducting mega-studies across MCOs and states to better understand best practices in the care of children with special needs. She proposed studying sickle cell, fetal alcohol syndrome, cystic fibrosis, and asthma where there were known to be significant variations in care.

Complaint and Grievance Systems[37]

Site visit states rely heavily on formal and informal complaint and grievance systems to alert them to potential quality problems. Examples from every site visit state illustrate the use of direct appeals by parents to Medicaid officials to resolve individual problems pertaining to the care of their child with special needs. While these parents came away generally satisfied that their issues were heard and

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[37] *Complaint and Grievance systems* are often made up of complaint, grievance, and appeal processes. The distinction between complaints and grievances is often murky and varies among states. Some states make no distinction. The most commonly used distinction between a complaint and grievance is that a *complaint* is an informal, usually verbal expression of dissatisfaction by an individual enrollee about any aspect of the MCO or the care it delivers. A *grievance* is a formal, usually written, expression of dissatisfaction. An *appeal* is a formal response to a notice from the MCO that the MCO intends to "reduce, discontinue, or deny" the provision of a specific service. Federal regulations govern the information included in the notice and the circumstances under which the service must be continued pending a decision on an appeal.

addressed, many expressed concern that systems are not always in place to respond to the needs of less vigilant parents. Medicaid officials also expressed reservations about a system built on "squeaky wheels" yet continue to depend on their input as a barometer for assessing program effectiveness.

An important distinction was found in states where informal appeals and complaints became opportunities to identify underlying system failures. In addition to resolving individual cases, Medicaid officials in these states worked directly with other state agencies, MCOs, and advocates to better understand what may have gone wrong and how to avoid the problem in the future. In this way, the "squeaky wheel" served a positive function of alerting MCOs and Medicaid officials to problems that most probably affected others as well.

The formal complaint and grievance system in each state for children with special needs is generally the same as that for other Medicaid managed care enrollees.[38] Although complaints, grievances, and appeals are all important sources of information, complaints are probably better suited than appeals as to serve as an early warning system for potential problems, for they cast the broadest net and are often raised before either a grievance or appeal. In terms of ensuring delivery of care to CSHCN, complaints also serve as the "first line of defense." If the issues can be resolved to the enrollee's satisfaction at the level of a complaint, the issue is likely to be resolved more quickly than through the appeal process and, of course, the issue will never reach the appeal process. Features of these systems that have particular relevance to children with special needs include:

- *By-pass MCO*: All site visit states except Michigan allow beneficiaries to go directly to the state with a complaint or grievance before exhausting an MCO's complaint system. Massachusetts does not allow a member to file an appeal of an MCO decision with the Medicaid agency until the MCO appeal process is completed.

- *Continuation of benefits during appeal*: All site visit states had provisions for continuation of benefits during an appeal. In Connecticut and New Mexico, this provision applied only when a member filed within a specified time after MCO notice of action (10 days in Connecticut; 13 days in New Mexico). The provision allowing benefits to be continued during an appeal was not always well understood by parents in one state and led to a reluctance to appeal in the early days of this program.

- *Tracking*: No program except Michigan's Special Health Plan tracks complaints and grievances concerning the care of a child with special needs separately from other complaints and grievances. Michigan required the Special Health Plan (which serves only Title V children) to document all inquiries, not just complaints.

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[38] According to the Health Care Financing Administration, waivers approved under the Interim Criteria require that states submit reports on the tracking and resolution of complaints specific to CSHCN.

Although not specifically designed for children with special needs, two initiatives were identified as having particular relevance to them. New Mexico plans to institute "settlement conferences" to attempt to mediate issues prior to fair hearing. Protocols will direct the format and procedures for these conferences. The Children's Health Council in Connecticut sponsors an information line for member inquiries and complaints. Staff have access to member provider and encounter data and stay in contact with the enrollee until the issue has been resolved.

Medical Necessity

Advocate and family informants, as well as informants representing state agencies other than Medicaid, reported that the majority of complaints and grievances about the care delivered by MCOs to CSHCN are in response to an MCO denial or reduction of service. Many of these denials are based on criteria for determining whether a given service is considered medically necessary. No single issue in quality oversight raised more comments during the site visits than the issue of medical necessity: how it is defined, and how the definition is applied.

Definition

Definitions of medical necessity are established as a way to determine whether to pay for a covered service in a specific situation. Definitions vary across state Medicaid programs and vary substantially between Medicaid and private insurance carriers. In addition, all state Medicaid agencies must allow for more generous coverage for services to children eligible under the federal EPSDT program if its general definition is more restrictive than that defined under federal EPSDT requirements. Two federal provisions tend to override a state's general definition of medical necessity for children eligible under EPSDT. First, federal statute requires a service to be covered if found to be medically necessary to correct or **ameliorate** defects and physical and mental illnesses and conditions, not only restore or improve a condition. Second, the service must be covered if identified during an EPSDT screen.

Table 13 presents the general medical necessity definitions and EPSDT-related coverage guidelines in each of the site visit states. In Michigan, a definition of medical necessity is also presented that applies only to the State's Special Health Plan.

All site visit states include in their contracts general definitions for medical necessity that address the amelioration of decline, as well as the maintenance, restoration, and improvement of functioning. In all states but New Mexico, explicit provisions are also included in MCO contracts regarding coverage criteria that must apply under EPSDT. New Mexico, while not including the specific federal EPSDT language, references federal regulation.

Initially, Delaware allowed MCOs to establish their own definition for medical necessity. Shortly thereafter, the state Medicaid agency worked with advocates and the Disability Council to develop a standard definition that was introduced in the 1999 contracts with MCOs.

Table 13: Site visit state medical necessity definitions as defined by contract

State	Definition
CO	*General:* requires services that reduce or ameliorate (1) physical, mental, cognitive, or developmental effects of illness injury or disability; (2) pain or suffering; also requires services that will assist in achieving or maintaining maximum functional capacity on ADLs.
	EPSDT: specifies that MCOs must meet EPSDT requirements for medical necessity.
CT	*General:* includes health care that is provided (1) to correct or diminish the adverse effects of a medical condition or mental illness; (2) to assist an individual in attaining or maintaining an optimal level of health; (3) to diagnose a condition; or (4) prevent a medical condition from occurring.
	EPSDT: specifies that MCO must cover benefits not normally covered if condition is found during screen and service is medically appropriate.
DE	*General:* services to restore and improve as well as ameliorate the decline of a condition, including physical functioning.
	EPSDT: specifies that MCO must cover treatments deemed medically necessary to ameliorate problem identified in EPSDT screen.
MA	*General:* services (1) reasonable calculated to prevent, diagnose, prevent the worsening, or alleviate, correct, or cure conditions that endanger life, cause suffering or pain, cause physical deformity or malfunction, threaten to cause or to aggravate a disability, or result in illness or infirmity; and (2) for which there is no comparable medical service or site of service available or suitable for the member requesting the service that is more conservative or less costly; and (3) are of a quality that meets generally accepted standards of health care.
	EPSDT: requires coverage of all medically necessary services to correct or ameliorate condition discovered in EPSDT screen.
MI	*General:* on-site reviews monitor provision of medically necessary services (as reflected in MCO developed clinical practice guidelines).
	EPSDT: must provide services covered under State Medicaid Plan needed to correct or ameliorate defects, physical or mental illness, and conditions discovered in EPSDT screen. (Also specified that some services not included in a State plan may be available through EPSDT.)
	Specialty Health Plans: services necessary for the prevention, diagnosis, or treatment of illness/injury/conditions and/or to alleviate pain; also includes services which promote, maintain, or prevent deterioration of function, in accordance with accepted standards of medical practice.
NM	*General:* services that are essential to prevent, diagnose, prevent the worsening of, alleviate, correct, or cure medial conditions that endanger life, cause suffering or pain, cause physical deformity or malfunction, threaten or cause or aggravate a handicap, or result in illness or infirmity of a member.
	EPSDT: MCO must meet EPSDT requirements.

Implementation of Medical Necessity Criteria

Numerous problems were identified by informants in site visit states with respect to how medical necessity coverage criteria are applied by MCOs serving children with special needs.

Acute versus chronic care

Advocates, families, and providers often reported that during initial enrollment into Medicaid managed care, MCOs frequently denied services that were intended to treat chronic conditions. Persistent appeals were required before the scope of the covered benefit was understood by MCO staff responsible for utilization management decisions. Two factors were identified as contributing to these early denials. First, MCOs applied the same criteria for medical necessity to Medicaid members as they were accustomed to using in their commercial populations before realizing the Medicaid definition was broader. (Implementing a broader definition requires changing an MCO's claims processing system as requirements for claims payment were usually established for commercial contracts before the MCO entered the Medicaid market.) Second, inadequate emphasis was placed on the distinctions in definitions during state-sponsored training and orientation programs with MCOs. Provider, parent, and advocate informants in most states stressed that MCOs continue to place a higher burden of proof on services that may be needed long term, even after receiving clarification from the Medicaid agency about coverage requirements. MCOs do not necessarily disagree with the claim of a higher level of scrutiny for these requests. One MCO requires its medical director to personally review treatment to all members in long-term therapy.

Variances from fee-for-service

Some parent informants complained that services are being denied that were routinely approved under fee-for-service. The example frequently cited is that of respite care. While it is true that respite care is often provided under fee-for-service, it is generally not a Medicaid covered benefit. Lack of close scrutiny under fee-for-service means services like respite care which, except under a home and community based waiver, should not be covered by Medicaid, often are paid for by Medicaid. For their part, MCOs may be making legitimate determinations that respite care is not a covered benefit. In Colorado, many therapy services require no prior authorization under the state's PCCM program but may require approval by an MCO. These differences don't make one system right and the other wrong. They do, however, cause concern to parents who, under fee-for-service arrangements, are accustomed to a more permissive application of medical necessity criteria

Approval for name brands

Providers and parents repeatedly spoke of problems in getting approval for specific brands of diapers, equipment, and medications. Parents told stories of long periods of trials and errors in testing different brands and finally settling on a product that works only to have it denied when a child enrolls in Medicaid managed care. As one parent described, it is the simple things in life for her child that often make all the difference, such as the fit and feel of a specific diaper. These parent and care provider informants work hard with their MCOs to get approval only to have to start over again when the next request is made. For their part, some MCOs realize the importance of not requiring less costly substitutions while others continue to attempt to uphold their policies. Almost uniformly, MCOs spoke of changing their formularies to accommodate requests for special medications and nutritional supplements.

Educationally versus medically necessary services

Many children enrolled in Medicaid managed care also participate in programs for the delivery of medical services in the schools. The Individuals with Disabilities Education Act (IDEA) established a child's entitlement to educational and related services, including health care. According to Part B (once called Part H) of the Act, schools are required to provide therapeutic and other health-related services necessary to support and enhance a child's learning. These services are defined in an Individual Education Plan (IEP) and are paid by Medicaid on a fee-for-service basis in all site visit states. However, the scope and intensity of services included in a child's IEP oftentimes affect the extent and type of service requested of the MCO. Despite efforts by state Medicaid agencies to clarify requirements in this area, many MCOs and school-based programs reported that they were still struggling to determine whether a particular service serves primarily an "educational" or "medical" purpose or, when there is overlapping responsibility, which entity is payor of last resort Each has financial incentives to shift costs to the other, often requiring state agencies to serve as final arbiters. Since both public payors are typically payors of last resort, this is a federal regulatory issue that could benefit from federal guidance.

Court-ordered treatment

Judges do not always consider medical necessity in their judgements. States use different strategies to address requests that fall outside the norm or, in many cases, were not possible to fulfill. State Medicaid and Child Welfare agencies frequently meet with judges to consider alternatives, especially in cases where residential treatment is proposed but not available. MCOs typically worked closely with state agencies in all cases of court-ordered treatment. admitting their limited experience in this area.

Delays in authorization

Even when requests for services are ultimately approved, provider and parent informants complained that the process was lengthy and delayed the onset of care. Long-term therapies, DME, and pharmacy are frequently mentioned as problem areas in this regard. Provider informants challenged the competence of MCO staff making initial determinations. Even when the MCO's medical director made the decision, some providers questioned the director's knowledge about the needs of specific CSHCN. One provider noted that even requests that follow nationally recognized practice guidelines are frequently denied. Specialist informants in particular expressed dismay over a system that does not respect their knowledge of the complex needs and treatment requirements of children. Parent and provider informants alike spoke of a process that tried to "wear you down," requiring constant vigilance to get the care a child requires. Replacement wheelchairs for a growing child, a wheelchair strap for a child with no muscle control, and intensive therapies to assist a child dress or negotiate stairs, these and others were given as examples of hard-won requests.

Determinations of medical necessity were considered by most informants to be at the heart of Medicaid managed care for children with special needs. One parent observed that the root of the problem is the tension between MCOs concerned that “open-ended” criteria will lead to service abuse and a specialist claiming to know what is best for the child. Throughout site visits, recommendations were made to improve the process in this area:

- MCOs should forego prior authorization requirements when requests follow nationally recognized practice guidelines.
- States should establish state-level medical review boards to render decisions on requests that meet certain thresholds of cost or duration.
- States and MCOs should assure families and providers are informed of the right to continuation of service during an appeal.
- MCOs should eliminate policies such as a requirement that specific services be reviewed every three months for a child with chronic illness whose condition will not improve.
- States should conduct ongoing training regarding medical necessity definitions under EPSDT.

Collection and Use of Encounter Data

Encounter data has become a critical component of many state payment and quality oversight systems. Although states vary in their confidence in encounter data, all acknowledged its increasing value and use in monitoring the performance of MCO contractors. In addition, as encounter data has been used increasingly as a basis for risk adjustment of payments, states contend that its quality has gradually improved.

All site visit states require MCOs to submit encounter data, and all but two states (Massachusetts and Michigan) verify encounter data through the EQRO or other state contractor. Michigan MCOs report on only 14 elements required for risk adjustment but will begin full reporting in 1999 for its general MCOs and in 2000 for its Special Health Plans. Data are submitted directly to all site visit state Medicaid agencies and, in the case of Connecticut, to the Children’s Health Council as well.

Three problems were reported with respect to the quality of encounter data. First, most states expressed lack of confidence in behavioral health data. This was largely related to the more diffused arrangements for delivery of behavioral health services and complications arising from creating uniform and compatible reporting systems. Second, the absence of uniform provider identifiers across sites and MCOs make provider-specific profiling difficult if not impossible in many states. Third, problems of under-reporting were detected in Colorado when compared to information included in the medical records. Despite problems, site visit states are optimistic that the quality of the data is improving and reported using encounter data for multiple purposes, among them:.

- Rate setting and/or risk adjustment (Colorado, Delaware, and Michigan)

- Sample selections for special studies and surveys (Delaware)
- Comparative reporting across MCOs (New Mexico)
- Provider-specific reports (Connecticut)
- Notifications to MCOs on member compliance with EPSDT periodicity schedule (Connecticut)

Although not currently done, New Mexico reported the ability to merge encounter, eligibility, Title V, and state-funded claims to help ascertain enrollment of children with special needs in Medicaid managed care. Presently, only encounter and eligibility data are used to review high risk enrollees. Connecticut maintains a separate encounter file on children in foster placement for use in monitoring their care by the Children's Health Project.

Systems of Quality Oversight

Site visit states developed different approaches for assuring that the components of their quality improvement efforts worked together as an overall oversight system. The most prevalent among these approaches were the establishment of oversight committees and regular meetings with MCOs and other stakeholders.

Communication was widely reported as the key to improving quality under Medicaid managed care for children with special needs. Parent, advocate, and MCO informants urged states to cultivate close working relationships across state-level agencies whose constituents and programs are served through managed care. Independent oversight bodies, such as those established by the legislature in Connecticut, are considered valuable but not a replacement for strong and capable state program administrators.

For many informants, the contract represents the framework for how the delivery system should work. Parent and advocate informants are largely satisfied with the scope and specificity of the contract. To them, the issue is one of enforcement and vigilance on the part of state Medicaid agencies to ensure consistent interpretation of contract provisions. MCOs, on the other hand, request that contracts be made more specific, such as in the area of standards for the delivery of care coordination.

State Medicaid agencies generally understand the complexity of managed care for children with special needs but sometimes lack the data, tools, or resources to detect problems as rapidly as they would like. Across states, genuine interest exists among state Medicaid agencies, MCOs, and other stakeholders to learn from other states about effective approaches for monitoring and improving the care provided children with special needs.

One state Medicaid agency representative told of her approach to quality oversight. She described consumer and provider surveys, special studies, performance measures, and complaints as pieces of a puzzle. No one piece allows for a full picture. Together, however, they provide a picture of how the system is working. This staff person spoke of the challenges to organizing and assembling the pieces of quality oversight systems for managed care programs serving children with special needs. Full information may not be available to allow for a complete picture. However, enough pieces are in place to suggest a pattern of performance.

Quality: Summary of Study Question Findings

Can States Meet the Interim Criteria for Quality of Care?

States have moved incrementally toward implementing quality of care systems that fulfill the requirements envisioned in HCFA's Interim Criteria. (It is important to note that none of the site visit states were operating a waiver to which the Interim Criteria applied at the time of the site visits. The efforts reported here all predate the release of the Criteria.) But, to date, none had established programs that would fully implement the Criteria. The states cited low enrollment numbers and lack of performance measures specific to the population as barriers to implementing quality programs such as that envisioned in the Criteria. They are optimistic that they will be able to move closer to the ideal as the number of CSHCN enrolled in managed care grows and the state of the art in performance measurement and quality evolves. In the interim, states conduct qualitative studies in the areas of behavioral health, care coordination, and service integration and stratify general performance measures in several cases where the numbers allow.

