Transitioning to Medicaid Managed Care: Children with Special Health Care Needs

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October 1999

Supported by:
The Henry J. Kaiser Family Foundation
Health Care Financing Administration
ACKNOWLEDGMENTS

This paper is the sixth in the series "Transitioning to Medicaid Managed Care," co-sponsored by The Henry J. Kaiser Family Foundation and the Health Care Financing Administration (HCFA). Funding from The Kaiser Foundation made this work possible. We would like to thank our Project Officers, Alina Salganicoff of The Kaiser Foundation and Patricia McTaggart of HCFA, for their insight and support of this initiative. In addition, we would also like to thank Sally Richardson, former Director of the Center for Medicaid and State Operations at HCFA, and Risa Ellenberger of The Kaiser Foundation for their assistance in organizing this meeting.

This paper would not have been possible without the contributions of the participants in the June 21, 1999, Symposium, "Transitioning to Medicaid Managed Care: Children with Special Health Care Needs." Their knowledge and experience were critical to the success of the Symposium and the development of this document; we appreciate their input and their time in reviewing a draft of the paper. They are: Gretchen Adeson from the National Association of Children's Hospitals; Louise Bannister from Massachusetts Medicaid; Mary DeWane from CalOptima; Judith Dolins from the American Academy of Pediatrics; Marla Golden from New Jersey Medicaid; Jack Hoadley from the Office of the Assistant Secretary for Planning and Evaluation, U.S. DHHS; Kay Holmes from Delaware Medicaid; Carol Irvin from Mathematica Policy Research, Inc.; Charles Milligan from New Mexico Medicaid; Rebecca Pasternik-Ikard from Oklahoma Medicaid; Barbara Popper from Family Voices; Lisa Potetz from March of Dimes; Cheryl Roberts from Virginia Medicaid; Phyllis Siderits-Sloyer from the Florida Title V program; Robert Smedes from Michigan Medicaid; Colleen Sonosky from the George Washington University Center for Health Services Research and Policy; Sandra Tunis from Centene Corporation; and Linda Wertz from Texas Medicaid.
EXECUTIVE SUMMARY

With the growth of Medicaid managed care, more states are including children with special health care needs in their managed care programs. For example, the percent of states enrolling SSI children into risk-based managed care increased from 32% in 1990 to 71% in 1998.¹

Though they comprise a very diverse group, children with special health care needs generally require a broader scope of services and for a longer term than the general population. Their health care needs are complex, requiring extensive and specialized services, which are often more costly than the services provided other children. Children with special health care needs are not simply “little adults” with the same chronic conditions and disabilities as others; they have health and developmental needs that require age-appropriate care, providers with expertise, and family and community support systems.

In an effort to identify key issues in Medicaid managed care for children with special health care needs and examine the ways that states have addressed those issues, the National Academy for State Health Policy (NASHP) convened a symposium in June of 1999 of state Medicaid officials and representatives of managed care organizations (MCOs), provider associations, advocates, research organizations, and the federal government. The symposium was co-sponsored by The Henry J. Kaiser Family Foundation and the Health Care Financing Administration (HCFA). This paper offers a summary of the symposium discussion.

A major concern of symposium participants centered on identifying children with special health care needs. They noted that the capacity to identify all CSHCN does not currently exist, largely because there is no one definition of these children to put into practice nor is there consensus on the use of a single tool or process by which to conduct that identification.

Furthermore, the BBA created a new definition of CSHCN that does not reflect those long in use by states, and symposium participants noted that the BBA definition is somewhat problematic in identifying the universe of children who may have special health care needs. It excludes children who have special health care needs but are not in one of the identified aid categories. State Medicaid agencies know from experience that many of the children who are eligible for Medicaid because they qualify for Temporary Assistance for Needy Families (TANF) also have complex health care needs. For example, the TANF child who has a severe asthma condition will not be defined as special needs, using the BBA definition, nor will a child who becomes homeless or who is awaiting foster care placement.

Regardless of how children are identified or by whom, symposium participants stressed the importance of having a more precise and measurable definition of special needs, a clear understanding of why the children are being identified, and a protocol for how the information will be used by the states, the MCOs, and by HCFA.

In addition to developing effective systems for identifying CSHCN, symposium participants focused on other major issues related to providing these children with comprehensive care. They included:

- assessing MCO capacity for providing adequate and appropriate care;
- enrolling CSHCN in managed care systems;
- assessing the clinical and non-clinical needs of CSHCN;
- providing the full spectrum of benefits that CSHCN need;
- coordinating care for CSHCN;
- financing/payment systems for managed care programs that enroll CSHCN;
- ensuring quality of care;
- establishing linkages with other key organizations, providers, and agencies; and
- working with stakeholders through the development and administration of the program.

States feel that they have made considerable progress in developing appropriate managed care models for CSHCN and would like to continue their efforts. They hope that the current scrutiny by Congress and HCFA (as reflected in the BBA) does not result in reversing the slow, but steady progress that they feel they have made. Provider and children's advocates expressed reservations about the transition to managed care for CSHCN, however. They feel that the lack of quantifiable results and the volatility of the managed care marketplace are cause for caution in pursuing a managed care delivery system for these children.
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INTRODUCTION

This paper is based upon the sixth in a series of symposia co-sponsored by The Henry J. Kaiser Family Foundation and the federal Health Care Financing Administration (HCFA). The series, "Transitioning to Medicaid Managed Care," is convened by the National Academy for State Health Policy (NASHP) and is designed to bring small groups of State Medicaid officials and others together to explore the critical issues that they confront in building Medicaid managed care programs. Each symposium focuses on a single topic of interest.