States look for guidance on the development of appropriate stratification methodologies that would allow a state to compare MCO's performance on existing measures across populations and plans. Repeated requests were received for protocols and/or guidelines for conducting studies specific to children with special needs and for the development of performance measures specifically designed for CSHCN. Opportunities for cross-state "mega-studies" were also suggested to alleviate problems of small numbers and statistical significance, especially for select clinical areas.

How do States Monitor and Evaluate MCO Performance in Quality of Care for CSHCN?

For the most part, states rely on methods other than performance measures and special studies to assess the quality of care provided by MCOs to children with special needs. Principal among those methods are complaints and grievances and consumer surveys. Complaint reporting in particular is the underpinning in most states for detecting individual problems that may have system implications. Performance measures and studies, although useful in gaining broader understanding of the overall performance of a program, are considered too retrospective to be of value in day-to-day oversight. State agency, parent, and advocate informants are alert to the need for a "real-time" response system that provides early warnings to potential problems. Site visits underscored the value of tracking complaints and grievances to determine quality problems, yet few states have designed separate tracking systems for CSHCN.

How do States Ensure Quality of Care for CSHCN in the Fee-for-Service System?

Efforts at quality oversight are spotty in fee-for-service and tend to focus more on surveillance and utilization review than quality monitoring and improvement. Only with the advent of managed care have some states begun to use performance measures to assess and compare the quality of care under fee-for-service. Advocate informants, while acknowledging the improved systems available under managed care to assess quality, refer to a beneficiary's open access to services as a strong quality protection under fee-for-service. Especially in the areas of DME and home health, advocates stressed the potential damaging effect that delays and denials can have on quality.

How Do State Practices in Quality of Care Vary According to State Characteristics?

Two state characteristics tend to influence a state's quality oversight system. First, states with specialized managed care programs have better opportunities for evaluating the quality of care to these children given the controlled nature of how they are identified and served. While enrollments are yet too small to conduct such analyses, these settings offer natural experiments for evaluating the care of CSHCN enrolled in managed care. Also, the design of special programs allows program administrators to concentrate on program features and monitoring tools unique to the needs of this population.

Second, states with histories in managed care for their general Medicaid population prior to the enrollment of children with special populations felt advantaged in designing oversight systems for these populations.

Do the Criteria on Quality of Care Address the Most Significant Issues Faced by Children with Special Needs?

Site visits informants emphasized the need for both retrospective, long-term assessments of quality as well as early warning and response systems to real and potential problems. While HCFA's Interim Criteria address retrospective assessments, they do not provide real-time identification of problems. Parents, advocates, and providers underscored the importance of complaint systems and medical necessity determinations as two essential features for monitoring care to children with special needs. The two features are very much inter-dependent and relate to the need for clear and unambiguous language pertaining to medical necessity and the oversight of systems used by MCOs in their interpretation. In this regard, one suggestion was made to require the establishment of an independent medical review board for the purpose of making initial determinations or reviewing determination denials. State officials and parents made a more moderate proposal for the periodic review of MCO denials by the state Medicaid agency or its delegate. For their part, MCOs generally requested more specific guidelines outlining federal and state expectations, especially in the area of care coordination. Several also requested more training in areas such as the differences in coverage that stem from the broader definition of medical necessity that most states require MCOs to use for Medicaid enrollees, and on what to expect other organizations and agencies that also serve CSHCN to provide. Reviewers pointed out that the MCH/Medicaid TAG might be a good group to work on these issues.

VII. COORDINATION OF CARE

Interim Criteria

Concerning issues of coordination of care for CSHCN, the Interim Criteria require that:

-- *The State requires an assessment of each child's needs and implementation of a treatment plan based on that assessment.*

-- *The State has required the MCOs/PHPs to provide case management services to children with special needs.*

-- *The State has developed and implemented a process to collaborate and coordinate with agencies and advocates which serve special needs children and their families.*

-- *The State has a process for coordination with other systems of care (for example, Medicare, HRSA Title V grants, Ryan White CARE Act, SAMHSA Mental Health and Substance Abuse Block Grant Funds) or State/local funding sources.*

-- *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.*

Introduction

Children with special needs have complex problems that often require the care of multiple medical specialists and mental health practitioners, school and community-based therapists, as well as a myriad of agencies supporting the nutritional, developmental, transportation, and social support needs of the child and family. HCFA's Interim Criteria require a state, either directly or through contracts with its MCOs, to develop, implement, and manage a treatment plan based on an individual assessment of a child's needs in coordination with other agencies and programs serving special needs children and their families. The Interim Criteria are at once specific to the agencies with which a state and MCO must work but quite general as to the nature and meaning of the actual coordination and case management activity.

States have long served children with special needs through categorical and block grant programs on a fee-for-service basis. These programs typically require children to meet specific clinical and/or financial requirements to qualify. Some of these programs may be disease-oriented (e.g., the Ryan White program for children with HIV/AIDS) while others serve a specific public health function across a broad population (e.g., EPSDT screening, childhood immunization). States may also provide optional "targeted case management" services to assist beneficiaries in gaining access to needed medical, social, educational, and other services. Targeted case management allows states to coordinate a broad range of activities and services beyond the bounds of the Medicaid program.

In designing their Medicaid managed care programs for children with special needs, states make two important determinations. First, states determine the scope of responsibility an MCO has with respect to meeting the medical as well as developmental, educational, and social support needs of children and their families. Second, states decide the extent to which an MCO may act independently in assessing and meeting those needs or is required to work in coordination with programs and providers not directly under the control of the MCO. HCFA's Interim Criteria impose provisions that are likely to influence state determinations in each of these areas.

Current Practice in Care Coordination for CSHCN

Each site visit state reported requiring care coordination for children with special health care needs enrolled in Medicaid managed care. However, substantial variation exists across states and MCOs in terms of the scope and intensity of care coordination, the methods for providing care coordination, who receives care coordination, and the entities with which a state or MCO must coordinate. This section reviews current practice in each of these areas with observations from stakeholders regarding the effectiveness of the care coordination activity.

Definition of Care Coordination

HCFA's Interim Criteria infer four components that are generally used to describe the care coordination function:

- Assessment of need,
- Development of a treatment plan,
- Case management to assure implementation of the plan, and
- Coordination of care across providers.

The terms "care coordination" and "case management" are often used interchangeably by site visit states. Table 14 reports definitions used by states in their contracts with MCOs. These definitions are often less precise than specific provisions found elsewhere in the contract.

Table 14: Site visit state definitions of care coordination and/or case management in MCO (not including PHP) programs

State	Definition of Care Coordination and/or Case Management
CO	*MCO:* must have "written policies and procedures to ensure timely coordination of provision of covered services to its members to promote and assure service accessibility, attention to individual needs, continuity of care, maintenance of health, independent living, and fiscal and professional accountability."
	Case Management: includes screening for special health care needs, development of individual treatment plan as necessary, treatment follow-up, monitoring, and process to update/revise as necessary.
	EPSDT Case Management: is a coordinated system that follows the enrollee through EPSDT screening and treatment.
CT	*EPSDT Case Management:* includes (1) development of plan of care; (2) making referrals for related medical, social, and educational services; (3) providing assistance in scheduling appointments and arranging transportation and interpreter services; (4) coordinating plan of services through contacts with family and caregivers; (5) monitoring the quality of services; (6) providing health education; and (7) providing advocacy as needed.
DE	*MCO:* must have "satisfactory case management systems for coordinating service delivery with out-of-network providers, including behavioral health providers and ongoing service providers."
MA	*MCO:* case management is defined as the coordination of services under the Contract by a Care Coordinator to certain enrollees with complex medical, psychological, and/or social needs or conditions.
MI	*MCOs:* no definition other than "as required under EPSDT case management."
	Special Health Plans: includes the following activities: (1) participation in the initial assessment of a child's medical, social, and functional status; (2) arrangements for service delivery; (3) arrangements for periodic review and reassessments of child's needs; (4) advocacy for needed social, educational, and other support services; (5) preparation and maintenance of case records including the Plan of Care; (6) distribution of Care Plan to family, providers, and community resources indicated in Plan; and (7) assisting with transitions out of SHP.
NM	Physical health and behavioral health services must be integrated into a clinically coordinated managed care system that makes the needs of the member the first priority.
	EPSDT Case Management: includes assessment, development, and implementation of plans of care, mobilization of use of "natural helping" networks, coordination and monitoring of delivery of services, evaluation of effectiveness of services, and revision of the plan of care, if necessary.

The lack of a uniform definition for care coordination and/or a state's expectations in this area was widely reported as confusing by informants, including MCOs, parents and advocates, providers, and state agencies. Several areas were likely to cause confusion:

- The scope of services an MCO must coordinate varies. One state (Colorado) requires the MCO to coordinate "covered services." Other site visit states address more generally the need to coordinate medical, social, educational, mental health, support services, and/or other noncovered services. Many of these services are outside the MCO's contract and thus outside the control of the MCO to coordinate.

- When a state develops its own definition for care coordination, MCOs do not always understand that the comprehensive definition for EPSDT case management, as mandated by federal regulation, still applies.

- A lack of clarity exists in some states as to whether care coordination represents a function or a dedicated position. Providers in particular often remarked that they are unaware of a child's care coordinator when in fact the function may be performed across multiple positions within an MCO. Although all MCOs have case managers or care coordinators, only Massachusetts and Michigan specifically required such positions.

- Case management is sometimes perceived by MCOs and others as serving a utilization management purpose rather than addressing the unique needs of a child. Provider and parent informants in particular expressed concern that, without more standard guidelines, case management means "cost management." This perception is not always faulty in that MCOs, providers, and families reported that utilization management nurses often perform case management functions via phone without ever having any face-to-face contact with a child.

Several states recognize the ambiguity of their definitions and are working to better understand and clarify expectations. Connecticut conducted an audit of different approaches to care coordination. The State, under the sponsorship of the Children's Health Project, is planning a forum to discuss its findings and the feasibility of designing guidelines for MCOs in this area.

Under fee-for-service, care coordination is not a generally held principle except as practiced under EPSDT for eligible children and within individual programs for children with special needs. For example, the Kaileigh Mulligan program in Massachusetts provides care coordination for children with multiple or serious disabling conditions. Care coordination is an underlying principle of Early Intervention and Title B programs in the school for children with developmental delays or disabling conditions. While programs vary in the types of children served and the level of direct service provided, most aim to work with families in coordinating medical and social support services through a single care manager. Site visit states have different arrangements for coordinating these programs under Medicaid managed care and, as will be discussed later in this chapter, vary in the success of their coordination efforts. Similarly, home and community-based waiver programs are designed as care coordination models to keep eligible children from placement in institutions or hospitals. Aside from these and other specialized programs, however, states generally describe their care coordination activities under fee-for-service as utilization review and attempts to manage aberrant service use through prior authorization requirements. The only exception was New Mexico. This State's Medicaid agency reported that the children served by their Medically Fragile and EPSDT Case Management programs received extensive care coordination services in both fee-for-service and through MCOs.

Assessment of Need

The Interim Criteria require an assessment of each child's needs and the implementation of a treatment plan based on that assessment. This language infers the need for an in-person evaluation of a child's status. In practice, however, full assessments are not routinely provided nor are they always considered necessary. For example, an MCO serving a general population may conduct a telephone screen at the time of enrollment to determine who may be at risk for hospitalization or more intense services. Those found to be "at risk" may be scheduled for a complete assessment and the development of a treatment plan. On the other hand, screens may not be appropriate in programs targeted specifically to children with special needs since all children, by definition, are "at risk." In these cases, the MCO is likely to conduct an in-person assessment of a child's clinical, mental, and social support needs and develop a treatment plan based on those needs.

Colorado, Massachusetts, and Michigan require the MCO to conduct an assessment to determine a child's needs at the time of enrollment and whenever there is a change in status. None of these states specified whether the assessment had to be in-person. All MCOs noted obstacles in reaching new enrollees, thus sometimes diminishing opportunities to conduct a screen or assessment. Assessments on those that can be reached are conducted by phone, mail, or in-person.

The requirement for an assessment in other site visit states is triggered by the need for specific services or events. Connecticut requires an assessment to determine the need for EPSDT case management services and upon placement into foster care. Before reducing services, MCOs in Delaware must conduct an in-home assessment. New Mexico requires MCOs to check for compliance with EPSDT periodicity schedules within six months of enrollment as well as to ensure adherence with screening requirements applicable to children with special needs.

No state requires the use of a standardized assessment tool. "Assessment" forms range from a two-page screening tool to an 18-page, multi-disciplinary evaluation. MCOs were found to sometimes do more or fewer assessments than the Medicaid agency requires. Not all MCO informants in Delaware are aware of the state's policy regarding the need for an in-home assessment prior to reducing services. This requirement was made subsequent to the contract through separate policy notification. Despite the lack of a state requirement, one MCO in New Mexico conducts a screen of all enrollees within 90 days of enrollment. Officials in this State plan to make this a requirement in the next contract.

Development of a Plan of Care

The three states requiring assessments of all children with special needs (Colorado, Massachusetts, and Michigan for children enrolled in the Special Health Plan) also require that a plan of care be developed.

Other site visit states have requirements related to specific services and/or circumstances that prompt the need for an assessment.

For example, Connecticut requires that a care plan be developed for providing care to EPSDT members with physical or mental health conditions when the coordination of medical, social, and educational services is warranted. The plan of care in Delaware must be developed as part of the required in-home assessment. In New Mexico, a plan of care is required for each child receiving private duty nursing, home health care, personal care, inpatient psychiatric services, residential treatment, outpatient and partial hospitalization, treatment foster care, behavioral health, case management, or hospice services. Recently, the state also required MCOs to develop manual back-up plans for technology-dependent children in the event of Y2K power failures. State officials reference that no similar capacity for rapid assessment and planning would have been possible under fee-for-service.

MCOs and PCPs acknowledged that requirements for a plan of care are meaningless unless information is shared across providers. To date, MCOs have made only limited use of web-based technologies to inform providers regarding the status of a child or to facilitate on-line consultations. Concern over privacy protections and patient confidentiality was cited as hampering these efforts, especially in the area of behavioral health.

Authorized Signature

Three states (Delaware, Michigan, and New Mexico) require the PCP to sign the plan of care, although experience shows that not all do. Michigan further specifies that the family sign the plan of care and that the family and other service providers must agree to the plans developed by Special Health Plans. In this State, one percent of total capitation payments made to the MCO are withheld until the MCO demonstrates that it obtained the parent's signature on 99% of the plans of care prepared during the contract year. Even when a PCP signs the care plan, his or her level of involvement in its development is not always satisfactory. Several PCPs noted uncertainty about how care plans were developed and/or desire a more active role in their development. One physician described a lengthy process of justification that is required when he wishes to order additional services prior to signing a care plan.

Continuity of Care

Many CSHCN have existing treatment plans and providers at the time they enroll in Medicaid managed care. All states have some provision in their contracts requiring the MCO to honor existing plans or providers until an assessment is completed or to otherwise avoid abrupt changes in member treatment plans and caregivers. Several methods are used for assuring continuity of care:

- MCOs in Colorado and Special Health Plans in Michigan must allow a transition period (90 days in Colorado, 60 days in Michigan) during which a member may continue to receive covered services from the current providers.
- Delaware requires MCOs to continue existing services until a home visit is conducted and parents are notified in writing.
- In Massachusetts' *Special Kids Æ Special Care* program, the MCO is required to develop transitional plans acceptable to the Child Welfare agency if continuity of providers for children in foster care cannot be maintained after enrollment.

MCOs and PCPs expressed frustration over the lack of information that is available to them at the time a child enrolls and thereafter that could facilitate continuity of care. Massachusetts and Michigan routinely provide information on a child's existing service providers at the time of enrollment into the states' special health plan. New Mexico routinely provides information on fee-for-service prior authorizations. However, other states did not supply such information at the time of the site visits. Parent, provider, and state agency informants were sometimes skeptical of the MCOs' motives for reviewing historical data, believing it may be used to control rather than continue historical service use.

Problems in continuity of care were also identified post enrollment. For example, one PCP was unaware when his patient was prescribed psychotropic drugs by another provider, even though the prescribing mental health provider is located within the same MCO. This PCP was not clear on the cause of the breakdown, whether it resulted from confidentiality or technological concerns but, regardless, it had a clear impact on care coordination.

State reservations about sharing information often center on issues of confidentiality. A draft Memorandum of Understanding between Connecticut's Departments of Social Services and Public Health aims to establish policies for when data can be released without the individual approval of families. A six-agency agreement on confidentiality has been adopted in Delaware, yet no database exchange would be allowed with schools. The Multi-Purpose Collaborative County Boards in Michigan are working with families to allow access to records across agencies, especially in the area of mental health.

Continuity of care is disrupted whenever a child's existing provider is not part of an MCO's network. Parents emphasized the longstanding and intimate nature of many of these relationships given the presence of caregivers in the home on a regular basis. Parent informants indicated that MCOs, in looking for the most cost-effective service providers, do not appreciate the trauma a child and family experience when having to start over with new providers and/or vendors of service. Changes in personal care assistants and DME vendors were noted as being particularly traumatic, sometimes more so than changes in physicians.

Scope of the Plan of Care

The scope of an assessment typically corresponds with the scope of services an MCO is responsible for providing. Thus, an MCO that is accountable for behavioral health services would include an evaluation of mental health status whereas MCOs for which behavioral health is a carve-out may not.

Parent and advocate informants raised three issues with respect to the scope of the care plan.

- MCOs were viewed as having a medical orientation. When seen through this lens, the plan of care tends to address clinical and therapeutic services while downplaying or ignoring developmental or social support services needed to enhance a child's well-being.

- The Plan of Care is child-focused and does not see the child with special needs within the context of his or her entire family. Sibling issues are seen as especially important as they frequently are overshadowed in the home of a child with special needs.

- Those closest to the child, the PCP and/or care coordinator, are not always in a position to issue final authorization for services.

In contrast, the Plan of Care produced by Michigan's Special Health Plans serves as a prior authorization, relieving many parents and providers from having to make their case each time a service is ordered.

Coordination with Other Care Plans

Even after a child enrolls in Medicaid managed care, he or she may participate in early childhood development or school-based programs funded under a combination of federal and state sources. Two of these programs, Early Intervention and Special Education, operate under national guidelines for children with developmental delays or disabilities. Services are identified through a care planning process, known as the Individual Family Service Plan (IFSP) and the Individual Education Plan (IEP), respectively. Services identified on the IFSP are paid on a Medicaid fee-for-service basis in site visit states with two exceptions. MCOs were required to cover the IFSP evaluation in New Mexico and all medically necessary IFSP services in Delaware. All site visit states pay IEP services on a fee-for-service basis.

Site visits raised several issues regarding the integration of the IFSP and IEP processes under Medicaid managed care. Connecticut is the only state that requires the signature of the PCP on IFSPs and IEPs. MCOs in Delaware may not apply prior authorization requirements to services identified on the IFSP, if the PCP signs the plan. Despite these provisions, however, PCPs and MCOs in these two states reported that they were infrequently consulted in the development of an IFSP or IEP and often do not receive copies of the completed plan. (Delaware is making efforts to ensure that MCOs receive copies of the completed plan, and MCOs are hopeful that they will begin to get this information soon.) This situation illustrates that simply mandating the MCO to coordinate is unlikely to prove effective without the cooperation of others responsible for delivering care to CSHCN.

MCO, parent, and Medicaid informants uniformly expressed frustration with the IFSP and IEP process under managed care. Among their chief concerns:

- Paying IFSP and IEP services under fee-for-service is seen as fragmenting care and the accountability of the MCO.

- MCOs and Title B school-based programs often disagree over what services should be designated “medically” versus “educationally” necessary. Since these determinations affected how services are paid, each party has incentives to shift responsibility to the other. A recent Supreme court ruling in favor of providing nursing care to a ventilator dependent child in school has left unanswered the question of who must pay for these services.

- PCP and MCO informants feel disconnected from the IFSP and IEP processes. PCP informants noted the slow turnaround in getting copies of the IFSP which, when received, are often found useful. In other cases, having been uninvolved in the evaluation process leading to the plan, PCP informants questioned the basis for service determinations. In one case, the PCP expressed concern regarding authorization for a home health aide rather than a public health nurse. If the school district is unable to provide a service identified on the IEP, the MCO is sometimes requested to do so, even when related to the educational needs of a child.

- MCO care coordinator informants are not aware of or asked to participate in evaluations for IEPs. Copies of the IEP are often not shared or are frequently incomplete.

- The task of coordinating and reconciling an ISFP with MCO coverage oftentimes falls to the parent. Lack of interface between medical and social services occurs even when persons developing both plans are located within the same umbrella agency.

MCOs are not always aware when a child is being served by another agency. This is particularly true in large metropolitan areas where children may participate in specialty clinics or programs. In Connecticut, on the other hand, Child Welfare routinely provides information to MCOs to assure smooth service transition. Even where good communication exists among service agencies, MCOs expressed frustration with the multiple bureaucracies providing care to these children, each with their own program rules and benefit packages.

Several examples of joint case management/coordination were identified when a child was served through multiple agencies. A BHO in New Mexico convenes monthly meetings with MCO staff to consider issues related to the care of children enrolled in both programs. As a result of these meetings, joint case management sessions were instituted for these children, who frequently include those with brain injuries, those with severe emotional disorders, or those who are served through the juvenile justice system or foster placement. One MCO in New Mexico initiated similar joint management of children served through the state's waiver program for medically fragile children.

How Care Coordination/Case Management Services are Delivered

HCFA's Interim Criteria will place requirements on states to ensure that MCOs provide case management services to children with special needs. All site visit states have such a requirement although only Massachusetts and Michigan explicitly require that the MCO have a care coordinator or case manager. Despite the absence of requirements in the other states, all MCOs were found to have positions variously described as care coordinators, service coordinators, or case managers.

Duties and Responsibilities of Care Coordinator

Duties for care coordinators are defined in many different ways by MCO, provider, parent, and state agency informants. Most everyone agrees that a care coordinator should assist the child and/or family in accessing needed services. Other functions include:

- conducting assessments,
- developing a plan of care,
- authorizing services,
- arranging for needed services external to the MCO,
- monitoring the child's status and keeping providers informed,
- coordinating service delivery across providers and agencies, and
- providing health education and advocacy as needed.

The scope and intensity of care coordination services varies greatly across states and MCOs. While many MCOs spoke the "language" of care coordination or case management, parent and advocate informants frequently described MCOs as providing utilization management functions. Parent informants described a delicate role for the MCO with respect to care coordination. Some parents cautioned against believing that any MCO could or should ever replace the role each parent must play in coordinating care for a child. Whether it be advocating for additional services, locating acceptable providers and vendors, or resisting the tendency of providers to compartmentalize treatment, parents alone are seen as having the responsibility to remain informed partners in their child's care. While conceding their need to stay actively involved, parent informants emphasized the critical role care coordinators could play to ease family burdens and facilitate timely care. Parents spoke frequently about the benefit of having a single point of contact within an MCO to navigate the system and bureaucracy and to look beyond the immediate needs of the child to those of the family. For parent with few supports, care coordinators may need to play more active roles in motivating or educating parents and children regarding their care and responsibilities.

Who Performs Care Coordination?

Multiple models were identified for providing care coordination. Some models are directed by the state while others are still evolving as MCOs gain experience in serving children with special needs.

- Utilization review model: Case managers of many MCOs are in actuality performing traditional prior authorization and utilization management functions. In several cases, case managers are located off-site with only telephone contact with members, families, and PCPs. These arrangements are frequently supplemented with an advocate or care coordinator on site with responsibilities for linking members to community programs and providers. Although these activities are also primarily conducted via telephone, in-person or home visits are arranged as necessary.

- Activist model: Some MCOs have what could be described as “activist” case managers. MCOs in Massachusetts and New Mexico locate care coordinators in the community to assure children get needed services. Case managers meet with children and their families at home and in the hospital, and may accompany a child to a PCP appointment or a wheelchair fitting. Case managers in a Colorado BHO are called “Navigators,” reflecting their skills at helping parents navigate the school and other systems of care impacting their child’s performance.

- Split model: Special Health Plans in Michigan have a two-tier system of care coordination. At the plan level, a care coordinator is assigned responsibilities for prior authorization and utilization management. Members choose a local coordinator from among agencies under contract with the plan, including physician practices, home health agencies, mental health centers, and local health departments. Care plans are developed by the local coordinator subject to the review and approval of the plan-level coordinator. When issues arise regarding proposed services, the plan-level coordinator might contact the PCP and/or family directly. Over time, it is anticipated that more responsibility will be delegated to local coordinators.

- Disease management model: A pilot program in Delaware focuses on the medical management of children with cerebral palsy. Coordination is conducted by a physician and nurse working in collaboration with social workers as necessary.

- Team approach: One MCO participating in Colorado’s special needs program has developed a team approach composed of an RN, intake worker, outreach worker, supervisor, and planning person. Located at the MCO, the team develops the plan of care, gathers information from parents, and assures service coordination. This MCO has found most problems to be non-medical in nature, with parents needing guidance on how to access services. As a result, classes are held to better acquaint parents of children with special needs on Medicaid and the health care delivery system.

- Independent model. Some informants stressed the advantage of having neutral parties (not MCO staff) serve as care coordinators and advocates for the child. A pilot program in Massachusetts that uses independent care coordinators located in physician practices was cited as an example of how the system should work. Care coordinators in this model are hired by the State's public health agency through a special grant . The role of the care coordinator extends across medical and social service delivery. Another informant who works in a home and community-based care waiver program suggested that the waiver funded care coordinators could focus on the overall coordination of care provided to a child, freeing the MCO to concentrate on its strength in medical management. Without authority to order and direct services, however, it is sometimes unclear whether the independent model will work in areas of conflict.

The above models reflect different approaches which, in some cases, may not be easily replicable in other programs. An audit in Connecticut documented different approaches to care coordination under Medicaid managed care. The State was planning a roundtable to discuss its findings and the feasibility of designing guidelines for MCOs in this area.

Parent, PCP, and specialist informants identified similar characteristics for an effective care coordinator/case manager. The case manager should understand both the system and the disease pathology of the child. Most importantly, he or she must know how to get services approved and accessed within the system. Staff turnover of these positions is seen as a major problem, reducing their effectiveness and long-term value to parents and providers alike. Also, the role of coordinating care outside an MCO's covered benefit package is not universally felt to be the responsibility of the MCO. Many informants stressed that MCOs are qualified and equipped to manage medical care but lack understanding of the broader delivery system serving children with special needs. Even with good intentions, MCOs are not likely to be informed of program rules and policies that allow service plans to be cobbled together to meet the needs of these children. In addition, parent and advocate informants questioned whether the MCO was in a position to truly advocate for the child since the MCO has a financial stake in the services provided.

Who Receives Care Coordination?

No standard approach is used to determine which children receive care coordination. Contracts in Delaware, Massachusetts, and Michigan's Special Health Plan require that all children with special needs (as defined by the state and/or who are participating in a program designed for special need children) receive care coordination. Massachusetts and Michigan qualify the requirement to children where the family or child is willing to receive the service, although Michigan still holds the Special Health Plans accountable to be sure coordinated care is received.

Most informants, including parents and advocates, agree that the need for care coordination services varies tremendously across children, even those considered to have special needs. Some children may have stabilized medical conditions and strong support systems. Other children with chronic conditions may experience more frequent acute episodes and/or have need for greater home and community based support. MCOs have employed different strategies for responding to variations in need within subsets of their enrolled special needs population, among those subsets:

- medically at-risk under 21 years (New Mexico);,
- chronically mentally ill (New Mexico);
- medically at-risk up to age three who are not developmentally delayed (New Mexico);
- EPSDT members who have a physical or mental health condition that makes the coordination of medical, social, and educational services medically necessary;
- people with disabilities, including children (Massachusetts);
- determined by the MCO (Delaware);
- homeless (Massachusetts);
- children in the custody of the State (Massachusetts); and
- referrals from PCPs or case managers (all site visit states).

Criteria for receiving case management can create perverse incentives at the service delivery level. One physician spoke of the absurdity of having to be hospitalized as a condition for a child to receive case management services. Meanwhile, the hours spent by this physician and his office nurse to arrange and manage home-based support to avoid hospitalization go unrecognized.

Coordination of Care Across Providers and Programs

One of the more specific areas addressed in HCFA's Interim Criteria is the need for coordination across the many providers and programs serving children with special needs. The Interim Criteria distinguish between the responsibility of the state in this regard and the obligations of MCOs. States, for example, must have a process for coordinating with other *systems of care* (e.g., Medicare, Title V, Ryan White CARE Act) or state/local funding sources. MCOs, on the other hand, must coordinate health care services with specific *providers of care*, such as mental health, local health departments, and home and community based waivers.

Site visit states use different strategies to meet both requirements. It is generally found that programs where the state took a leadership role in facilitating opportunities for early and frequent involvement of other systems of care had improved provider coordination at the delivery level.

State-level Coordination Activities

The quality of working relationships between MCOs and local providers was reported as generally reflective of the atmosphere of coordination across funding agencies at the state level. Where state agencies work well together in understanding the impact of Medicaid managed care on their constituents and programs, direct benefit can be seen in improved coordination of those services at the local level.

- Child Welfare's early participation in the development of Connecticut's managed care contracts helped shape coordination at the local level.

- Delaware's mental health department, which serves as a public MCO, maintains a statewide data base that links to Child Welfare for use in the management of care to children in foster placement.

- The fact that Michigan's Title V and Medicaid programs are co-housed in the same department was seen as pivotal to the state's ability to implement its managed care program for children with special needs.

In contrast, MCO and provider informants in these and other site visit states referenced rivalries between state agencies that have affected their ability to work effectively at the service delivery level. In these cases, the MCO is dependent on the good will and personalities of individuals to work out issues without the sanction or help of the state agency. The blurring of responsibilities between MCOs and behavioral health providers is often serves as an illustration of the types of tensions that can exist if issues are not first worked out at the state level, particularly when behavioral health is carved out of managed care. Certain populations are seen as particularly vulnerable when agencies with overlapping responsibilities for a child's care do not effectively coordinate, among them: homeless children; children with brain injuries, autism, dual diagnoses of mental illness and substance abuse; and children who are aging out of the child welfare system.

MCO Coordination Agreements with State Agencies

All site visit states require MCOs to enter into coordination agreements with multiple state agencies whose programs serve children with special needs. The existence of these agreements does not necessarily mean they are executed. Site visit informants often described these provisions as "paper requirements," that in themselves do not necessarily result in improved coordination. All state agencies and MCOs describe the less tangible "people factor" that is essential to fulfilling the intent of such agreements.

Table 15 summarizes state requirements for MCO coordination agreements with state agencies. This table is difficult to interpret and compare across states given variances in state organizational structures. The provisions of these agreements are also not known, nor their impact at the service delivery level. Observations from state agency, MCO, parent ,and advocate informants regarding working relationship suggest several important lessons:

- Early involvement of state agencies in the design of Medicaid managed care programs and contracts enhances the likelihood of meaningful participation later.
- Mechanisms for ongoing communication across state agencies create "systems thinking" and solutions to problems.
- The state Medicaid agency has an important role in helping to lay the groundwork for MCO negotiation of coordination agreements with other state agencies.

Table 15: Required coordination agreements with state agencies

State Agency	**CO**	**CT**	**DE**	**MA**	**MI**	**NM**
Public Health/MCH/Early Intervention	**U**	**U**	**U**		**U**	
Mental Health/Substance Abuse/Mental Retardation		**U**	**U**	**U**		
Education		**U**	**U**			
Social Services				**U**		
Home and Community Based Waiver Programs						**U**
Children Youth and Families		**U**	**U**	**U**		**U**

MCO Coordination Agreements with Community Providers and Services

Site visit states vary in the level of specificity of contract requirements for coordination agreements between MCOs and community-based providers and services.

Table 16: Required coordination agreements with community providers and services

State Agency	**CO**	**CT**	**DE**	**MA**	**MI**	**NM**

General – community providers serving CSN	**U**	**U**		**U**	**U**	
Special CSN projects/committees		**U**				
Tertiary care centers			**U**			**U**
School-based clinics			**U**		**U**	**U**
Public health/immunization clinics						**U**
Mental health					**U**	**U**
Community health centers/rural health/Indian Health					**U**	**U**
Family planning					**U**	**U**

Table 16 does not enumerate all the arrangements MCOs have with respect to service provision. Rather the table summarizes the extent to which state contracts require MCOs to coordinate with specific types of providers.

Two issues were identified regarding coordination agreements. First, agreements are often reached in start-up stages of implementation and rarely referred to or refined thereafter. To be meaningful, opportunities should exist for involved parties to periodically review their working relationship and propose changes based on actual experience. Second, service subcontracts may be at odds with the goal of coordination agreements. A specialist noted that one MCO contracts with his tertiary care center for medical services but, for reasons of cost containment, does not subcontract with the center's lab and x-ray services. As a result, families are forced to go across town for service, often having to return to his office for medical consultations. This specialist conveyed how these arrangements transfer burden and costs to families who are already carrying heavy loads. On the face of it, however, this MCO is in compliance with the care coordination and network adequacy provisions of their contracts with the state Medicaid agency.

Care Coordination: Summary of Study Question Findings

Can States Meet the Interim Criteria for Care Coordination?

Site visit states, although not yet subject to the Interim Criteria, have policies in place that partially meet the criteria. Some, but not all, children with special needs, as defined by HCFA, receive assessments, treatment plans, and case management services. Some states and all MCOs have criteria for determining which children require such services although these were found to vary across States and among MCOs within a state. All states and all MCOs develop coordination agreements and have processes in place to collaborate with other agencies in the care of children with special needs. However, the scope and effectiveness of these practices vary widely across states and MCOs.

The general lack of specificity of HCFA's Interim Criteria for care coordination makes assessment of compliance difficult. Terms such as "assessment" and "case management" are found to have multiple meanings which, when practiced, fulfill very different intentions. Assessments are translated by some as risk screens. Case management is interpreted to encompass the full range of services identified under the federal EPSDT definition and, by others, to mean utilization management. States and MCOs develop many strategies for coordinating with agencies and programs with responsibilities for the care of children with special needs. Literal compliance with these provisions, however, does not always render effective working relationships.

How do States Monitor and Evaluate MCO Performance in Care Coordination for CSHCN?

As described more specifically in the chapter on **Stakeholder Input**, all states establish committees and forums for ongoing participation across state agencies, advocates, and MCOs. Oftentimes initiated during the planning phases of Medicaid managed care in these states, these vehicles serve an essential ongoing purpose in addressing issues that require the coordination of multiple agencies and/or programs.

Three other tools are used by states and MCOs to monitor and improve their care coordination activities. These are described more fully in the preceding chapter on **Quality of Care**.

- Consumer surveys are used universally across the states as a method to solicit direct and regular feedback on consumers' experience with care. However, only one site visit state had developed specific questions targeted to the unique circumstances of children with special needs.

- Special studies serve a more focused approach to assessing whether MCOs are fulfilling care coordination responsibilities. One study in Delaware developed a series of indicators specifically targeted to monitoring MCO performance in coordinating care for children with special needs. Another study in Connecticut audited MCOs with respect to their approach for care coordination and, as a result, planned to conduct a forum for identifying best practice guidelines.

- Complaints and grievances serve a more limited purpose in identifying areas where an individual child's care coordination needs may not be met. Multiple complaints and/or trends over time provide states with warning signs that problems may represent system failures and require system solutions across agencies.

- Communication is identified as the single most essential component for monitoring and improving care coordination. Generally it was found that the success of care coordination at the service delivery level frequently reflected the ability of agencies and programs to work together effectively at the state level.