This symposium, held on June 21, 1999, in Portland, Maine, convened 28 individuals, representing State Medicaid agencies, managed care organizations, provider associations, advocacy organizations, research organizations, and the federal government. They focused their discussion on risk-based Medicaid managed care programs for children with special health care needs (CSHCN). The following states were represented: Delaware, Florida, Massachusetts, Michigan, New Jersey, New Mexico, Oklahoma, Texas, and Virginia. The participants also included representatives from the American Academy of Pediatrics; the National Association of Children’s Hospitals; the March of Dimes; Family Voices; CalOPTIMA (a county organized health system in Orange County, CA); Centene Corporation; Mathematica Policy Research, Inc.; The George Washington University Center for Health Services Research and Policy; The Henry J. Kaiser Family Foundation; Office of the Assistant Secretary for Planning and Evaluation (ASPE); HCFA; and NASHP.

BACKGROUND

With the growth of Medicaid managed care, more states are including people with special health care needs in their managed care programs. The number of states administering risk-based managed care for some portion of SSI beneficiaries has risen from 11 in 1990 to 32 as of June 1998. More than 2.6 million SSI beneficiaries were enrolled in Medicaid managed care and more than 2 million of them were enrolled into comprehensive managed care organizations (MCOs).2 Further, we know that the percent of states enrolling SSI children into risk-based managed care increased from 32% in 1990 to 71% in 1998.3 The vast majority of states enroll populations with special care needs in the same MCOs and primary care case management systems (PCCMs) that cover non-disabled populations.4

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3 Ibid.

Historically, children with special health care needs (CSHCN) have received their care through Medicaid's fee-for-service system. For many consumers and providers, fee-for-service seems preferable to managed care because it offers the freedom to choose one's provider and to practice medicine without constraints. State Medicaid officials also acknowledge that fee-for-service is easier in some ways than managed care; they don't have to be concerned with upper payment limits or budget neutrality and beneficiaries and providers don't feel as restricted by certain requirements for referrals.

But, according to state participants at the symposium, many of the advantages of fee-for-service diminish in light of the potential benefits of a managed care system. They noted that, though families may feel that they have more choice of providers in the fee-for-service system, it is not unusual for a patient to wait up to eight hours to be seen in the emergency room or in a provider's office. Follow-up care is likely to be somewhat patchwork for both family and provider, with little clarity as to who is managing the care and little guarantee of continuity. For children with special health care needs in particular, fee-for-service cannot provide an overall commitment to assembling and coordinating the varied and complex services that a given child might require. A recent study, conducted by Health Systems Research, Inc., corroborated these opinions, finding that fee-for-service arrangements "cannot assure that CSHCN have access to the broad range of specialty services and ancillary therapies they might need, ... and have no explicit case management component to permit comprehensive assessments of children’s needs, the development of a plan of care, or the coordination of service delivery.”5 Finally, in fee-for-service there are few, if any provisions, to control the quality of care or to monitor how it is delivered.

**Concerns About Medicaid Managed Care for CSHCN**

Managed care may hold much promise for children with special health care needs, but as it covers a growing number of these children, many are concerned that mechanisms are in place to ensure that special needs enrollees can and will receive the care that they need. Though they comprise a very diverse group, in general, children with special health care needs require a broader scope of services and for a longer term to maintain their health and ability to function than the general population. Their health care needs are complex, requiring extensive and specialized services, which are often more costly. Children with special health care needs are not simply "little adults" with the same chronic conditions and disabilities; they have health and developmental needs that require age-appropriate care, providers with expertise, and family and community support systems.

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There is no one profile of a child with special health care needs. These children require services for conditions as varied as asthma, attention deficit and behavioral disorders, diabetes, sickle cell anemia, cystic fibrosis, spina bifida, and cerebral palsy. “They can be children with unstable or deteriorating conditions such as muscular dystrophy or HIV infection. Some have congenital anomalies, such as cleft palate, or are born with problems making it difficult to digest or metabolize food. Often a child has more than one condition.”

The issue of whether persons with special health care needs are receiving adequate care in managed care has commanded the attention of Congress, HCFA, state agencies, provider associations, consumer advocacy organizations and others. Each has voiced its concerns about how managed care cares for persons with special health care needs, and children in particular. They question whether managed care systems:

- have adequate network capacity and appropriate providers to meet the needs of CSHCN;
- have an understanding of the complex needs of CSHCN;
- have the ability to link with other systems of care and support; and
- have financial incentives that encourage access to care for CSHCN.

There is also concern about the lack of data regarding the number of children with special care needs and how they are identified and the absence of documentation regarding their actual care delivery experiences.

**The Balanced Budget Act of 1997**

The Balanced Budget Act of 1997 (BBA) enacted several provisions aimed at addressing some of these concerns. The BBA made reforms to Medicaid managed care requirements for all populations in the areas of enrollment, disenrollment, default assignment and access standards. It directed the Secretary of the Department of Health and Human Services to conduct a study to ascertain whether the health care needs of individuals with special health care needs and chronic conditions are adequately met in Medicaid managed care. In addition, it prescribed what children may be considered special needs when enrolling in managed care. While the BBA amendments permit states to mandate managed care enrollment for most Medicaid enrollees through a state plan amendment instead of obtaining a waiver, they exempt certain groups of eligibles from this provision. States must still seek a 1915(b) or 1115 waiver if they wish to enroll children under age 19 who are:

- eligible for supplemental security income under Title XVI (SSI);
- receiving services through a family-centered, community based, coordinated care system under section 501(a)(1)(D) of the Title V Maternal and Child Health Services Block

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Grant and are defined by the state in terms of either program participation or special health care needs;

- described in section 1902(e)(3) of the Social Security Act (Katie Beckett children);
- receiving foster care or adoption assistance under part E of Title IV; or
- in foster care or otherwise in an out-of-home placement.\(^7\)

The purpose of this list is to exclude, or protect, certain eligibility groups from mandatory participation in managed care without due attention to their specialized needs. In identifying those groups of Medicaid eligibles that are exempt from mandatory managed care, the list also serves as a definition of children with special health care needs. It is being used to identify which children may have special health care needs by virtue of their eligibility category and their source of service delivery.

**HCFA’s Initiatives**

In response to Congress’ concerns and directives, HCFA has initiated several projects addressing Medicaid managed care delivery for persons with special health care needs. The agency issued a guidance to states in October 1998, entitled *Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs*. This document provides a framework for states to consider in designing their managed care programs. As a component of the study required in the BBA, HCFA, and the American Public Human Services Association (APHSA) developed a survey to assess what states are doing to assure that the needs of populations with special health care needs are being met in managed care. APHSA released the survey to states in early June 1999. HCFA has also released a draft of *Interim Review Criteria for Children with Special Needs* for evaluating 1915(b) waiver applications and renewals. These criteria were developed in response to certain managed care requirements of the BBA regarding enrollment of the five groups of Medicaid-eligible children, identified in the BBA, in mandatory managed care programs. To further their understanding of CSHCN in Medicaid managed care and to gain States’ input on the *Interim Criteria*, HCFA and ASPE have initiated a study of State activity in Medicaid for these children, to be conducted by NASHP, under contract with The George Washington University Center for Health Services Research and Policy.

**Other Initiatives**

In addition to HCFA’s initiatives, the Health Resources and Services Administration (HRSA) has funded the preparation of a technical assistance document entitled *Optional Specifications: Purchasing Medicaid Managed Care for Children with Special Health Care Needs*. This document, currently under development, will serve as a “toolbox” for states as they develop

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\(^7\) Balanced Budget Act of 1997, Section 4701.
contracts with managed care organizations to enroll CSHCN.\(^8\) The U.S. General Accounting Office (GAO), upon the request of certain members of Congress, is conducting a study on the safeguards available for children with special needs who are enrolled in capitated Medicaid plans.

Numerous national provider associations, advocacy organizations, and consumer groups have played an active role in lobbying Congress and HCFA about the importance of ensuring the protection of children with special health care needs in Medicaid managed care.\(^9\) They have organized their constituencies to express their concerns, and they have developed written materials targeted to a variety of audiences: assisting managed care plans in serving CSHCN, providing guidance to pediatricians and other providers in assembling a comprehensive plan of care for their patients, and educating families and consumers about managed care and how to access services.

**Intent of June 20, 1999 Symposium**

In this context, the National Academy for State Health Policy, with co-sponsorship from HCFA and The Henry J. Kaiser Family Foundation, convened a symposium on children with special health care needs. The purpose of the symposium was to identify key issues in Medicaid managed care for children with special health care needs and examine the ways that states have addressed those issues. Participants identified those strategies and components that have been successful and what remains a challenge in providing comprehensive care to children with special health care needs within managed care. The discussion focused on the following major issues:

- identifying Medicaid-eligible children with special health care needs;
- assessing MCO capacity for providing adequate and appropriate care;
- enrolling CSHCN in managed care systems;
- assessing the clinical and non-clinical needs of CSHCN;
- providing the full spectrum of benefits that CSHCN need;
- coordinating care for CSHCN;
- financing/payment systems for managed care programs that enroll CSHCN;
- ensuring quality of care;

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\(^8\) These purchasing specifications are being prepared by the George Washington University Center for Health Services Research and Policy, in consultation with officials from Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), Health Care Financing Administration (HCFA), Office of Assistant Secretary for Planning and Evaluation (ASPE), and the Department of Education (DOE).

\(^9\) As example, these organizations include, but are not limited to: National Association of Children's Hospitals, American Academy of Pediatrics, Children's Defense Fund, Association of Maternal and Child Health Programs, American Psychiatric Association, Family Voices, March of Dimes, National Health Law Program, Child Welfare League, and National Association of WIC Directors.
• establishing linkages with other key organizations, providers, and agencies; and
• working with stakeholders through the development and administration of the program.

Participating states provided examples of certain issues and program components in their respective states during the discussion. These are noted in the paper simply as illustrations of how these nine states have developed their programs. Tables 1 - 7 detail selected program characteristics of the states’ managed care programs that are particularly important to CSHCN. This information is not to be interpreted as ‘best practices,’ but, rather, as an illustration of the variety of initiatives taken in states.

The intent of this paper is to present the content of the day’s discussion and summarize the perspectives of the participants as to what the outstanding issues are in providing appropriate managed care coverage to children with special health care needs. Though some background information is incorporated in the document so as to provide a context for the summary, the paper is not meant to be a thorough analysis of the status of Medicaid managed care for CSHCN nor does it attempt to provide a comprehensive review of, or reference to, the applicable literature. Please see the bibliography for additional reading on the subject.

Table 1: Medicaid Managed Care Programs: States Participating in Symposium
This table provides basic information about the managed care programs of the 9 states. The data is based on NASHP’s 1999 Guidebook and input from individual states.