How do States Ensure Care Coordination for CSHCN in the Fee-for-Service System?

Care coordination under fee-for-service is found within a limited number of specialized programs where children are generally required to meet specific clinical criteria to qualify. Funding parameters often limit the number of children served in these programs. Case management services are also available under EPSDT which, when the need is identified during a screen, includes a range of services such as assistance in making appointments or referrals for transportation or interpreter services, health education, coordination with other care providers and family members, and advocacy as needed. Similarly, "targeted case management" is available as an optional service to assist beneficiaries in gaining access to needed medical and support services. Targeted case management allows states to coordinate a broad range of activities and services beyond the bounds of the Medicaid program.

How Do State Practices in Care Coordination Vary According to State Characteristics?

No consistent trend was observed that linked how well a state performs in care coordination to specific characteristics of the state. Two anecdotal observations may be indicative of the complexity and/or success of care coordination efforts. First, MCOs and their providers noted the difficulties of remaining informed about other sources of care that are received by a child given the multiple clinics and programs serving specialized needs of children in large urban areas. They stressed that the scope of outreach and coordination efforts in these areas should be far more extensive than they currently are.

Second, informants observed that how state agencies are organized and administered can either facilitate or impede coordination across agencies. For example, the successful establishment of Michigan's Special Health Plan for children was attributed, at least in part, to the fact that Title V and Medicaid are housed within the same Department. More important than the location of an agency within a given department are the structures that promote inter-agency communication on a high-level and regular basis. Informants repeatedly observed that good state coordination facilitated strong collaborations at the local level.

Do the Interim Criteria on Care Coordination Address the Most Significant Issues Faced by Children and their Families?

Informants concur that HCFA's Interim Criteria are appropriate and represent factors important to the care and well-being of children with special needs. The Interim Criteria, however, leave unanswered many important elements that may ultimately affect the impact of care coordination on a beneficiary's health status and care needs.

- No clear definition of care coordination exists and, as confirmed through the site visits, states and MCOs have multiple approaches to how they characterize their care coordination activities.

- The term "assessment" is subject to multiple interpretations and, without specification, may be viewed as a screening tool or multi-disciplinary evaluation.

- The Interim Criteria likewise require that a treatment plan be developed for each CSHCN. The scope of the treatment plan is not defined nor are the key parties responsible for its development identified.

Some state and MCO informants seek clarification on each of these questions while others expressed reservation about HCFA becoming too prescriptive. The latter argued that it is the nature of the care coordination function to be individualized and that, by requiring uniformity, resources may be diverted away from those who need them most. For example, a child with chronic conditions who was stabilized under the care of a provider may not need to be assessed at the time of enrollment. Assuming a stable home situation, case management services may also not be warranted. While systems must be in place to provide such services when needed, some informants felt that judgment, not standards, should determine when those services were needed.

A broader philosophical question was raised during site visits regarding the appropriate role of the MCO in providing care coordination services. Although there is no dispute that MCOs should coordinate care within the scope of their covered benefits, questions persist on the extent to which MCOs should be held accountable for coordinating care across the broader array of community and school-based services. Parent and advocate informants in particular stressed the need for neutral parties who could advocate for the child without regard to fiscal implications. Such arrangements, however, do not resolve the question of authority to order services or resolve conflicts. Some parent informants also emphasized that they were, and should be, the person with primary responsibility for making decisions regarding the care of their child. All systems of care coordination must recognize and support them in that role.

VII. PAYMENT METHODOLOGY

Interim Criteria

Concerning payment methodology, the Interim Criteria require that:

The State develops a payment methodology that accounts for special needs populations enrolled in capitated managed care.

Introduction

CSHCN are often described as those who have more intensive and extensive medical or behavioral health needs than other children. Certainly many of the children who belong to one of the groups included in the BBA-definition of CSHCN can be described that way. The Interim Criteria language requires states to develop a means of paying capitated MCOs that accounts for special needs populations. A number of key informants commented on the need for adequate and fairly distributed resources. However, few other than the purchasing agency and the MCOs commented on the strengths and weaknesses of the current system or had ideas for improvement. This could be due to the fact that most of those interviewed (outside these two groups) were not well enough informed about how the system currently operates to have an opinion about it.

If the managed care system is to function properly for CSHCN, funding must be adequate to pay for the care needed by CSHCN (and other special needs populations), and those funds must be distributed so that MCOs serving a greater proportion of CSHCN receive a commensurate proportion of the available money. If the MCOs are not appropriately reimbursed, they may try to avoid enrolling high cost children, avoid providing medically necessary services, or lose money (perhaps enough money to withdraw from the program). Many of these same reimbursement concerns also appear to apply to providers.

In addition to concerns about the adequacy and equitable distribution of payments, Medicaid agencies voiced interested in building reimbursement systems that not only minimize disincentives that interfere with the provision of care but that also create incentives for MCOs to improve their care. These issues are addressed in this chapter through a discussion of the following topics:

- Capitation Payment Strategies
- Risk-Sharing and Reinsurance
- Financial Incentives
- Blended and Coordinated Funding

- Payment to Providers

The payment strategies listed above are used alone or in combination to ensure appropriate payment. For example, Michigan pays the MCOs participating in its CSHCS program prospective capitation payments that vary by health status, offers risk-sharing (currently in the form of a no-risk contract), and will pay financial incentives if the MCOs reach certain goals.

Payment method is clearly an important piece of the CSHCN system. Since our site visits, an MCO in one of the site visit states has withdrawn from the Medicaid managed care program, citing lack of adequate compensation as a reason for withdrawal.

Capitation Payment Strategies

Capitation payment strategy is the primary method Medicaid agencies in the site visit states use to ensure that MCOs that serve a greater proportion of CSHCN receive a greater proportion of the funds available. Medicaid agencies accomplish this by varying the capitation rate they pay for an individual enrollee based on a range of factors related to the likely cost of serving the enrollee. In other words, they pay more for an enrollee who is likely to cost more.

The factors states use in this determination can be divided into two categories: demographic (age, sex, etc.) and enrollee health status. Either type of factors can be used to distribute funds in proportion to the population served, as required in the Interim Criteria. The site visit states seemed to agree, however, that demographic factors by themselves may not be sufficient and that Medicaid agencies need to develop a system that incorporates health status as a factor in capitation payment. Of course changes to the system need to be carefully considered.

- Enough enrollees must belong to each rate cell to ensure statistical validity, yet the cells must divide enrollees into enough groups to ensure that payment truly reflects cost.

- The system must be relatively easy to administer for both the Medicaid agency and MCO.

- The MCOs must understand the system and the rate calculation in order to be assured that they will be paid appropriately.

Demographic Factors

As Table 17 indicates, all of the site visit states vary their capitation payments to MCOs by a series of demographic variables. (PHP reimbursement is separately discussed.) As previously noted, this variation is meant to ensure that MCOs receive higher payments for those who cost more. For example, the capitation payment for an SSI eligible child is higher than that for a TANF child. By varying capitation rates by eligibility group and age, Medicaid agencies have found that, using only information that they carry in their MMIS systems, they can accommodate much of the variation in cost between CSHCN and other children.

Table 17: Factors by which Medicaid agencies vary capitation payments to MCOs

State	CO	CT	DE	MA	MI	NM
Age	U	U	U	U	U	U
Sex	U	U	U	U	U	U
Geography	U	U	U	U	U	U
Eligibility Group	U		U	U	U	U
Health Status	U		U after 1/00, for SSI only		U CSHCS program only	U

Because the number of enrollees in the rate cells created by demographic factors is usually quite large, the information the rate cells are based on is likely to be statistically valid. Demographic factors are also relatively easy to administer as they are almost always recorded in the Medicaid agency's eligibility subsystem. However, too many people in some rate cells can make it difficult to ensure that payment totally reflects variation in cost among the people who make up each rate cell. For example, a state might pay one rate for all female children under age 18 in a given county. While the rate would be based on a large enough population to ensure statistical validity, there are likely to be very wide variations in cost among the members of that rate cell. Using only these variables, a Medicaid agency would pay the same amount for a ventilator dependent child as for one with attention deficit disorder. Making finer distinctions requires the use of heath status as a variable, as described in the next section.

Purchasing agencies in the site visit states are less likely to vary the capitation rates paid to BH/PHPs by these same factors. For instance, the two states with BH/PHPs have less concern about the role of health status in their rates as they either use only one contractor in a geographic area (Colorado) or in the entire state (Massachusetts). As a result there is no division of financial resources among multiple contractors in a geographic area. So there need be no concern that one contractor will enroll a more costly population than another. Colorado's Mental Health agency only varies the capitation payments made to its county-level BH/PHPs by geography and eligibility category. This State expressed some concern that varying the rate by geography perpetuated historical division of resources. (BH/PHPs operating in areas where people had little access to care before the managed care program do not receive the resources they need to improve access because payment is based on historical costs in the county.) Colorado is working to develop a method for addressing this concern.

Health Status

The Medicaid agencies in Colorado and New Mexico have further refined their capitation payment systems for all their MCOs by implementing systems that vary capitation payments by enrollee health status. Michigan also uses health status in its payments to the MCOs participating in the special program for Title V children but not for those participating in the State's general MCO program. The other site visits were all either considering or implementing such systems. Delaware implemented a system for adjusting payments made for SSI enrollees by health status on January 1, 2000.

Colorado and Delaware use the Disability Payment System (DPS). Michigan uses a variation of this system developed for the State by the creator of the DPS system. The DPS assigns enrollees to various cost categories based on the diagnoses listed on encounter records or claims submitted for services. These agencies reported selecting this system because it was based upon Medicaid specific information from a number of states.

In order to simplify administration, encounter/claims information is not examined every month. Rather, these agencies periodically examine a "snapshot" of an MCO's/eligibility category's enrollment composition in order to establish new rates. In Colorado, for example, the following basic process is used to adjust rates for health status. (As previously mentioned, Colorado uses the DPS to adjust payments for health status and also adjusts for other factors such as age and sex. Please note this description is a simplified version of the process since this report is not targeted to those involved in the technical aspects of rate setting.)

1. The developers of the DPS analyzed Medicaid data from several states to determine which diagnoses were good predictors of future high costs. They found that 2,400 diagnoses were good predictors and divided these 2,400 codes into 43 separate categories based on illness and body part indicated by the code. They also established a category for "no diagnosis."

2. Colorado then analyzed its historical fee-for-service claims data to determine the relative impact on the future cost of serving an individual who belonged to one of the 43 diagnostic groups. Membership in one of the groups was determined by the presence on at least one claim submitted for the individual of one of the 2,400 diagnoses codes (or "no diagnosis") that make up the groups. People belonging to more than one group were counted in each group.

3. Every six months the previous twelve months of encounter data from each MCO are analyzed to determine how many enrollees in each MCO belong to one of the 43 major diagnostic groups (using the methodology described in Step 2 above).

4. The information about the impact on future costs of enrollees who belong to each of the 43 categories is combined with the relative concentration of members of these groups among each MCO's enrollment to produce MCO specific capitation rates that account for the health status of the individual MCO's enrollees. This is done for each major eligibility group within each MCO.

5. The Medicaid agency pays the specific rate calculated for each eligibility group within each MCO for the next six months and then begins again the process of producing a new set of health status adjusted capitation rates.

Michigan uses a different approach for making health status adjusted payments to MCOs participating in its program for Title V children (including Title V children who also receive Medicaid). This State had information for calculating payment for this program from both the Title V and Medicaid agencies. Studying the costs of potential enrollees in its specialized program, Michigan found that most of the variation in the cost of caring for individual enrollees could be attributed to:

- the child's qualifying Title V diagnosis (if the child was over one year of age when he or she qualified),
- the existence of private insurance, and
- the child's need for in-home nursing care.

As a result, Michigan established capitation rates for the MCOs participating in the specialized program that vary by these factors. Unlike Colorado, the information is not collapsed to produce an MCO specific rate. Instead, each enrollee is assigned, upon enrollment,[39] to one of four diagnostic groups based on the Title V qualifying diagnosis and to a fifth diagnostic group if the child needs in-home nursing care. Two pre-established rates exist for each of the five diagnostic categories. One rate is paid for each member of the diagnostic group who has private insurance and another, higher rate, is paid for each member of the group who does not have private insurance. The same rates are paid regardless of the specific MCO the child chooses to join. The Title V qualifying diagnosis is re-examined every year when families apply to continue their Title V eligibility.

Both MCOs and Medicaid agencies reported satisfaction with these systems as a means for fairly distributing funds among MCOs. Almost all MCOs and a few Medicaid agency informants raised the overall low funding of the Medicaid managed care program as an area of concern. This has also been an issue in at least two of the states that are considering implementing health status adjusters. As one MCO noted: "Insufficient funds are insufficient funds no matter how they are divided up."

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[39] Because children must apply for and receive Title V services in order to participate in the plan, qualifying diagnosis are available for all enrollees. This situation would not exist in other programs.

Issues in Calculating Capitation Rates

The belief that resources are insufficient almost always arose from the Federal requirement for an Upper Payment Limit (UPL). The UPL is the maximum amount that can be paid to MCOs under a managed care waiver. According to Federal regulation, this amount may not exceed the amount that would have been spent on fee-for-service to provide care to the enrolled population.

Several site visit states saw the UPL as a growing problem for the following reasons.

- The UPL does not allow Medicaid agencies to compensate MCOs for the administrative requirements they must meet to participate in the program, requirements that do not exist in the fee-for-service system (quality program requirements, submission of encounter data, etc.).
- The UPL does not allow for pent up need. In other words, if the fee-for-service system provided poor access to care, the historical cost of caring for beneficiaries on fee-for-service would be artificially low. If MCOs contract with sufficient providers to improve that access, they will spend more money than was spent on fee-for-service, but the UPL would prevent Medicaid agencies from paying the MCOs more.

- The UPL does not allow state agencies to compensate MCOs for providing critically important enabling services, such as care coordination, that are not provided in the fee-for-service system.

- Finally, as more beneficiaries are enrolled in MCOs, less information is available regarding the costs of enrollees on fee-for-service. As a result, the UPL calculation has to rely on projections from increasingly older data.

In addition to these concerns, in at least one state the Medicaid agency and some MCOs disagreed about the method used to project the UPL. This State based its projections on fee-for-service data for those beneficiaries who remained on fee-for-service. The MCOs did not feel this was a good way to project the costs of serving those who were enrolled in MCOs. Nor did the MCOs feel that the State's projection method adequately represented increases in costs due to utilization increases. Other states mentioned the importance of bringing MCOs into the UPL calculation process so that they better understand the basis of the calculation. One state even asserted that the need to ensure that the MCOs understood the calculation was more important than the technical aspects of the calculation.

Risk-Sharing and Reinsurance

Risk-sharing and reinsurance are means of accommodating unexpected variations in cost. By their nature, unexpected variations in costs cannot be accommodated by capitation payment which depends on explainable variation in cost. Use of these strategies may be particularly important for CSHCN who have a wide range of cost experience.

Among the site visit states, Connecticut and Massachusetts offer risk-sharing pertinent to CSHCN to the general MCOs. Connecticut addresses the cost of inpatient psychiatric stays, especially those stays that are necessitated by the lack of another place for the child to live. The issue of children remaining in the hospital because of no available alternative placement came up in a number of the site visit states. However, only Connecticut had established a risk sharing arrangement to accommodate it. This State pays 75% to100% of the costs of medically necessary stays beyond 15 days and 100% of all administratively necessary days.

Massachusetts provides risk corridors for all MCOs serving SSI beneficiaries. In other words, if the overall cost to an individual MCO of caring for SSI beneficiaries (adults and children) as a whole exceeds a certain amount, the Medicaid agency will pay the MCO more. On the other hand, if the overall costs are lower than a certain amount, the MCO returns money to the Medicaid agency.

Massachusetts and Michigan both offer risk-sharing to the specialized health plans that serve only CSHCN. Both programs[40] are currently operating under no-risk contracts. If they lose money serving enrollees, the Medicaid agency will cover the MCO's loss. Conversely, the MCOs in these programs cannot make a profit. Both the MCOs and Medicaid agencies in these states reported that a no-risk contract allows them to pilot a new project and develop new care delivery systems with confidence that neither will lose money. Both states plan to move to risk corridor arrangements in the future, but the specifics of these arrangements have not yet been defined.

Finally, at least one state (New Mexico) required MCOs to obtain commercial reinsurance from a private company. The reinsurance coverage must be sufficient to cover probable outlier cases or over-utilization that is greater than expected.

Financial Incentives

Medicaid agencies and others express growing interest in using incentives to manage MCO and PCCM provider behavior. Some of these incentives are not bonus payments but other types of "rewards" that can ultimately increase the MCO's income. For example (as discussed in the Enrollment chapter), Michigan and New Mexico do not pay a financial bonus to general MCOs that perform well in annual quality reviews and on specific HEDIS measures. Instead, these states reward high performance by assigning more of those beneficiaries who do not choose an MCO to the MCOs with the best

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[40] The Massachusetts program mentioned here is a pilot program.

performance, increasing the enrollment of these MCO's and, consequently, the total amount paid them in capitation payments .

Three of the site visit states reported establishing financial incentives related to MCO performance relevant to CSHCN. These are shown in Table 18.

Table 18: Financial incentive arrangements in site visit states

State	Incentive Arrangement
CT	1% of capitation rate paid to MCOs is withheld to be paid based on individual performance in EPSDT participation, dental access, consumer satisfaction (including a separate survey of CSHCN parent satisfaction), and behavioral health outcomes
MA	Established a series of financial incentive and penalty payment for the behavioral health PHP which could result in additional payments to the BHO of $6.7 million. If all, 19 goals were achieved; several of these goals relate to serving children in foster care and other CSHCN.
MI	The Special Health Plans will receive a bonus equal to 1% of total capitation paid to the plan for each of the following goals they meet and will be assessed a 1% penalty for each goal they fail to meet. • complete 99% of Individual Health Care Plan within 60 days • 99% of enrollees choose care coordinator within 60 days • 99% of enrollees choose PCP within 60 days

In two of these states, both the Medicaid agency and the contracted MCO commented that they thought these arrangements were successful because they helped both parties identify what was most important for the program and contractor to achieve.