<table>
<thead>
<tr>
<th>DE</th>
<th>FL</th>
<th>MA</th>
<th>MI</th>
<th>NJ</th>
<th>NM</th>
<th>OK</th>
<th>TX</th>
<th>VA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authority</td>
<td>1115</td>
<td>1915b</td>
<td>1115</td>
<td>1915b</td>
<td>1915b</td>
<td>1915b</td>
<td>1115</td>
<td>1915b</td>
</tr>
<tr>
<td>Model</td>
<td>Risk</td>
<td>PCOM/Risk</td>
<td>Risk/PCCM</td>
<td>Risk/PCCM</td>
<td>Risk</td>
<td>Risk</td>
<td>Risk</td>
<td>Risk/PCCM</td>
</tr>
<tr>
<td>Total MMC Enrollment (as of 7/1/99)</td>
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<td>865495*</td>
<td>526665</td>
<td>794961*</td>
<td>396006</td>
<td>210000</td>
<td>201737</td>
<td>402500</td>
</tr>
</tbody>
</table>

* Enrollment as of 10/98; NASHP Guidebook.
IDENTIFYING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

One of the primary concerns in providing adequate care to children with special health care needs is being able to identify who they are. There was widespread agreement among the participants that the capacity to identify all CSHCN does not currently exist, largely because there is no one definition of these children that can be put into practice. Further, there is no single tool or process by which to conduct that identification. The definition of CSHCN has been approached in two major ways: by eligibility code and by risk status. The first uses certain eligibility categories as a proxy for those individuals who have special health care needs. The second is an epidemiological approach, aimed at identifying the universe of children with special health care needs by their health condition or ‘at risk’ status. The discussion among the participants focused on the difficulties and drawbacks of both approaches and the challenge to Medicaid managed care to identify a finite number of children who need special services. Historically, state Medicaid agencies have tended to use an epidemiological definition rather than a categorical approach in identifying CSHCN. Since eligibility is not always a good marker of whether a child has special health care needs, they have focused on health needs, regardless of the eligibility category. As discussed below, the new emphasis on identification through eligibility categories creates certain challenges for State Medicaid programs.

BBA Requirements for Identifying CSHCN

The BBA of 1997 identified certain eligibility categories to be excluded from mandatory managed care participation, unless the state obtains a waiver. These categories are those that the Congress believes are most likely to include children with special health care needs and therefore, require special consideration before including them in managed care. The draft Interim Review Criteria for 1915(b) waivers requires states to identify those children in each of the five categories to be covered under managed care, as part of the waiver application and renewal process. When participants were asked how these categories could be used to identify CSHCN, significant impediments were identified.

A key impediment that was identified was the nature of federal categorical programs serving children, each of which has different requirements for eligibility, data collection and administration. State Medicaid agencies are usually able to identify those special needs children who are characterized as such because of their aid category for Medicaid eligibility. These categories include SSI, foster care, Katie Beckett, and adoption placement. There can be certain administrative obstacles, however, when there are separate state agencies conducting eligibility determination and administering Medicaid.

- SSI eligibility identification can be problematic because of the length of time it takes the federal Social Security Administration (SSA) to establish SSI eligibility. In particular, infants up to one year of age may be missed for a period of time while their SSI determination is pending.

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• Foster care children can also be difficult to pick up if their placement is only temporary and/or if they are still identified by a TANF eligibility code. There is often a lag between the child being removed from the home and the Child Welfare agency making the necessary changes on the Medicaid eligibility file. In some instances the child may be out of the home for several weeks before the eligibility code is changed in the Medicaid system.

**Title V and Medicaid: Identification Issues**

Children receiving Title V present a particular challenge for Medicaid agencies to identify because of the differences in eligibility criteria and program administration between Title XIX and Title V. Despite the fact that State Medicaid agencies are required under federal law to enter into coordination agreements with the state’s Title V agency, Title V children are not automatically apparent to Medicaid. In many states, Medicaid eligibility data does not include information about whether the child is also receiving Title V services, nor are all Title V services covered by Medicaid so that they can be identified by claims. Since Title V is not an entitlement program like Medicaid, in some instances children may qualify for Title V services but be placed on a waiting list because of insufficient funds. As a result, their need for care may, in fact, increase as they await services from Title V and identification by Medicaid.

The programmatic relationship between Medicaid and Title V has a significant effect on each state’s approach to identifying CSHCN for Medicaid managed care, funding services, and coordinating them between the two programs. In most states, the two programs are mutually exclusive in terms of eligibility and funding. Two of the states represented at the symposium are the exception: Florida and Michigan. They have integrated the two programs’ eligibility functions and funding, and therefore, have facilitated the identification of Title V recipients.

• Florida developed a special managed care plan, the Children’s Medical Services (CMS) network, for children with special health care needs. The Medicaid agency has an interagency agreement with the state Title V CSHCN program, Florida Children’s Medical Services, to provide a managed care system for these children. With this

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10 TANF is the Temporary Assistance for Needy Families program, which replaced the AFDC program. The TANF population consists of low-income families who are eligible for cash assistance and Medicaid.

11 State Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) programs are funded through Title V of the Social Security Act, the Maternal and Child Health Services Block Grant. The CSHCN program is mandated to develop family-centered, community-based systems of services for children with chronic conditions and to provide or arrange for the delivery of these services to low-income children.

12 Section 1902(a)(11)(B) of the Social Security Act.
arrangement eligible Title V children are automatically identified as participants in Medicaid’s managed care program.

- Michigan has integrated the state’s Title V and Medicaid programs in one agency, making it relatively easy to identify those Title V CSHCN children. The state initiated a managed care program specifically for children eligible for both Title V CSHCN and Medicaid in 1997, known as the Children’s Special Health Plan.