Coordinated Funding

Several informants expressed concern that there were not enough resources in a single system to provide for the needs of CSHCN. There was also a continuing theme throughout our site visits of "finger pointing" among the agencies that serve CSHCN. For example, in all of the states we visited, at least one, and usually several, informants expressed concern about therapies. The disagreement usually centered around whether the therapy was medically necessary and should be provided by the MCO or whether it was educationally necessary and should be provided by the school (Part C program).

This same issue turned up between MCOs and various other agencies in each of the site visit states. For example, in at least two states the Child Welfare agency and the MCOs had issues around payment for inpatient stays, some of which may have been due to lack of an alternative placement for the child. Similar disagreements arose between the MCOs and Juvenile Justice system, Title V agency, and Early Intervention programs in at least one of the site visit states. Finally, similar disagreements were found between private insurers and MCOs, and private insurers and other state agencies that serve CSHCN. In the midst of this disagreement, it is possible that a child could fall through the cracks and not obtain the needed service from any agency. These disagreements certainly add to parents' stress and uncertainty over who, if anyone, will pay for certain services.

As discussed in the Coordination of Care chapter, the boundaries between agencies and MCOs may need more clarification, and a system may need to be developed for resolving individual disagreements. However, another potential solution was mentioned by a few informants who suggested that by coordinating funding and making a single entity responsible for a broader package of services, border issues might more easily be resolved. Several informants commented that the separate flow of funds to agencies and providers and the consequent separate reporting back to funders (usually federal agencies) prevented any agency or MCO from treating the child as a whole. Also, one informant felt that making a single entity responsible could have the added benefit of combining (and as a result reducing) the administrative costs of the programs. This could free up additional funding for services.

As shown in Table 19, a few of the site visit states reported that they had successfully coordinated funds. In all instances, the agencies and the MCOs reported satisfaction with the results of the arrangement. Most of these arrangements are for the full package of services provided by the two agencies. However, Massachusetts' arrangement was developed to address a specific issue that was of concern to the Child Welfare and Medicaid agencies.

Table 19: Coordinated funding arrangements in site visit states

State	Coordinated Funding Arrangement
CO	Mental Health PHPs receive capitation payments from Medicaid and Mental Health agencies, funds from both agencies are used by the PHP to provide all state-funded mental health services
	Some MCOs have begun contracting with the Title V agency to provide care coordination. In these cases Title V and Medicaid MCO funding support the same staff who coordinate care for both organizations. The Medicaid agency also contracts with the Title V agency to fund specialty clinics (hearing aids, etc.) in rural areas. The clinics receive both Title V and Medicaid funding.
DE	Medicaid agency pays the Children's Mental Health Agency a per user per month bundled payment to provide mental health care to children. This is combined by the Mental Health agency with other state funds to provide children's mental health services to Medicaid and non-Medicaid eligible children
MA	Child Welfare and Medicaid agency both pay the behavioral health PHP. The PHP uses this funding to provide a range of services (Medicaid and non-Medicaid covered) to children in foster care, including establishing Transitional Care Units (new service) to allow intermediate placement of foster care children in hospital who are leaving the inpatient setting but for whom a residential placement is not available. The Medicaid agency pays for the portion of the service that is medically necessary and the Child Welfare agency pays for the remainder.
MI	Both the Title V agency and the Medicaid agency pay capitation to the two Special Health Plans that serve only Title V beneficiaries (both those that also receive Medicaid and those that do not). The Title V agency pays for all enrollees, and the Medicaid agency pays for those who are Title V and Medicaid eligible; about 50% of MCH block grant goes into the Title V agency's payments; MCOs provide both Medicaid and Title V services.
NM	The Child Welfare agency and the Medicaid contracted MCOs are coordinating funding to provide "multi-systemic therapy" to children in foster care. This is a very intense level of therapy that is not a Medicaid benefit but that the Child Welfare agency and the MCOs believe will be of benefit to the children they both serve.
	The Child Welfare and Medicaid agencies, as well as the Medicaid contracted MCOs, are jointly developing a partially grant-funded project to better link school-based health services (including primary care) to the PCP. The school-based health center will ultimately receive funding from all three partners in the effort to provide health care to children in the school.

Payment to Providers

Another reimbursement issue that several key informants, especially providers, mentioned was the issue of payment to providers. Although MCOs receive a prospective capitation payment from the purchasing agency, the payment arrangements between providers and MCOs vary greatly. This is true even within the same MCO. For example, the MCO may pay a capitation payment to primary care providers for primary care services but reimburse specialists and others through a fee-for-service arrangement. Other MCOs may reimburse all providers through a fee-for-service arrangement. Finally, some MCOs may pay separate, and different, capitation payments to several different, perhaps all, types of providers including: primary care providers, hospitals, DME providers, etc.

Payments by MCOs to providers were subject to the same concerns as payment from the state to the MCO. The concern is, once again, do enough resources exist in the system and are they fairly divided among providers?

In theory, MCOs could address the issue of fair division of resources by adjusting the capitation rates they pay to providers by health status. No provider reported that any MCO did so. At least two providers reported that the capitation payments they received from the MCO for provision of primary care were not adjusted by health status. Both providers were located in states where the MCOs also did not receive health adjusted rates from the Medicaid agency. Both reported they were losing money because the capitation payment they received for serving primarily CSHCN was the same as that received by other primary care providers who did not serve many CSHCN. One of these providers was mentioned by several key informants including both the Medicaid agency and MCO as an “exemplary” provider of care to CSHCN. Neither provider felt that capitation was an unworkable system for them. They did feel, however, that the amount paid by the MCO needed to recognize the population they served. This is much the same argument that MCOs in these states make to the Medicaid agency regarding MCO payment.

None of the purchasing agency or MCO informants in the site visit states reported addressing this issue. Some felt that it was inappropriate for the agency to do so because it would be too great an interference in MCO negotiations and operations, and the agencies would prefer to manage through outcomes. It is possible that Insurance agencies in some states regulated the amount of risk that MCOs could pass on to providers, but no informant mentioned that during the site visits.

The issue of fair division of resources is of slightly less concern among providers who receive fee-for-service payments from the MCO. In this situation, those who provide more or more intensive services will bill more frequently and for those more intense services. As a result, providers who serve CSHCN will receive a greater proportion of available resources than those who do not. This reimbursement method does not totally resolve the issue. Several providers pointed out that it takes longer to serve a

CSHCN than it does other children and that even the amount paid for an extended visit does not adequately reflect the time it takes to care for CSHCN.

The issue of adequate resources is an issue both in situations where the MCO pays the provider via capitation and where the MCO pays the provider via fee-for-service. Provider informants questioned whether the Medicaid agency's payments to the MCO are sufficient and whether the MCOs devoted enough of the payment they received from the Medicaid agency to provider payment. Particular concerns were expressed about whether MCO administrative costs drew on resources that were formally available for provider payment. Although no provider specifically mentioned the UPL as a barrier, concerns such as lack of payment for administrative costs that do not exist under fee-for-service (i.e., quality studies, encounter data production, etc.) are the same as those raised by others regarding the barriers created by the UPL.

Reimbursement in Fee-for-Service and PCCM Programs

Reimbursement for PCCM and fee-for-service are both discussed here because, in those site visit states with PCCM programs, they are essentially the same method. One of the states reimburses PCCM providers at fee-for-service plus a small case management fee. The other reimburses solely through fee-for-service but enhances the rate paid for preventive office visits.

The concerns discussed in the last section about fee-for-service payments by MCOs to providers also exist for fee-for-service payments by Medicaid agencies to providers. Provider informants reported that Medicaid agencies frequently pay low rates for services in comparison to other payers. Most Medicaid agencies reported having sought, with varying levels of success, additional funding to raise rates paid to some providers but felt that their rates were still low relative to other payers in the state. Finally, some providers that specialize in serving CSHCN again expressed concerns about fair division of existing resources in the Medicaid fee-for-service system. These providers reminded us that it takes longer to serve a CSHCN than it does other children, and they did not feel that the current CPT classifications of office visits adequately reflected the time it took to care for CSHCN.

Payment: Summary of Study Question Findings

Can states meet the Interim Criteria regarding payment methodology?

Site visit states already met the Interim Criteria requirements for payment methodology. The Interim Criteria requires states to develop a payment methodology that accounts for special needs populations enrolled in capitated managed care. All had done so. Most used the relatively simple method of varying payment by eligibility group and age. There also appeared to be a growing consensus among the states that capitation payments need to be adjusted by health status in programs that serve people with special needs; those states that did not have such a system at the time of the site visits were either developing or considering one. Finally, some states also used risk sharing to account for unpredictable costs. Others were beginning to use reimbursement to create incentives for MCOs to better serve these children.

The Interim Criteria do not address PCCM programs since they are not capitated. However, state practice in reimbursement for PCCM programs is much the same as that for fee-for-service programs and the same concerns exist for both.

How do state reimbursement practices in fee-for-service system address the needs of CSHCN?

There was less concern about fair distribution of existing resources in the fee-for-service system. Providers bill the Medicaid agency for the number of services they provide, and if they provide a more intense service, their billing reflects that. However, there is some argument that caring for CSHCN takes even more time and resources than is reflected in the existing billing codes. There is also concern that Medicaid payments in general are too low to ensure that providers are reimbursed adequately for the services they provide.

How do state practices in managed care reimbursement vary according to state characteristics?

Little variation exists among the site visit states in reimbursement practices by state characteristic. There is, however, variation by program type. Those programs that use a single contractor to serve all enrollees in a geographic area are less likely to vary capitation payments by demographic or health status because there is less need to do so. Both of the specialized programs for serving CSHCN were using no-risk contracts at the time of the site visits. They were not used in any of the other programs. Also, coordinated funding was more likely to occur in the specialized programs that deliver only behavioral health services than in programs where MCOs delivered comprehensive services.

Do the Interim Criteria on payment methodology address the most significant issues faced by children and their families?

Children and their families identified the following concerns related to reimbursement.

- Payment should be adequate and fairly distributed.

- MCOs and other agencies that also serve CSHCN need to work out who is responsible for payment of some services.

The Interim Criteria for payment methodology address only the issue of fair distribution of payment to MCOs. However, the other issues may be beyond the scope of the Interim Criteria. The issue of adequate Medicaid payment to MCOs is governed by:

- the UPL, which would require a change in federal regulation to address;[41] and
- overall state funding priorities, which are generally decided in the Legislative branch of state governments.

Payment responsibility and coordinated funding are related issues. Working out both would require the cooperation of a number of state agencies that do not report to HCFA. It may also require the cooperation of their respective federal oversight agencies. However, informants agreed that clarifying the payment responsibilities of various programs that serve CSHCN and their families was extremely important. Finally, informants who were involved in efforts to coordinate funding found them to be effective ways of leveraging existing resources to better serve CSHCN.

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[41] HCFA reported that at the time of the report it was is in the process of changing federal regulation regarding the UPL.

IX. STAKEHOLDER INPUT

Interim Criteria

Concerning stakeholder input, the Interim Criteria require that:

The State has in place a public process for the involvement of relevant parties (e.g., advocates, providers, consumer groups) during the development of the waiver program and has sought their participation in that process.

Introduction

Stakeholder input can be invaluable to implementing, operating, and evaluating programs. Stakeholders can be particularly helpful in helping Medicaid agencies better craft programs that meet the needs of special populations because stakeholders may have more in-depth knowledge of the needs of special populations and the local delivery system than do state Medicaid officials. Stakeholders can include anyone who has an interest in the delivery of care to CSHCN: families, consumers, providers, advocacy groups, community organizations, state agencies, MCOs, and the general public.

All site visit states recognized the benefit of stakeholder input on managed care program operations by establishing numerous methods for obtaining that input. Few of these efforts focus solely on CSHCN or others with special needs. Also, a range of stakeholders usually participates in each effort. Each of the efforts discussed below provided input to the Medicaid agency on matters concerning CSHCN. This analysis does not include efforts by the Medicaid agency to inform stakeholders about their programs. It addresses only those efforts that were undertaken specifically to gather information from stakeholders. All of the efforts discussed here, as well as those designed primarily to provide information to stakeholders, are described in more detail in Appendix C.

Table 20: Strategies for obtaining stakeholder input

State	**CO**	**CT**	**DE**	**MA**	**MI**	**NM**
Advisory Committees/Meetings	**U**	**U**	**U**	**U**	**U**	**U**
Hiring Consumers	**U**				**U**	**U**
Special Activities During Waiver Development/Contractor Selection Process	**U**	**U**	**U**	**U**	**U**	**U**
Consumer Surveys/Focus Groups	**U**	**U**	**U**	**U**	**U**	**U**

As Table 20 indicates, Medicaid agencies are most likely to use advisory committees and consumer surveys/focus groups to obtain input from stakeholders on an ongoing basis. Also state Medicaid agencies uniformly conduct special activities during the waiver development/contractor selection process. However, the site visit states reported hiring consumers less frequently.

Advisory Committees and Meetings

Of the two methods most used by the site visit states to obtain stakeholder input on their program operations, Medicaid agencies cited the use of advisory committees and meetings as their preferred source for ongoing input from stakeholders. These committees represent a range of stakeholders and generally provide information on many aspects of program operation and evaluation, not simply the development of the waiver request. However, these committees usually do provide input to that process as well as the more operational aspects of a managed care program.

Table 21: Use of ongoing advisory committees and meetings in Medicaid managed care

State	CO	CT	DE	MA	MI	NM
Medicaid Advisory Committee Reviews Managed Care Policies Related to CSHCN[42]	U		U			U
Managed Care Advisory Committee Initiated by Medicaid agency	U			U	U	U
Managed Care Advisory Committee Initiated by Another Government Agency	U	U	U			
Managed Care Advisory Committee Initiated by Consumers			U	U		
Plans Required to Include Consumers on Boards	U				U	U

Groups Established by the Medicaid Agency or MCO

Three site visit states got input from their Medicaid Advisory Committees (MAC) on their managed care program operations, as well as, their overall Medicaid policies. Colorado and New Mexico

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[42] All states are required to establish Medicaid Advisory Committees (MACS) to advise the Medicaid agency on its policies and operations. Primarily providers and consumers are invited to become members of the MAC. These members serve for a pre-specified length of time.

asked the parent of a CSHCN to sit on the MAC and represent that special needs group. Colorado also established a MAC for People with Disabilities (MAC-D) specifically to review Medicaid policies (fee-for-service and managed care) for their impact on adults and children with disabilities. The MAC-D also selects the topic for one of the special studies the State's EQRO conducts each year.

Medicaid agencies in four site visit states also established groups that include parents of CSHCN specifically to advise on their managed care programs and sometimes portions of that program, such as the development of studies of the quality if care provided to CSHCN and others. Most of these groups also include MCOs, advocates,[43] providers, and other state agencies[44] that serve CSHCN. The New Mexico group meets on an informal basis, while those established in the other three states are formally established committees. Colorado and Massachusetts both have several groups for various purposes. Michigan's group is difficult to classify as it was established by the Title V agency, which operates the specialized program that serves Title V children, primarily to advise the agency on the operation of that program. However, since the Medicaid agency and Title V agency both belong to a single department, the Medicaid agency has also used this committee to advise them on its general MCO policies.

Among the site visit states, Colorado makes the heaviest use of the Medicaid agency established committee approach (as measured by number of Medicaid established committees for various purposes). The Medicaid agency in this State

- modified their MAC to better represent CSHCN;
- established a special MAC for people with disabilities;
- established the Disability Working Group specifically to advise them on contract development each year;
- established an advisory committee with a membership of 50% parents and consumer advocates for a three-year grant project to help them improve care coordination for children with special needs; and
- established several other advisory groups for people with disabilities to advise them on specific projects such as developing HEDIS-like measures for people with disabilities.

The Medicaid agency views the work of these groups as integral to their program's function. This State involves stakeholders, including parents of CSHCN and MCOs, in almost all aspects of their planning, including the planning of quality improvement studies. This State does not develop the policy or study and then have the groups review the result but rather involves stakeholders from the beginning of the process. Both the Medicaid agency and advocates and consumers involved in this work report

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[43] Examples of advocacy groups often included by Medicaid agencies are: Family Voices, Developmental Disability Councils, and ARC.

[44] Examples of other state agencies Medicaid agencies frequently included in these groups are: Title V, Child Welfare, and Education.

satisfaction with this approach. (Other stakeholders who were not involved in this work reported being unaware of these efforts and, as a result, were not satisfied with the process.) The Medicaid agency finds that the consumers provide valuable insight. By participating in ongoing groups, involved stakeholders can learn about the topic and issues over time. Advocate and consumers know that they have a real impact because they see many of their ideas and suggestions put into place, and the on-going involvement provides them the opportunity to understand why other of their suggestions are not implemented. This can be a difficult balancing act for the Medicaid agency as it is important for ongoing relationships that all stakeholders know that they have the "ear" of the Medicaid agency, not just those involved in committees.

Establishing and staffing these groups requires time and resources from the Medicaid agency. These groups need to get feedback and may need time to learn enough about an issue to make an effective contribution. Also, many parents are very busy taking care of their children and, for them and others, finding the time and freedom to attend these meetings can be difficult. As one advocate noted, "This works well for those that are in the loop, but not everyone is in the loop." The Medicaid agencies that established these groups similarly say that it is difficult to involve those other than the "usual suspects."

Although the states find establishing ongoing advisory committees to be an effective way of obtaining the information they need to allow them to better address the needs of CSHCN, they have found that they cannot rely on them as the sole method of obtaining input because the stakeholders participating in the committee may not be fully representatives of those enrolled in the program. (Site visit states have tried, with varying degrees of success, a number of methods of encouraging participation in these activities. Strategies have included providing a meal as part of the meeting, paying for the expenses associated with attending the meeting, and holding meetings during evening hours.)

Two of the site visit states have taken this integration of consumer input into the program to a further level. These states require MCOs to establish consumer advisory boards. In addition, Michigan requires the Special Health Plans it contracts with to serve CSHCN to have at least one board member who is a consumer. The two states with MCO-level boards report that these can be effective, but that their effectiveness depended on the commitment of the individual MCO to making them work.

Medicaid agencies also reported some difficulties in involving other state agencies that care for CSHCN. The specific agency varied from state-to-state but the difficulties generally seemed to stem from two sources.

- Historical "turf" issues that can get in the way of the two agencies working together on any project may cause both sides to view the other as insincere in these efforts.

- Reluctance to accept the idea of managed care as a means of serving CSHCN, much less view it as a potential benefit for these children, may mean that some agency staff do not make the necessary effort to provide constructive input.

Groups Established by a Government Agency Other Than Medicaid

Four site visit states reported advisory groups that were established by a government agency other then the Medicaid agency. In these states, stakeholders report that the committee is valuable because it is seen as a neutral group that all stakeholders can trust.

Three site visit states used groups established by entities to which the Medicaid agency reports. Connecticut had two advisory committees established by the legislature. Delaware had two established by the Governor (one of these only operated during program implementation). In one state this affected the dynamics of the group and program functioning. Some MCOs in this state reported that they were not sure to which agency they reported (Medicaid or advisory). Both the Medicaid agency and the MCOs also reported that they felt that the committee sometimes overstepped its advisory role. Other stakeholders felt these groups were effective in making the program more responsive to the needs of consumers. Finally, Colorado has an advisory committee established by HCFA's regional office that addresses state-level issues.

Connecticut and Massachusetts reported using advisory groups that were established by sister agencies. In Connecticut, both the Child Welfare and MCH agency established advisory committees that include the Medicaid agency, MCOs, consumers (including parents and foster parents of CSHCN), and providers. Massachusetts' Child Welfare agency established a similar group to guide the development and operations of their *Special Kids* **Ì** *Special Care* program for foster children with very complex medical needs. The Child Welfare agency and MCOs in Connecticut both report that the committee established by the Child Welfare agency has been particularly successful. The meetings have resulted in a better understanding by the MCOs of the special needs of children in foster care such as:

- the importance of obtaining an exam by experienced providers soon after removal from the home;
- an above average need for mental health services;
- the need for efficient transfer of records upon placement changes;
- the potential need for additional services or medications to make placement changes go more smoothly; and
- the need to establish extra confidentiality protections for these children.

Several of these issues have been addressed by the committee and by efforts the Child Welfare agency has worked on with individual MCOs. For example, the Child Welfare agency and MCOs developed a system to provide extra protection to sensitive information about the children in foster care but still allow foster parents to access the information they need to care for the children. Also, one MCO developed a special brochure to help foster parents more quickly recognize signs that might indicate a child's need for mental health services.

Both the agency and the MCOs reported that a key to the success of this group was that the Child Welfare agency felt that the existing system used to deliver care to children in foster care was not working well, viewed the MCOs as potential vehicles to improve that care, and wanted to work with the MCOs to make sure that happened. It was also helpful that the Child Welfare agency and MCOs all soon realized that many of these children were "high utilizers," particularly of mental health services and that better care coordination (for example, by making sure that records were transferred) and earlier intervention (allowing outpatient rather than inpatient care and preventing the breakdown of placements, for instance) would pay off relatively quickly.

Groups Established by a Non-Government Agency

The Medicaid agencies in Delaware and Massachusetts regularly attend meetings established by agencies outside the government. In Massachusetts, the Medicaid agency attends meetings of the Consortium for Children with Special Health Care Needs. This group is convened by New England SERVE and allows for discussion of the issues related to serving children with special health care needs by state agencies, advocacy groups, parent groups, and health care providers. The Medicaid agency has found involvement in these activities provides them information they can use to improve their program. For example, this group is developing a definition of care management. The group has found Medicaid's involvement to be beneficial because the agency is a major funder of care provided to CSHCN and, as a result, has much experience to contribute. The Medicaid agency is also a member of the advisory group for the Pediatric Alliance for Coordinated Care and is working with that group on data sharing to better inform their understanding of caring for children with special needs at community-based pediatric settings.

In Delaware, the Medicaid agency, enrollment broker, and MCOs regularly attend meetings of the Delawareans with Special Needs: Medicaid Managed Care Panel. This group was established by parents of CSHCN to advise the Medicaid agency on the transition to managed care and the needs of children with disabilities. After implementation, the monthly meetings continued, but the focus switched to program operations and evaluation. The parents, the Medicaid agency, and the MCOs reported that they find the meetings a valuable forum to identify and problem-solve issues related to CSHCN (both as individuals and as a group). Often, problems are resolved simply by the exchange of information. For example, one parent reported that she learned that MCOs had to continue services during an appeal of service denial at this meeting. MCOs also reported learning the nuances of Medicaid covered services for CSHCN through a discussion of common problems.

The parents in the group felt that the presence of the Medicaid agency (as the purchasing agency and interpreter of the contract) and the MCOs (as those responsible for delivery of care) are necessary to the group's effectiveness. It is also worth noting that although this group was established by parents, it encountered the same problems in obtaining broad representation of parents of CSHCN enrolled in Medicaid managed care as those established by other agencies. None of the parents at the first meeting of this group had children who were enrolled in Medicaid managed care.

Hiring Consumers

Medicaid agencies in three site visit states hired consumers (parents of CSHCN who were themselves not receiving Medicaid and staff of advocacy organizations) as a way of obtaining stakeholder input. All three were very pleased with the results and found them an effective way to further integrate consumer input into their managed care programs. No state reported hiring consumers to advise them on their PCCM or fee-for-service programs. The three states used two different models of hiring consumers.

In Colorado and Michigan parents of CSHCN were hired as state or plan staff. Colorado used grant funds to hire two parents for the term of the grant. (This State is now seeking permanent funding for this position.)   Michigan hired parents as staff at the State level and also required it's Special Health Plans that serve only children receiving Title V services (regardless of whether the child also receives Medicaid) to hire consumers as staff. Both of these states use these staff to provide outreach to families, develop informing material relevant to parents of CSHCN, and advise them on how program policies will affect CSHCN and their families. In addition to the personal understanding of the needs of CSHCN that these staff members can offer, they also provide better access to the opinions of other parents who are more likely to discuss their concerns with someone who "has been there."

New Mexico hired consumers by developing contracts with six CBOs, such as the ARC of New Mexico. These contractors were at first hired to inform their constituencies about the new managed care program and identify providers that were especially important to their constituencies so that MCOs could make extra efforts to recruit them.

The Medicaid agency found that these groups could get better access to their constituencies than they could. Not only did the groups have a more up-to-date mailing list, but families were used to turning to these agencies for advice. As a matter of course, families turned to the CBO for advice about what to consider when selecting an MCO. The Medicaid agency also found the input of these contractors valuable during program phase-in. These groups were aware of common practice patterns and were able to advise the Medicaid agency when it was important for MCOs to have contracts with providers who were not located in the phase-in area to protect continuity of care for children located in the phase-in area.

At the time of the site visits the role of these CBOs was growing to include an element of evaluation. For example, several of these contractors are currently charged with conducting focus groups to better understand the experience of their constituencies in managed care. The Medicaid agency feels that the existing relationship between the contractors and the families of CSHCN will enable them to gather a more representative group than the agency or other contractors would be able to gather. The participation of the CBOs was viewed as an enhancement by both consumers and the MCOs.

Waiver Development/Contractor Selection Process

All six states made special efforts to involve stakeholders in the waiver development or contractor selection process. All of the site visit states distributed to numerous stakeholders documents for comment, among them waiver requests, Requests for Proposals/ Information,[45] and contracts. These efforts tended to be less formal than the public comment most states incorporate into their general Medicaid rulemaking process.

Purchasing agencies (Medicaid and sometimes the Mental Health agency) generally mail these documents to advocates, providers, consumers, other state agencies and anyone else who requests a copy. Several agencies, such as Colorado's Mental Health agency, also post these documents on their agency's Website so that anyone who has access to the Internet may comment. Others solicit comments during special meetings. For example, Michigan's Medicaid and Title V agencies held over 80 meetings in various parts of the state to solicit input during contract development, and Colorado's Medicaid agency held an all-day meeting review each section of the contract with advocacy groups and others. These efforts can result in extensive input. For example, Colorado's Mental Health agency reported that they received over 400 comments during the public comment period for the development of its new mental health managed care contract.

Connecticut was the only site visit state that reported a legislatively mandated notification and public review process for all managed care waivers. Following the public review period, the General Assembly's committees of Cognizance, Appropriations, and Human Services review the waiver document and all public comments and questions. Stakeholders interviewed in Connecticut felt that this process ensured that all members of the public could comment on the waiver document and be assured that their comments would be taken into consideration. Stakeholders further reported that review by the Committees provides them with recourse if they feel that the Medicaid agency has not taken their concerns seriously.

Finally, Michigan included consumers (adults with disabilities) in its readiness review team, the group that visits each MCO before the MCO is allowed to begin enrollment. The teams that visit the general MCOs include two consumers, and those that visit the Special Health Plans include three consumers.

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[45] Requests for Proposal/Information (RFP/RFI) are the documents that states use to transmit participation requirements to prospective bidders and the information the bidders must submit as part of the contractor selection process.

This process ensures that people who have experience as CSHCN contribute to the decision to allow Medicaid enrollment into each MCO.

Consumer Surveys/Focus Groups

Although consumer surveys/focus groups are discussed in more detail in the **Quality** chapter of this document, they are important to mention here. Consumer surveys and focus groups can be important vehicles for obtaining consumer input. A continuing concern voiced by many informants (both Medicaid staff and others) is the difficulty of obtaining input from a broad representation of consumers. Those who are among the poorer Medicaid beneficiaries tend not to be well-represented on advisory groups. Those who are not literate or speak a language other than English do not find it easy to comment on documents written in English. Those who are not used to speaking up for themselves or have had bad experiences in other systems may be reluctant to complain for fear of losing their benefits.

Site visit states identified consumer surveys and focus groups as a means of obtaining input from a broader group of CSHCN and their families, if they are developed and administered correctly. Those who have difficulty reading are unlikely to respond to a long written survey even if it is translated into a language they understand better than English. Also, telephone surveys can only reach those who have access to a telephone, which many Medicaid beneficiaries, especially those in very rural areas (such as reservations) may not have. Finally, surveys that only seek to determine over-all enrollee satisfaction are often not terribly useful; however, those that seek information pertinent to operational issues such as the wait for an appointment or a new wheelchair can be very useful.

Assessing the Effectiveness of Consumer Input Processes

Many informants mentioned that it is important that the purchasing agencies and MCOs not only obtain stakeholder input but that they use it. General consensus was that the best way to determine whether an agency or MCO had an effective process was to examine the changes they made as a result of the process. Most felt that demonstrating change was a better measure of the effectiveness of the stakeholder input process than the number and types of avenues available to gather input. All site visit states reported that they had changed their program, sometimes extensively, due to consumer input.

Stakeholder Input: Summary of Study Question Findings

Can states meet the Interim Criteria for stakeholder input?

The site visit states all already exceeded the Interim Criteria, despite the fact that none had renewed their waiver since the development of the draft criteria and were, therefore, not yet subject to these requirements. They all had multiple avenues for gathering stakeholder input into not only the development of the waiver program but also into the program's ongoing operations, including evaluation. They all included the three groups of stakeholders mentioned in the Interim Criteria (advocates, providers, and consumer groups). All also included consumers, MCOs, and at least one other state agency that serves CSHCN and their families (i.e.,Child Welfare, Title V, etc.). They all also demonstrated that they had made changes to their programs as a result of that input. Most of these efforts centered around the MCO programs. Several site visit states had also created avenues of ongoing consumer input into individual MCO operations.

In the two site visit states with PCCM programs, the Medicaid agencies used some of these same methods to gather input on those programs. However, less emphasis was placed on gathering stakeholder input on PCCM program operations than it was on MCO operations. This is due, perhaps, to the relative simplicity of the PCCM programs and their frequently limited impact on the ability of CSHCN to access services. Certainly, many consumers and providers expressed less concern about PCCM programs.

Despite existing extensive efforts, almost all site visit states expressed a desire to involve a broader representation of stakeholders. Some requested assistance in developing ways of involving more than the usual suspects, so that the concerns of all could be heard. Many Medicaid agencies reported that involving stakeholders is not always easy. Not only do parents have other concerns, but the past relationships among agencies and a resistance to the idea of managed care may make some agencies and entities reluctant to provide needed input.

How do states monitor and evaluate MCO performance in stakeholder input for CSHCN?

The site visit states monitor and evaluate MCO performance in obtaining and using stakeholder input in different ways. In those states that require MCOs to hire consumers or establish consumer advisory boards, they examine whether or not the MCO has done so. They also may look at items such as meeting minutes, job descriptions, and written policy statements. Also, some Medicaid agencies know that the MCO is using stakeholder input from the products produced by such input. For example, the special brochure produced for foster parents in Connecticut is tangible proof that the MCO is getting and using input from the Child Welfare agency. Finally, the state-level stakeholder input process serves as a source of information regarding MCO responsiveness to stakeholder input.

How do states address stakeholder input for CSHCN in the fee-for-service system?

The formal avenues for stakeholder input on the fee-for-service program are often limited.

- The MAC serves as a source of ongoing input into program operations;
- The rulemaking process usually ensures that stakeholders have an opportunity to comment on new rules; and
- The legislative process allows all citizens to have an impact on general Medicaid policies.

In addition, New Mexico reported holding a forum to gather input from stakeholders on how to improve the EPSDT screening rate for both fee-for-service and managed care. Also, Michigan reported that the advisory committee for their CSHCS program advises them on both managed care and fee-for-service policies.

All of the stakeholder input efforts states reported as applying to the fee-for-service program also apply to managed care programs. Almost all of the efforts described in this chapter of the report were specifically developed to obtain stakeholder input on managed care and operate in addition to those that apply to the fee-for-service system.

How do state practices in stakeholder input vary according to state characteristics?

Very little variation existed among the states. States with newer programs did not appear to use different or more extensive methods than states with older programs. However, those with older programs reported that they had developed their stakeholder input efforts after learning the importance of stakeholder input through mistakes made during program implementation. Newer programs reported learning the importance of stakeholder input from the mistakes of other states. The two states with specialized programs for CSHCN did not appear to use different approaches than those with only general programs. More rural states did not vary significantly from more urban states. Finally, both large and small states regularly took their stakeholder input efforts “on the road.”

Do the Interim Criteria on stakeholder input address the most significant issues faced by children and their families?

The Interim Criteria focus on stakeholder involvement in the development of the program. However, most informants emphasized that stakeholder input was as important, if not more important, for ongoing program operations and evaluation. Also, many of those interviewed reported that it was important to be clear that involvement included not only listening to their concerns but addressing them as well. Some emphasized the importance of family centered care for CSHCN and their families and the need for input from families to produce that result. As previously mentioned, seeing changes result from stakeholder input was frequently mentioned (by both Medicaid agencies and others) as the best measure of a successful strategy .

X. SUMMARY OF FINDINGS REGARDING THE INTERIM CRITERIA

Key informants generally felt that the Interim Criteria's major topic areas, which are discussed in detail in the preceding Chapters, focus on the general topics of interest to CSHCN and their families. However, they did express concerns with some of the specific requirements and standards within the topic areas. Further, many of the informants felt that certain provisions in the Interim Criteria need clarification and rethinking. Finally, informants noted that certain issues within the general topic areas, such as access to services and care coordination, warrant increased emphasis because of their critical importance to CSHCN and their families. Specific findings for each of the major topic areas identified in the Interim Criteria are presented here. It is important to keep in mind when reviewing these findings that none of the site visit states operated under the Interim Criteria at the time of the site visits. Therefore, the assessment of state activity relevant to the Interim Criteria speaks to how well informants thought the Criteria would serve CSHCN and how states would need to change their programs to meet the Interim Criteria.

Definition

- The BBA definition of CSHCN meets the purpose for which it was primarily designed: allowing states to easily identify when they need to obtain a waiver before requiring children to enroll into managed care, according to key informants for this report.

- Informants were of the opinion that the BBA definition does not work well for program operation and evaluation purposes, such as enrollment, quality, and care coordination. Prior to the BBA, all Medicaid agencies had developed other definitions, with the assistance of stakeholders, that they and other stakeholders felt better served these specific services. Thus, they were reluctant to change their programs to rely on the BBA definition for these purposes.

- Informants noted that a significant overlap exists among the five groups of children that compose the BBA definition. Also, some children could be excluded from the BBA definition while others with similar levels of medical need might be included because of differences in family income, eligibility options selected by the state Medicaid program, and service and population options selected by the state Title V agency. As a result, the BBA definition cannot be relied on to produce a consistent count of CSHCN across states, nor can the number of children in each of the five groups simply be added together to produce an accurate count of the number of CSHCN in each state.

- Informants felt that the BBA definition does not address the most critical needs of CSHCN and their families, whose concerns center around ensuring that the program meets the individual needs of the children.

Identification and Tracking

- Most informants reported that the need to identify the child as having special health needs is less important than the need to identify and meet those needs. They did not view the BBA definition as useful in that effort.

- At the time of the site visits, none of the Medicaid agencies reported tracking the experience of BBA-defined CSHCN on a regular basis because each had developed a variety of other definitions that better met the specific needs of CSHCN within the state. However, if required, all Medicaid agencies could identify all children in the five BBA groups. (receiving Title V-funded care coordination was the exception in five of the six states).