Challenges to the State Medicaid Agency in Identifying CSHCN

Symposium participants noted that the BBA definition of CSHCN is somewhat problematic in identifying the universe of children who may have special health care needs. It excludes other children who have special health care needs but are not in one of the identified aid categories. State Medicaid agencies know from experience that many of the children who are eligible for Medicaid because they qualify for TANF also have complex health care needs. For example, the TANF child who has a severe asthma condition will not be defined as special needs, using the BBA definition nor will a child who becomes homeless or who is awaiting foster care placement. The eligibility systems used by states were not designed to collect information or track beneficiaries based on their medical needs; their sole purpose has been to maintain financial and demographic eligibility information. And since a child can develop special health care needs overnight - through the development of a serious illness or change in family circumstances or environmental conditions, the periodic eligibility interface does not provide a very timely means of identification.

Medicaid eligible children who are served by other public programs such as the Special Education Program, the Early Intervention Program, and the Children’s Mental Health Services Program13, may also be identified as children with special health care needs. Though there may be a financial link between Medicaid and these programs, there is not necessarily an eligibility link that readily identifies the children as needing specialized services through Medicaid, unless they are SSI-eligible. That identification process is largely dependent on the particular agreements that the Medicaid agency may have with the other state programs. It is also subject to confidentiality requirements that can pose further obstacles to the state Medicaid agency’s ability to identify children with special health care needs. Both the Federal government and states have strict confidentiality requirements for many public programs -- including Title V, Special Education, and Mental Health -- that prohibit the sharing of enrollee information among programs. State agencies and managed care plans have tried various approaches to overcome this barrier, including the following two examples:

13 The Special Education Program is operated by the Office of Special Education and Rehabilitative Services (OSERS) of the Department of Education; the Early Intervention Program is also operated by OSERS; and the Children’s Mental Health Services Program is operated by the Substance Abuse and Mental Health Administration of DHHS.
Florida secured a change in its state statute regarding confidentiality requirements to facilitate information exchange between certain agencies.

CalOPTIMA included explicit agreements regarding the sharing of enrollee information in its memoranda of understanding with the various public agencies serving children with special health care needs.

The Role of the MCO

MCOs are largely dependent on the state to provide accurate eligibility code information that will identify those children who fit the BBA’s definition of special health care needs. Since they have no access to claims history for new enrollees, they often have no information about the children or their needs. Similar to the State Medicaid agencies, MCOs cannot necessarily identify Title V children. MCOs are at a further disadvantage because of the lag time between eligibility determination and the receipt of updated codes from the Medicaid system. Since most states transmit eligibility information on a monthly basis to the MCOs, it may be several weeks before the MCO learns of a child’s change to SSI or foster care status. According to one MCO representative, this can present enormous problems in delivering appropriate care, since children’s needs are often at greatest risk right after they have been removed from their family and put in foster care.

In the case of TANF children with complex health care needs, it may be the MCO that first identifies them when providing the required EPSDT screenings and services. And, as Medicaid managed care matures and babies are born with health plan coverage, it becomes the MCO’s responsibility to identify those children with special health care needs. The burden is upon the MCO to inform the state of those children whom it identifies. There are often reporting difficulties between the state and the MCO that jeopardize the successful transfer of information, however. Further, it is often difficult to incorporate the information that is provided by the MCO into the state’s eligibility information system, due to incompatibility between the two systems. Consequently, it can be very difficult to gain an accurate number or picture of children with special health care needs being served by the MCO.

Other Approaches to Identifying CSHCN

Agencies, organizations, and advocates that focus specifically on maternal and child health issues have taken a different approach in defining CSHCN. They have used the child’s health status for purposes of identification rather than their particular eligibility for assistance. The following definition of CSHCN is promoted by the Maternal and Child Health Bureau (MCHB), State Title V programs, and certain advocacy and provider organizations:

*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.\textsuperscript{14}

State participants discussed their interest in being able to identify children based on their risk status but they were reluctant to embrace such an expansive definition because of the challenge of determining a finite number of special needs children to be covered by the Medicaid program. They were concerned that such a population-based definition may not be a realistic approach to identifying CSHCN for Medicaid managed care.

Despite the lack of consensus on the definition of CSHCN, there was considerable agreement that it would be helpful to have a tool to identify these children. It was noted that several assessment tools are currently in the development and testing stage, including the FACCT tool, which is being developed by the Foundation for Accountability and the National Committee for Quality Assurance (NCQA),\textsuperscript{15} the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) and a shorter version of QuICCC, known as QuICCC-er.\textsuperscript{16} States were reluctant at this point, however, to endorse a particular tool given the current discussion about how to define CSHCN.

Participants also had varying opinions as to what entity would be the most appropriate to administer such a tool. Some participants felt that the responsibility should stay with the state Medicaid agency, others noted that an enrollment broker can provide that function, while still others suggested that it be left to the MCOs. One participant commented that a single source of identification is not sufficient; even if an enrollment broker performs the initial identification screening, a MCO must be able to perform the same function so that it can identify those children whose situation changes after enrollment.

States have adopted various approaches to identifying those children who have special health care needs, beyond the use of Medicaid aid categories. Some have developed their own tools to assess special needs during the enrollment process.

\textsuperscript{14} 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 MCHB on October 28, 1998.

\textsuperscript{15} The FACCT survey is administered through the mail and has multiple questions based on functional limitation, reliance on compensatory mechanisms or special services/assistance, and service use beyond routine. It is being tested by MCOs.

\textsuperscript{16} The QuICCC screening tool consists of 39 questions that are designed to be administered orally (face-to-face or telephone) to the parent or guardian. The questions are based on functional limitation, reliance on compensatory mechanisms or special services/assistance, and service use beyond routine. The QuICCC-er tool has 17 questions and preliminary testing indicates that it picks up 95% of what the QuICCC identifies.
• Oklahoma analyzed the utilization patterns of its disabled population, including children, to be included in the transition to the MCO model; identifying the top 10% by cost as an indication of those with special needs. Medical case managers within the state Medicaid agency called these individuals, including the families of identified children, and completed an outreach profile to get an indication of the type and severity of the child’s health needs. These initial calls were found to be particularly effective as a means of further explaining the managed care system. The information that is collected is then communicated to the MCO upon enrollment. MCOs and child advocates have praised the state’s effort to identify special needs children by this method.

• Both New Jersey and Delaware use their enrollment broker to gather information that identifies children with special needs. The enrollment broker conducts an assessment, using a questionnaire that ascertains the new enrollee’s health care needs.

• New Mexico uses fee-for-service claims to identify CSHCN, including those for prescriptions, DME, targeted case management, private duty nursing, therapies, and behavioral health. The State then informs its MCOs when these children enroll, so that the plans are able to conduct early assessments and develop plans of care.

**Summary**

Regardless of how children are identified or by whom, symposium participants stressed the importance of having a more precise and measurable definition of special needs, a clear understanding of why the children are being identified, and a protocol for how the information will be used by the states, the MCOs, and by HCFA. One of the states’ greatest concerns is that there be a means of communicating the data between MCOs and the state agency so that the children get the services they need and are monitored throughout the duration of their eligibility. States need to have the infrastructure so that they can track identified children, relay the information to other appropriate players, and conduct numerical and qualitative analyses as necessary.

**HOW TO ENSURE CSHCN GET THE CARE THAT THEY NEED**

The aim of the Medicaid agency is to ensure that children with special health care needs have access to appropriate care, whether through fee-for-service or a managed care system. With the shift to managed care, states have the opportunity to overcome the fragmented nature of fee-for-service care, where specialty services are not always coordinated with primary care. They also have the obligation to make sure that the child has continuity of care, including continuity of providers from fee-for-service to managed care. State representatives at the symposium felt that risk-based managed care has improved the delivery of care for children with special health care needs. It has fostered more proactive approaches in assembling appropriate care than the laissez-
fare model of fee-for-service. Family advocates reminded participants, however, that care for the child with special needs can be enormously difficult, complex, and frustrating for families, regardless of the delivery system. Managed care systems must be able to deliver that care and improve its quality and coordination. Parents and providers remain concerned that the care will be compromised because of financial incentives that may prohibit the MCO from providing the intensity of care required by CSHCN.

**Enrollment**

Enrollment in managed care represents a fairly significant change for CSHCN and their families. It is critical that these families understand how the delivery system for their child is going to work once enrolled in managed care and that they have support during the transition. One symposium participant noted that many families feel a certain safety and trust with the providers of other public programs that provide specialized services for their children, such as Title V, special education, early intervention, and mental health providers. It may be in the best interest of the families for the Medicaid agency and MCOs to involve these agencies and providers in the education and enrollment process.

State Medicaid agencies can be well-served by laying the groundwork prior to implementation of their managed care program for populations with special needs and by taking extra time during the enrollment process itself.

- Oklahoma initiated enrollment for the aged, blind, and disabled (ABD) Medicaid populations in July 1999; it was staggered over a four-month period to allow sufficient time for education. As noted above, medical case managers within the Medicaid agency are contacting those Medicaid beneficiaries who have high utilization, as indicated by their claims history. The purpose of the contact is to learn about their care needs and their current providers and then match the enrollee with a MCO that can meet their needs. In one instance, staff were able to match a child who sees seven specialists with a particular MCO so that he could maintain his relationship with the majority of his providers. Parents are very grateful for this contact and the time that is spent in ensuring the best care for their child. If a potential enrollee is in active treatment and would not have appropriate access through any of the contracted MCOs, the State may delay enrollment and follow up with the individual after completion of treatment. Oklahoma is requiring its participating MCOs to allow specialists to be primary care providers, when appropriate, to maximize the enrollment opportunities for the ABD population.

- Texas conducted four roll-outs of managed care programs in 1996. Through that experience, the Medicaid agency determined that it needed to allow more time for the initial enrollment process. In their most recent roll-out, they allowed six months to educate potential enrollees initially and choose their MCO. This appears to have resulted in a voluntary choice rate of 80% and consequently, less auto assignment.
• The Michigan Department of Community Health, which houses the State’s Title V and Title XIX programs, implemented a managed care program specifically for children with special health care needs in 1997. Pediatricians, families, state agencies, provider organizations, children’s hospitals, MCOs, and child advocates collaboratively developed a plan for this initiative, based on three guiding principles: 1) families are experts, 2) the treatment plan and the delivery of care should be family-centered, and 3) active coordination between primary care physicians and specialists is essential. Each participating MCO must demonstrate how these principles are incorporated in its delivery system for special needs children. Those families who have enrolled their children find security in knowing that health care and providers will be tailored to the needs of their child. Michigan discovered, however, that some families did not want to enroll their children in a specialized plan, despite its extensive planning and interviews with parents and children to develop this option. They chose to remain in the mainstream MCO because they felt that there was a certain stigma attached to the specialized plan.

Some states have found great success in using their enrollment brokers to identify CSHCN, educate the new enrollees and their families, and monitor their access to care.