- States reported that it would be most difficult to identify those children receiving Title V-funded care coordination. Establishing systems to identify specific Medicaid beneficiaries who are receiving Title V funded care coordination services will require both Medicaid and Title V agencies to devote staff time and funding to the effort. Some of these agencies may be reluctant to do so, as there is no other reason for communicating this information between the two.

Enrollment and Disenrollment

- The availability and transfer of information in the enrollment process was identified as the key issue in enrollment and disenrollment by a range of stakeholders. The receipt of information by the MCO is not specifically addressed by the Interim Criteria.
    - S Families want to know which, if any, aspect of their child’s care will be disrupted by the move to managed care and how to access care in their new MCO.
    - S MCOs want accurate and complete contact information for new enrollees, as well as information from claims or encounter data about services the children were receiving prior to enrollment so that they may prevent disruptions in care.

- Many of the Interim Criteria for enrollment and disenrollment are not pertinent to PHPs, because there is no more than one PHP per geographic area in the site visit states.

- All site visit states had policies in place that met the Interim Criteria regarding the following; however, these policies were not specific to CSHCN and their families. Rather, they included CSHCN along with all other beneficiaries.
    - S Disenrollment for just cause
    - S Forbidding MCO disenrollment of an enrollee due to health status

  - S Outreach efforts to reach potential CSHCN and their families

- Enrollment counselors were generally provided with information about available primary care providers, specialists, and hospitals in each MCO's network for use in helping all beneficiaries select an MCO. Most Medicaid agencies did not provide further information and training specific to CSHCN. Informants generally felt that this information was sufficient to help CSHCN and their families select a managed care option. Some were concerned that going beyond this information would affect the neutrality regarding choice of MCO that enrollment brokers must maintain.

- Those who do not choose a managed care option are to be assigned to an MCO that either includes their current provider or that is capable of serving their particular needs.
  - S Medicaid agencies reported that they do not contract with any MCO that cannot meet each child's needs, therefore, all assignments meet this criterium.
  - S Children who do not contact the enrollment counselor cannot generally be assigned to an MCO that includes their current provider because the Medicaid agency has no information regarding the current providers used by children that are new to Medicaid.

Provider Capacity, Access to Specialists, and Access to Benefits

- While reporting that access to physicians was important to CSHCN, informants emphasized that access to other services more pertinent to their day-to-day functioning was at least as important, if not more so. Among the services specifically mentioned were home health, disposable medical supplies, durable medical equipment, and pharmacy services. Families also emphasized that it was important that these providers understand the special needs of their children. These issues are not addressed in the Interim Criteria.

- Informants reported that the specification of capacity standards and certain types of providers was not as critical as ensuring that procedures were in place to assure each child access to the full range of services each needs and that MCOs, which are in the position of authorizing services, fully understand the complexities of serving CSHCN.

- All site visit states had policies and monitoring procedures in place designed to assure specific primary and specialist provider capacity and access to care for all enrollees, including CSHCN. Informants, however, expressed the following concerns about the Interim Criteria.
  - S They were reluctant to require *experienced* providers as there are no commonly accepted standards that define *experienced*.
  - S They were reluctant to set a specific numerical standard because no generally accepted standards exist, standards would not be very useful if they did exist, and they would be difficult to define due to the diverse medical needs of enrollees.

S They were reluctant to specify particular specialist types with which MCOs must contract (although they often specified particular essential providers) because of the diverse medical needs of the enrolled population.

Quality of Care

- Informants emphasized the need for both retrospective, long-term assessments of quality and early warning and response systems to detect potential problems. The Interim Criteria address only long-term assessments.

- Many informants while agreeing with the need to assess the care provided to CSHCN felt that the state of the art in quality and performance measurement was not sufficient to enable them to address the needs of CSHCN. Many would like guidance and technical assistance from the federal government to help resolve some of these problems.

- All Medicaid agencies had developed specific performance improvement projects that addressed issues of concern for CSHCN; however, these projects almost always included enrollees other than CSHCN and were not designed to separately examine the care delivered to CSHCN.

- Few Medicaid agencies had measured the performance of MCOs specific to CSHCN, as envisioned by the Interim Criteria requirements, although all had measured performance to all children, all people with disabilities, or all enrollees on issues pertinent to CSHCN, such as the delivery of immunizations. In explaining the difficulties inherent in trying to isolate performance for CSHCN, agencies cited the lack of performance measures specific to CSHCN and populations too small to produce statistically valid results.

Coordination of Care

- All informants agreed that coordination of care was the key for CSHCN. However, there were widely varying interpretations about what is meant in the Interim Criteria by “assessment,” “treatment plan,” and “case management/care coordination.” This ambiguity increases the likelihood of confusion over which services are to be provided to CSHCN and the expected outcomes of care coordination, thereby decreasing the likelihood that care coordination will produce the desired results.

- The lack of agreed-upon definitions for some terms used in the Interim Criteria makes assessment of the Criteria and of states’ ability to implement them difficult. However:

  - S Some, but not all, BBA-defined CSHCN receive assessments, treatment plans, and case management services.
  - S Some states and all MCOs have criteria for determining which children need care coordination services. However, which children receive such services varied among the states.
  - S All states and MCOs develop coordination agreements and collaborate with other agencies in the care of CSHCN. The scope and effectiveness of these agreements vary among and within states and are often dependent upon the relationship between the state and federal agencies which oversee and fund the coordinating parties.

Payment Methodology

- The Interim Criteria address only the need for a payment mechanism that accounts for special needs populations enrolled in capitated managed care. Informants raised other issues including:
  - S Concern with the adequacy of overall payments to MCOs to accommodate the needs of CSHCN, especially given the limits the Upper Payment Limit imposes on compensation for requirements that do not exist in the fee-for-service system (such as quality studies and care coordination) or for additional costs incurred for meeting pent-up need due to lack of providers in fee-for-service.
  - S Concerns about adequate payment for providers from both MCOs and the fee-for-service system.
  - S Frustration about the difficulty in establishing payment responsibility for specific services among the multiple agencies that serve CSHCN.

- All Medicaid agencies met the Interim Criteria by adjusting payments by demographic factors such as age, sex, and eligibility category. There was also a growing consensus among the agencies of the need to move beyond these factors to base capitation payments on enrollee health status and to use payment to provide incentives to improve MCO performance

- All Medicaid agencies were making efforts to clarify the “gray areas” of payment responsibility or to coordinate payment from multiple agencies to eliminate those gray areas by making a single entity responsible for providing the services funded by multiple agencies.

Stakeholder Input

- All Medicaid agencies had public processes in place for the development of the managed care program. States typically involved in those processes those responsible for caring for CSHCN, including families, advocacy groups, providers, MCOs, and Medicaid and other state agencies.

- Informants, including Medicaid agencies, emphasized the importance of involving stakeholders in all aspects of managed care program operation and evaluation, not just program development. The Interim Criteria only specifies involvement in waiver program development.

- Informants emphasized the importance of measuring the results of stakeholder input by assessing the changes that result from that involvement. This issue is not addressed in the Interim Criteria.

LIST OF APPENDICES

LVII. Expert Panel Meeting Participant Lists

LVIII. Site Visit Protocols, Including HCFA’s Interim Criteria

LIX. Site Visit State Stakeholder Input Strategies

Appendix A

Expert Panel Meeting Participant Lists

State Activity Monitoring Medicaid Managed Care For Children with Special Needs

Thursday, October 14, 1999

Participant List

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State Activity Monitoring Medicaid Managed Care For Children with Special Needs

Monday, March 27, 2000

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Appendix B:

Site Visit Protocols, Including HCFA's Interim Criteria

State Activity Monitoring Medicaid Managed Care for Children with Special Health Care Needs

Medicaid Agency Site Visit Protocol

Purpose

Thank you for agreeing to be one of six states the National Academy for State Health Policy (NASHP) will visit to conduct a study of children with special health care needs (CSHCN). The Assistant Secretary for Planning and Evaluation (ASPE) and the Health Care Financing Administration (HCFA) have contracted with The George Washington University Center for Health Services Research and Policy (GWU) for a study of state activity in Medicaid (MCO, PCCM and fee-for-service systems) for CSHCN, to be conducted by the National Academy for State Health Policy (NASHP). NASHP will conduct detailed site visits in six states. We will produce a report from these visits that identifies and describes, using HCFA's interim draft review criteria for assessing mandatory managed care waivers that include CSHCN (attached) as a starting point, the key barriers to care CSHCN face and techniques states have developed to address these barriers, in all Medicaid delivery systems. (The Medicaid agencies in the six site visit states will receive a copy of the draft report for review prior to its release.) We wish to emphasize that our purpose is not to review state compliance with any criteria, but rather the following:

- HCFA will use the information from the resulting report to refine their interim draft review criteria for assessing mandatory managed care waivers that include CSHCN; and

- States will be able to use the information as a toolbox of ideas about what is and is not effective in ensuring the delivery of care to CSHCN.

As you know, under the Balanced Budget Act of 1997 (BBA) CSHCN are one of the few remaining groups for which states must obtain a waiver before mandating enrollment into managed care. The BBA defines CSHCN for purposes of deciding whether or not a state needs to obtain a waiver for mandating enrollment into their managed care program. This study, therefore, also uses this definition as the starting point for our discussions. The BBA definition includes individuals under 19 years of age who are:

(1) eligible under SSI;
(2) eligible under section 1902(e)(3) of the Act (Katie Beckett);
(3) in foster care or other out-of-home placement;
(4) receiving foster care or adoption assistance; or
(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, and is defined by the State agency in terms of either program participation or special health care needs (Title V agency services).

Potential Site Visit Participants

To gain a complete picture of your State's activities, we hope to spend the first day of the site visit with Medicaid agency staff, then spend the balance of our time meeting with other key stakeholders. This outline gives you a sense of our proposed approach. These are meant as loose guidelines, the actual time and participants will vary by state and will be determined in consultation with the selected site visit states. We would like to include those who are knowledgeable of how race and culture of CSHCN are addressed within the program in these interviews.

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- Medicaid agency staff, since different staff are involved in different aspects of the program it might be advisable for the Medicaid agency to schedule staff to participate at different times during the up to 8 hours we anticipate spending with the Medicaid agency. If the Medicaid agency uses an enrollment broker or has an EQRO, staff from these entities should participate in the appropriate parts of the discussion.
- MCO staff (Meet individually with three plans for 1 hour each – if the Medicaid agency contracts with a BHO, the BHO should be one of the three plans.)
- Advocates and Consumers – joint meeting (1.5 hours)
- Other State agencies that serve these populations – will vary by state.
    - MCH agency (1 hour)
    - Early Intervention and Special Education Programs' administrating agency, developmental disabilities agency, mental health/substance abuse agency (1 hour)
    - Child Welfare (foster care – 1 hour)
    - Agency responsible for administering Katie Beckett and/or Home and Community Based waivers, if these are separate from Medicaid agency (1 hour)
- County staff, if counties involved in delivering care to CSHCN (1 hour)
- Medical providers who deliver care to CSHCN – preferably those who serve large numbers of CSHCN.
    - PCPs – including, if possible one specialist who serves as a PCP for CSHCN (1 hour, will go to their offices if necessary)
    - Specialist physicians (1 hour, will go to their offices if necessary)
    - Children's hospital staff

The NASHP site visit team will meet as a team with: Medicaid agency staff and the advocates and consumers. The site visit team may split up for meetings with other interviewees so that up to two simultaneous meetings may be held with the remaining interviewees.

Requested Materials

Please provide as much of the material specified below as possible before the site visit. This will allow us to review them before we arrive and will likely answer many of our questions about "how" you ensure that CSHCN receive appropriate care. As a result we will take less of your time and be able to focus our site visit discussion on your evaluation of the criteria and lessons you have learned about effective means of ensuring the delivery of care to CSHCN. We do not expect that every state will have all of these documents and we anticipate that there may be other documents that the State has that are not listed. This list is meant as a "prompt" to help states identify existing material pertinent to the site visit purpose.

- Response to GAO survey on the delivery of care to CSHCN that was due October 20, 1999.
- Documents relevant to MCO (including BHO, if appropriate), PCCM provider, and fee-for-service provider responsibilities to deliver care to CSHCN. These may include waivers, contracts, provider agreements, manuals or administrative rules. **PLEASE** do not send any documents that do not contain information pertinent to expectations regarding the delivery of care to CSHCN.
- Instruments used to identify CSHCN
- Information sharing agreements among state agencies
- Documents outlining how responsibility is shared between the Medicaid agency, MCOs and other agencies that also serve CSHCN
- Information sent to new Medicaid beneficiaries
- Enrollment packets sent to potential managed care enrollees
- Enrollee surveys and their results, especially surveys of CSHCN and their caregivers
- Reports showing Medicaid agency, plan or PCCM provider performance on issues pertinent to CSHCN.
- Information on CSHCN utilization pre and post managed care
- Results of any special studies (by the Medicaid agency or EQRO) related to the delivery of care to CSHCN by MCOs, PCCM providers, or fee-for-service.
- Reports showing capitation rare calculations
- Agendas, participant lists or meeting summaries from any public meeting pertinent to CSHCN.
- Any existing written summaries of comments on waiver, request for proposals, or contracts provided by consumers, advocates, MCOs, etc.

Questions

A copy of HCFA's draft interim review criteria for 1915(b) waivers that enroll CSHCN into MCOs is attached. We have the following questions about each section of these criteria.

1. What are the key issues you faced in each area in providing care to CSHCN through capitated managed care arrangements (MCOs, including BHOs) in this area? How have you resolved them or what steps are you currently taking to resolve them?

2. How do these issues and resolutions differ from those encountered in your PCCM or fee-for-service program, if you have or had one?

3. How does the race and culture of a child with special health care needs impact the delivery of care? Are there any issues that need to be addressed?

4. Do the criteria address the key issues? If not how could they be modified (additions, modifications, and deletions) to do so? Why?

5. What means of monitoring MCO, PCCM provider, and fee-for-service provider compliance with requirements pertinent to the delivery of care to CSHCN have you found to be effective? What data do you collect?

6. What lessons have you learned in each of these areas about what works and does not work?

After we review each area of the criteria we have the following questions about the criteria as a whole.

1. Are the issues examined by the criteria the “right” issues for assessing the Medicaid agency’s ability to ensure the delivery of care to CSHCN? If not, what issues should be added or deleted? Why?

2. What overall lessons have you learned in your efforts to make sure the CSHCN receive the care they need?

State Activity Monitoring Medicaid Managed Care for Children with Special Health Care Needs

Site Visit Protocol

All interviewees except Medicaid agency

Purpose

Thank you for agreeing to be one of six states the National Academy for State Health Policy (NASHP) will visit to conduct a study of children with special health care needs (CSHCN). The Assistant Secretary for Planning and Evaluation (ASPE) and the Health Care Financing Administration (HCFA) have contracted with The George Washington University Center for Health Services Research and Policy (GWU) for a study of state activity in Medicaid (MCO, PCCM and fee-for-service systems) for CSHCN, to be conducted by the National Academy for State Health Policy (NASHP). NASHP will conduct detailed site visits in six states. We will produce a report from these visits that identifies and describes, using HCFA's interim draft review criteria for assessing mandatory managed care waivers that include CSHCN (attached) as a starting point, the key barriers to care CSHCN face and techniques states have developed to address these barriers, in all Medicaid delivery systems. (The Medicaid agencies in the six site visit states will receive a copy of the draft report for review prior to its release.) We wish to emphasize that our purpose is not to review state compliance with any criteria, but rather the following:

- HCFA will use the information from the resulting report to refine their interim draft review criteria for assessing mandatory managed care waivers that include CSHCN; and

- States will be able to use the information as a toolbox of ideas about what is and is not effective in ensuring the delivery of care to CSHCN.

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Potential Site Visit Participants

To gain a complete picture of your State's activities, we plan to meet first with Medicaid agency staff, then with other key stakeholders including: Health plans, advocates, consumers, other state agencies involved in the delivery of health care to CSHCN, and a variety of providers.

Requested Materials

Please provide as much of the material specified below as possible before the site visit. This will allow us to review them before we arrive and will likely answer many of our questions about "how" you ensure that CSHCN receive appropriate care. As a result we will take less of your time and be able to focus our site visit discussion on your evaluation of the criteria and lessons you have learned about effective means of ensuring the delivery of care to CSHCN. We do not expect that every interviewee will have all of these documents and we anticipate that there may be other documents that the interviewee has that are not listed. This list is meant as a "prompt" to help identify existing material pertinent to the site visit purpose.

- Any position papers you may have regarding policies pertinent to serving CSHCN in Medicaid managed care
- Information sharing agreements among state agencies
- Documents outlining how responsibility is shared between the Medicaid agency and other agencies that also serve CSHCN
- Information sent to potential or new Medicaid enrollees
- Enrollee surveys and their results, especially surveys of CSHCN and their caregivers
- Any manuals, guidelines, or agreements that specify pertinent policies.
- Reports showing Medicaid agency, plan or PCCM provider performance on issues pertinent to CSHCN.
- Information on CSHCN utilization pre and post managed care
- Agendas, participant lists or meeting summaries from any public meeting you organized that was pertinent to delivering health care to CSHCN through health plans
- Any existing written summaries of comments on waiver, request for proposals, or contracts provided by consumers, advocates, MCOs, etc.
- Results of any studies you have conducted regarding the delivery of care to CSHCN
- Response to GAO survey on the delivery of care to CSHCN that was due October 20, 1999.
- Instruments used to identify CSHCN

Questions

A copy of HCFA's draft interim review criteria for 1915(b) waivers that enroll CSHCN into MCOs is attached. We have the following questions about each section of these criteria.

I. What are the key issues in each area in providing care to CSHCN through Medicaid health plans (both those that deliver a range of care including physical health care and those that deliver only a limited set of services such as behavioral health care)? How have they been resolved or what steps are currently being taking to resolve them? What was your role in identifying and developing the response?

II. How do these issues and resolutions differ from those encountered in Medicaid's PCCM or fee-for-service program, if there is (or was) one?

III. How does the race and culture of a child with special health care needs impact the delivery of care? Are there any issues that need to be addressed?

IV. Do the criteria address the key issues in delivering care to CSHCN? If not how could they be modified (additions, modifications, and deletions) to do so? Why?

V. What is your role in monitoring MCO, PCCM provider, and fee-for-service provider compliance with requirements pertinent to the delivery of care to CSHCN? What would you recommend that the Medicaid agency do? What information do you get about the health plans? Would you like additional information to help you judge how well managed care is working? What would you like and why?

VI. What lessons have you learned in each of these areas about what works and does not work?

After we review each area of the criteria we have the following questions about the criteria as a whole.

1. Are the issues examined by the criteria the "right" issues for assessing the Medicaid agency's ability to ensure the delivery of care to CSHCN? If not, what issues should be added or deleted? Why?

2. What overall lessons have you learned in your efforts to make sure the CSHCN receive the care they need?

Interim Review Criteria for Children with Special Needs
June 4, 1999

When addressing these criteria, please provide the following information by each appropriate subset of children with special needs:

C The State's responsibilities in managed care programs enrolling children with special needs.

C The State's requirements for MCOs/PHPs enrolling children with special health care needs.

C How the State monitors its own actions and that of its contracting MCOs and PHPs.

C For foster-care children only, the provisions which address the broader, unique issues occurring because of out-of-home, out-of-geographic area placement.

State Responsibilities for Managed Care Programs Enrolling Children with Special Needs

C **Public Process**

The State has in place a public process for the involvement of relevant parties (e.g., advocates, providers, consumer groups) during the development of the waiver program and has sought their participation in that process.

C **Definition of Children with Special Needs**

The State has a definition of children with special needs that includes at least these five subsets :

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. In foster care or other out-of-home placement;
4. Receiving foster care or adoption assistance; or
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 is defined by the State in terms of either program participant or special health care needs.

C **Identification**

-- The State identifies and/or requires MCOs/PHPs to identify children with special needs. The State collects, or requires MCOs/PHPs to collect specific data on children with special needs. The State explains the processes it has for identifying each of the special needs groups described above.

C **Enrollment/Disenrollment**

The State performs functions in the enrollment/disenrollment process for children with special needs, including:

-- Outreach activities to reach potential children with special needs and their families, providers, and other interested parties regarding the managed care program.

-- Enrollment selection counselors have information and training to assist special populations and children with special health care needs in selecting appropriate MCO/PHPs and providers based on their medical needs.

-- Auto-assignment process assigns children with special health care needs to an MCO/PHP that includes their current provider or to an MCO/PHP that is capable of serving their particular needs.

-- A child with special needs can disenroll and re-enroll in another MCO/PHP for good cause.

-- 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 for individuals with mental health and substance abuse diagnoses -- against the enrollee.

C **Provider Capacity**

-- The State ensures that the MCOs/PHPs in a geographic area have sufficient experienced providers to serve the enrolled children with special needs (e.g., providers experienced in serving foster care children, children with mental health care needs, children with HIV/AIDS, etc.).

-- The State monitors experienced providers capacity.

C **Specialists**

-- The State has set capacity standards for specialists.

-- The State monitors access to specialists.

-- 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.

-- The State requires particular specialist types to be included in the MCO/PHP network. If specialists types are not involved in the MCO/PHP network, arrangements are made for enrollees to access these services (for waiver covered services only).

C **Coordination**

-- The State requires an assessment of each child's needs and implementation of a treatment plan based on that assessment.

-- The State has required the MCOs/PHPs to provide case management services to children with special needs.

-- The State has developed and implemented a process to collaborate and coordinate with agencies and advocates which serve special needs children and their families.

-- The State has a process for coordination with other systems of care (for example, Medicare, HRSA Title V grants, Ryan White CARE Act, SAMHSA Mental Health and Substance Abuse Block Grant Funds) or State/local funding sources.

-- 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.

C **Quality of Care**

-- 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.).

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

C **BBA Safeguards**

-- To the extent appropriate, the State has adequately addressed Balanced Budget Act (BBA) guidance that HCFA has issued to date.

C **Payment Methodology**

-- The State develops a payment methodology that accounts for special needs populations enrolled in capitated managed care.

C **Plan Monitoring**

-- The State has in place a process for monitoring children with special needs enrolled in MCOs/PHPs for access to services, 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 defines medical necessity for MCOs/PHPs and the State monitors the MCOs/PHPs to assure that it is applied by the MCOs/PHPs in their service authorizations.

Appendix C:

Site Visit State Stakeholder Input Strategies

State	Description	Involved Stakeholders	CSHCN Relevance
CO	*Disability Working Group* – est. to advise Medicaid agency on the needs of people w/disabilities as they want them reflected in the HMO contract	People w/disabilities, parents of CSHCN, advocates, and Medicaid agency	Includes parents of CSHCN; works w/Medicaid agency to develop HMO contract incl. contract provisions regarding CSHCN.
	Plan Consumer Advisory Boards – HMO contract requires each HMO to establish a consumer advisory board.	Consumers, HMO	Some include parents of CSHCN, role of Board varies with HMO
	Medicaid Advisory Committee for People w/Disabilities – est. by Medicaid agency to advise agency on program operations as they impacted people w/disabilities	People w/disabilities, parents of CSHCN, disability advocates, and Medicaid agency	Includes parent of CSHCN; selects topic for one of the EQRO studies each year (discharge planning for people w/special needs was selected last year); reviews outreach materials
	Quality Improvement Committee – est. by Medicaid agency to consult w/HMOs, providers, and consumer advocates on managed care quality issues	HMOs, providers, consumer advocates, and Medicaid agency	Includes CSHCN advocates; advises Medicaid agency on quality issues, including those effecting CSHCN
	Medicaid Advisory Committee – Federally required committee for all Medicaid agencies, with switch to managed care now advises the agency on those issues.	Providers, plans, advocates, consumers Medicaid agency	
	HEDIS-like measure task force – est. by Medicaid agency to assist them in developing HEDIS-like measures for people w/disabilities	People w/disabilities, parents of CSHCN, Medicaid agency	Developing HEDIS-like measures for people w/disabilities, some of which may be specifically for children
	Waiver Development Public Process – Medicaid agency held public meetings to inform stakeholders about the waiver program.	People w/disabilities, parents of CSHCN, advocates, providers, HMOs, and Medicaid agency	Parents of CSHCN could attend to learn about new program
	Contract Development Process – HMO contract distributed to numerous agencies and posted on State website for comments; Behavioral Health RFP distributed for comment by Mental Health Agency	People w/disabilities, parents of CSHCN, disability advocates, HMOs, providers, general public	Contract distributed to parents of CSHCN and their advocates for review.
	Safety Net Parent Staff – As part of the Safety Net project the Medicaid hired 2 parents of CSHCN to work on the project as part-time, limited term staff	Parents of CSHCN, HMOs, Medicaid agency	Involves the 2 staff who are parents of CSHCN in activities such as outreach and education to other parents and developing materials relevant to CSHCN

State	Description	Involved Stakeholders	CSHCN Relevance
	Safety Net Project Advisory Committee – Est. by Medicaid agency to advise the agency and the 4 HMOs that voluntarily participate in the project. Have developed CSHCN definition for the project and reviews all project activities	Parents of CSHCN, HMO, Medicaid agency, CBOs, disability advocates who are not parents, other state agencies (Public Health, Education, and Mental Health)	Includes parents of CSHCN; all activities focus on CSHCN – three project goals: (1) Identify CSHCN, (2) identify community organizations that serve CSHCN and develop relations between the HMOs and the organizations, (3) develop internal care coordination/case management systems in HMOs
	Medicaid Capitation Committee – monthly meetings est. by Mental Health agency to advise them on all major managed care activities and documents	Consumers (family members and youths), Mental Health Agency, advocates	Includes family members of CSHCN and CSHCN; allows input on program operations as they effect CSHCN
	Behavioral Health PHP Focus Groups – est. by Mental Health Agency (operates behavioral health program) to gather consumer input on how program has affected service delivery	Mental Health agency, consumers and CBOs that provide services to youth (separate focus groups were held of consumers and CBOs)	Included parents of CSHCN and agencies that serve them; provide opportunity to give input on how behavioral health program was working for CSHCN.
CT	*Medicaid Managed Care Council* – Advisory group est. by legislature to provide input to Medicaid managed care program; meets monthly	Legislative representatives; children's health advocates; consumers (including parents of CSHCN); State Medicaid, public health, and Foster-care agencies; providers; and MCOs (all appt. by Legislature)	Includes parents of CSHCN and children's health advocates; subcommittees have addressed: EPSDT and children's behavioral health
	Children's Health Council – Advisory group est. by legislature to oversee transition of children's health care services to Medicaid managed care and monitor program operations.	Children's health advocates; Medicaid agency, legislative staff, providers, MCOs, Public Health and Child Welfare agencies	Analyzes encounter data regarding EPSDT; operates children's health info line (provides info and serves ombudsman role for those who call in); will conduct a study of CSHCN w/in the next year
	Waiver Development Public Process – State statute requires public notification and review of all managed care waivers; waiver and all public comments and questions are reviewed by the Committees of Cognizance, Appropriations, and Human Services in Connecticut's General Assembly	All members of the public were provided an opportunity to participate	Included parents of CSHCN; provided opportunity to raise issues specific to CSHCN and their care
	Individual Meetings – Medicaid agency met with a number of stakeholder groups during the development of the waiver	Not specified	

State	Description	Involved Stakeholders	CSHCN Relevance
	Other State Agency Meetings – The MCH and Foster-care agencies have included MCO representatives on their advisory groups; work with them directly outside of the meeting structure; and MCO's invite Foster-care agency to their quarterly meetings	MCH agency, Foster-care agency, Medicaid agency, consumers (including parents/foster-parents of CSHCN), MCOs and providers	Foster-care and MCH agencies have developed direct relationships to MCOs for the children they serve
DE	*Delawareans with Special Needs: Medicaid Managed Care Panel* – Est. in 1996 by parents of CSHCN (first participating parents were not in Medicaid managed care) to advise Medicaid agency on transition to managed care and the needs of children with disabilities; monthly meetings continue to provide input on program operations and evaluation.	Parents of children w/disabilities, Medicaid managed care enrollees, Medicaid agency, enrollment broker, MCOs, and the general public – all meetings are open to the public	est. by parents of CSHCN, provides a forum to identify and problem-solve issues for CSHCN (individuals and as a whole)
	Interagency Coordinating Council – est. by Governor meets every other month to advise Medicaid agency on managed care; focuses on children w/special needs and other issues; meets every-other month	Parents of CSHCN, advocates, State Division heads	Includes parents of CSHCN and focuses on issues related to CSHCN in Medicaid managed care.
	Medicaid Advisory Committee – Federally required committee for all Medicaid agencies, with switch to managed care now advises the agency on those issues.	Providers, plans, advocates, Medicaid agency	
	Plan Management Meetings – Est. by Medicaid agency to provide an opportunity for the agency, plans, and enrollment broker to discuss issues and policies related to serving all Medicaid enrollees. Medicaid agency holds monthly meetings w/each HMO and w/all HMOs together.	Medicaid agency, HMOs, enrollment broker	Addresses issues pertinent to delivering care to CSHCN
	Oversight Committee – Est. by Governor to provide guidance during transition to Medicaid managed care; monthly meetings; discontinued after implementation	Mostly Department heads (Children Youth and Families, Public Health, Education, etc.), also some member of the public and advocates	Departments that serve CSHCN represented at meetings
	Waiver Development Public Process – Medicaid agency held focus groups and other public meetings to inform stakeholders about the new program. All meetings occurred between May 1995 and January 1996.	Providers, consumers	Parents of CSHCN could participate; provide input on aspects of waiver request pertinent to serving CSHCN

State	Description	Involved Stakeholders	CSHCN Relevance
MA	*Program Implementation Advisory Groups* – Medicaid agency est. advisory groups for new initiatives that include stakeholders; all program policy decisions discussed by group	Medicaid agency; other state agencies impacted by program, consumers, HMOs, BHO, providers (specifics will vary depending on nature of new program)	Parents of CSHCN participate when program involves CSHCN; provides opportunity to be involved in policy discussion and decision-making on programs serving CSHCN
	Medical Advisory Group – est. by Child Welfare agency to discuss all access and care issues for children in foster care and develop Special Kids Ì Special Care program; chaired by Child Welfare agency	Child Welfare agency, Medicaid agency, BHO, HMO piloting program, foster care providers, and medical providers	Includes those serving children in foster care; provides forum for discussion and resolution of problems individual children and children in foster care as a whole encounter.
	Pediatric Alliance for Coordinated Care – est. by CBO to enhance pediatric practice for CSHCN; locates care coordinators in selected pediatric practices; working to define care management	Providers, advocacy groups, parents of CSHCN, HMOs, Medicaid agency	Includes parents of CSHCN; provides opportunity to educate about care coordination needs of CSHCN
	RFI/Contract Development Public Process – RFIs/contracts distributed to numerous agencies for comments	Medicaid agency; other state agencies impacted by program, advocates, consumers, HMOs, BHO, providers, general public	Parents of CSHCN and their advocates can participate; provide input on aspects of RFI pertinent to serving CSHCN
MI	*Health Plan Advisory Council* – Advisory group est. by Medicaid agency which allows agency to coordinate and collaborate w/advocates	Medicaid agency, HMOs, advocates (including advocates that serve CSHCN and their families)	Includes advocates serving CSHCN and their families; provides opportunity to create linkages and give advice relating to issues important to CSHCN
	RFP/Contract Development Process – Medicaid agency held over 80 meetings held in various parts of the State during HMO/CP RFP/contract development to obtain input from stakeholders and inform them about program	Medicaid agency, HMOs, providers, consumers, all members of the public were provided an opportunity to participate	Opportunity for parents of CSHCN to learn about program and raise issues pertinent to CSHCN
	Parent Participation Program – Contract staff (mostly parents of CSHCN) hired by Medicaid agency to work on CSHCS program; part of program management team; administers Family Support Network consisting of 140 volunteers who, among other activities, educate families about CSHCS program	Medicaid agency, families of CSHCN, Special Health Plans	Makes staff who are parents of CSHCN integral to CSHCS program decisions; allows for parent-to-parent education about CSHCS program

State	Description	Involved Stakeholders	CSHCN Relevance
	Readiness Reviews – Medicaid agency's HMO, CP, and Specialty Health Plan readiness review teams included 2 consumers (adults w/disabilities)	Medicaid agency, adults w/disabilities	People w/experience as CSHCN involved in deciding whether HMOs may begin enrollment of Medicaid beneficiaries
	Subcommittee on the Managed Care Initiative – Subcommittee of Title V CSHCS advisory committee met with Medicaid and Title V agencies to frame philosophy and fundamental requirements for development of Special Health Plans	Parents of CSHCN, providers, HMOs and Medicaid agency	Mostly composed of parents of CSHCN, heavily involved in design of CSHCS program; instrumental in program design
	CSHCS Advisory Committee – Advisory committee to CSHCS program operations	Parents, children, or adults in the CSHCS program; providers; advocacy organizations; other people w/experience in health care for CSHCN and interested in the design of a model for CSHCN managed care	includes CSHCN and the people who care for them in operation of CSHCN program
	Speciality Plan Required Consumer Involvement – at least 50% of member services staff must be consumers (parent, former CSHCN, etc.); at least one member of plan board must be a consumer; The Family Centered Care Coordinator (who must have experience as consumer) must be part of the plan's executive staff	Parents of CSHCN, former CSHCN, specialty plan	Involves staff who are parents of CSHCN in activities such as outreach and education to other parents and developing materials relevant to CSHCN; consumer board member involved in making plan operation decisions; participation in health plan utilization management activity
NM	*Medicaid Advisory Committee* – Federally required committee for all Medicaid agencies, with switch to managed care now advises the agency on those issues.	Consumers, providers, plans, advocates, Medicaid agency	Includes parent of CSHCN; discusses issues relevant to CSHCN (e.g., cleft palate access to care; reviews contract) and makes recommendations for changes
	Quality Assurance Coordinating Council – est by Medicaid agency to oversee all quality assurance activities	Medicaid agency, Health Agency, Child Welfare agency, Health Policy Commission	Includes agencies serving CSHCN
	Outreach Services Contracts – Medicaid agency has developed contracts with six CBOs (e.g., ARC of New Mexico) for services related to Medicaid managed care.	Advocacy organizations, Medicaid agency	Some contracted CBOs serve CSHCN; Each CBO helps to educate its constituency on managed care, also helped identify key providers for inclusion in HMO networks
	Plan Consumer Advisory Boards – HMO contract requires each HMO to establish a consumer advisory board.	Consumers, HMO	Some include parents of CSHCN, role of Board varies with HMO

State	Description	Involved Stakeholders	CSHCN Relevance
	Liaisons w/Other Agencies – est. by Medicaid agency to coordinate managed care activities with other agencies involved in delivering care to beneficiaries; individual meetings; meeting frequency varies by agency	Medicaid agency, other State agencies (e.g., Child Welfare), Native Americans, Medical Society, school-based clinics	Provides a forum to resolve issues between Medicaid and other agencies that deliver care to CSHCN; worked with medical society to develop comparative formulary by HMO and uniform forms for requesting off-formulary drugs and requesting prior authorization for services.
	Highways to Health Fairs – over 80 meetings held in various parts of the State prior to program implementation to inform stakeholders about program	Medicaid agency, HMOs, providers, consumers, all members of the public were provided an opportunity to participate	Opportunity for parents of CSHCN to learn about program and raise issues pertinent to CSHCN;