• New Jersey’s enrollment broker uses specific questions on the enrollment form to assess the child’s condition and care needs, help the family understand the new delivery system, and determine appropriate providers for the child’s care. The broker has each MCO’s entire network on its data base so that it is able to make the best match of providers and preserve the enrollee’s continuity of care. With the TANF population, the enrollment broker has been successful in making contact with almost all new enrollees, resulting in a voluntary choice rate of 90%. State officials hope for the same success rate when enrolling the special needs population.

• In Delaware, the enrollment broker performs an education and outreach function as it enrolls beneficiaries into MCOs. It works closely with the MCOs’ providers, the maternal and child health agency, mental health and substance abuse agencies, and the education department, so that it has a complete picture of the care network and the various programs impacting the child’s care. It can then inform the enrollee and the family about how to access care for their child.

Participants in the forum raised the question as to what role the provider should have in the enrollment process. Some felt that providers might be helpful to their patients in choosing the MCO that can provide the specific care that the child needs. But others thought that this practice runs the risk of adverse selection if a provider has preferential contracts with certain MCOs. One participant noted that providers do indeed direct their patients to the highest paying MCO. In general, states were wary of sanctioning this kind of provider influence.

One of the objectives of the enrollment process in any Medicaid managed care program is to achieve a high rate of voluntary enrollment with either a MCO or a PCCM provider. Voluntary
enrollment means that the enrollee and/or family have consciously selected the managed care option that they want to be enrolled in and that best meets their needs. Voluntary enrollment becomes even more significant for people with special health care needs because of the importance of connecting the enrollee with the appropriate MCO and/or provider. This suggests that the enrollment process needs to be very “hands-on” to ensure that enrollees have every opportunity to choose the managed care option that is going to work best for them. This translates to a budget expense of which states need to be aware when developing their programs.

Involuntary assignment to a MCO, or auto-assignment, raises particular concerns for children with special health care needs. It can be detrimental for a child to be assigned to a MCO and, consequently, cut off from his or her established source of care because that provider is not participating in the MCO’s network. Further, it may be counterproductive to assign this population to a MCO or provider, such that they have little understanding of how their access to care has changed. Auto-assignment is an ongoing challenge for states as they craft their mandatory managed care programs. Some states use previous claims history, if it exists, in linking an enrollee with a MCO that can meet their needs through its network of providers. But, in many instances that information is not available, nor is it possible to accurately identify which provider is key in the enrollee’s care. States are struggling with finding the best method to auto-enroll CSHCN so that their particular provider needs are met.

Assessment

The assessment is an important component of a comprehensive system of care for the child with special health care needs. It is conducted in order to ascertain what services the child needs and the degree of intervention necessary. The screening tools described above can form the basis of that assessment. Most often, it is the responsibility of the MCO to perform the assessment, though information collected during the enrollment process can inform that process. Frequently, a child with special health care needs has been assessed previously by a pediatric specialist, a Title V program, a mental health provider, or through Individuals with Disabilities Education Act (IDEA) programs. The MCO and the PCP may find it valuable to obtain that information as they conduct their own assessment and prepare a treatment plan for the child. States can facilitate this process by providing training and information to the MCOs about the other entities and programs that provide care to children with special health care needs. States can also improve the assessment process by specifying any coordination requirements between the MCO and other agencies and providers in the contract.

The document, Optional Specifications: Purchasing Medicaid Managed Care for Children with Special Health Care Needs, currently in draft and still to be reviewed by states, suggests certain contract specifications for MCOs serving CSHCN. It describes the purpose of a treatment plan to “specify the items and services that are appropriate to prevent the deterioration of the child’s condition and to promote the development or maintenance of age-appropriate functioning by the
child. It suggests that the primary care provider develop the treatment plan in cooperation with a pediatric specialist familiar with the child’s care needs and the family, and incorporate any other recent assessment of the child and/or requirements contained in an Individualized Family Services Plan (IFSP) or an Individualized Educational Program (IEP). In Michigan, for example, all children with special needs receive an assessment and corresponding individualized treatment plan when they enroll in the Children’s Special Health Plan. Those services that are included in the treatment plan do not require prior authorization, which facilitates the provision of services for these children.

States have found that moving families into Medicaid managed care can uncover health care needs and provide access to care that had not been available previously. Managed care provides an opportunity to coordinate the assessment process with other special needs service providers and identify the full spectrum of needed care. In some instances, states report that the assessment process has resulted in increased enrollment in Title V programs as more children who qualify for those services are identified, as well.

**Benefits for CSHCN**

State participants in the symposium emphasized that managed care for children with special health care needs requires a flexible benefit system and that the funding should follow the treatment plan, not dictate it. The two key phrases associated with this population are “high touch” care coordination and “high tech” services. Both are necessary to provide adequate and appropriate benefits to these children. The benefits for this diverse population often encompass services beyond those included in a traditional benefit package and at an intensity that is not customary in commercial MCOs.

**Benefits in the MCO Contract**

The Early Periodic Screening, Diagnosis and Treatment program (EPSDT), Medicaid’s mandatory provisions for children under age 21, entitles all Medicaid-eligible children to certain benefits, including outreach and informing, screening, diagnosis and treatment, and access to providers who can provide EPSDT services. As more children, particularly those with special health care needs, are enrolling in managed care, it has become increasingly important to spell

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17 Excerpt from *Optional Specifications: Purchasing Medicaid Managed Care for Children with Special Health Care Needs*, in draft, section 103(b)(2), June 1999, Center for Health Services Research and Policy, The George Washington University Medical Center.

18 An IFSP is a plan of services developed by an early intervention agency pursuant to the Individuals with Disabilities Education Act (IDEA) which sets forth the early intervention services required by a child and the child’s family or caregiver. An IEP is a plan of services developed by an educational agency pursuant to IDEA, which sets forth the special education and related services required by the child.
out the EPSDT benefits in managed care contracts so that children have access to the full range of services.\(^{19}\)

Specialty care, home health and nursing services, durable medical equipment and supplies, rehabilitation therapies, pharmacy, and mental health and substance abuse services are all essential to maintain the health and independence of CSHCN. Though most are benefits that Medicaid routinely covers, they must be provided with greater frequency and wider scope to CSHCN than to the general population. Managed care can provide certain advantages in accessing these benefits because it can offer a flexible and responsive system. For example, a wheelchair can be made available to an enrollee very quickly when there are no complex, time consuming prior authorization requirements like those in the fee-for-service system.

In addition, family and community support services such as health education, support groups, transportation, home visiting, respite care, counseling, and parent-to-parent support can be critical in making the care delivery work for CSHCN. As states develop their managed care contracts they have to determine whether these types of services can be provided adequately in a capitated arrangement. They must evaluate the ability of the MCO to provide services that are outside of the scope of their usual benefit package. In some instances, it may be beneficial for MCOs to develop relationships with a provider, agency or organization that has a particular focus on meeting the needs of CSHCN\(^{20}\) as they craft a benefit package that is responsive to these children. One symposium participant advised MCOs to take advantage of the expertise of these providers as they develop their delivery system instead of reinventing the wheel.

As discussed previously, MCOs may not fully appreciate the complexities of providing services to Medicaid-eligible children with special health care needs. In particular, they may not understand the breadth and scope of the EPSDT requirements. A study conducted by the National Health Law Program suggests that Medicaid-eligible children are not receiving the EPSDT benefits to which they are entitled from the Medicaid program, either through fee-for-service or managed care.\(^{21}\) It is incumbent upon the State Medicaid agency to fulfill its obligation to provide those federally required benefits. Therefore, it is in the state’s best interest to be very explicit in its contracts with the MCO as to the extent of the MCO’s obligation to finance and provide those services. It is also advisable to provide training to both the MCOs and

\(^{19}\) The National Health Law Program (NHELP) has prepared a checklist for ensuring that EPSDT benefits are provided under managed care. Medicaid Managed Care and Children with Special Needs: An EPSDT Checklist is available from [http://nhelp.org/pubs/mc1997checklist-epsdt.html](http://nhelp.org/pubs/mc1997checklist-epsdt.html).

\(^{20}\) Often referred to as “traditional” providers or “safety net” providers, they may include: Title V providers for CSHCN; providers of special education services for school-aged children with disabilities; providers of early intervention services for infants and toddlers with developmental delay or disabilities; providers of mental health services; and providers of child welfare services, including foster care.

the providers as to what the service needs are for these children and what benefits must be
provided through EPSDT. This can prevent problems with coverage denial later on that could
result in possible harm to the child and/or delay in physical/emotional development.

Benefits Outside of the MCO Contract

In many instances, Medicaid managed care contracts do not include all standard Medicaid
benefits for children, particularly for CSHCN. States use “carve outs”\(^\text{22}\) to provide specific
services outside of the general capitated benefit package. They do so through either fee-for-

service reimbursement or separate capitated arrangements. Behavioral health benefits are often
carved out, as are Title V services, early intervention and health-related special education
services. Whatever the reimbursement arrangement for the carve-out, communication among the
state, MCO, and applicable provider is key so that the service delivery does not become
fragmented. Participants emphasized that all contracts clearly specify who has the responsibility
and authority for providing the service, the scope of the service, and how it will be coordinated
with other providers and components of the treatment plan.

Medical Necessity

Medical necessity standards are an essential component in determining whether a child with
special health care needs gets the care that he or she needs. In managed care, the term refers to
the criteria by which an MCO determines whether a particular service will be covered. The
definition that MCOs use in determining covered benefits for their commercial populations is, in
most instances, too limiting for CSHCN. As discussed in a recent study on *Defining Medical
Necessity*, “existing definitions of medical necessity may lead to the denial of services required
by children, youth, and adults with developmental disabilities, mental retardation, genetic
disorders, serious mental health problems, or other special health care needs. Most definitions
lack critical components that will promote appropriate care for this population.”\(^\text{23}\)

This is one of the main concerns of child health advocates: that commercial MCOs will justify
the exclusion or denial of coverage by applying a narrow definition of medically necessary care.
In fact, according to *A Nationwide Study of Medicaid Managed Care Contracts*, Third Edition,
“contracts (for Medicaid coverage) continue to utilize medical necessity specifications, in the case

\(^{22}\) A service “carve-out” is when specific services are provided outside of the enrollee’s general MCO
coverage. This can be done through one of two mechanisms; 1) direct coverage on a fee-for-service basis under the
state Medicaid program; and 2) coverage through a specialized managed care contract.

\(^{23}\) Ireys HT, Wehr E., Cooke RE. *Defining Medical Necessity: Strategies for Promoting Access to Quality
Care for Persons with Developmental Disabilities, Mental Retardation and Other Special Health Care Needs.*
of children, that are narrower than what is required under federal law."24 The federal statute creating EPSDT defines medically necessary care for children to include any service needed for the early diagnosis and treatment of a condition, regardless of whether it is covered for adults.25 The disparity between federal requirements and what is included in MCO contracts can lead to "service gaps" which, if defined ambiguously, can leave beneficiaries, plans, providers and states confused over who bears the financial and services obligation to furnish care."26 Consumer and provider organizations advocate for a pediatric definition of medical necessity in states' contracts with MCOs, including the inclusion of specific EPSDT language.27 Further, they recommend the adoption of specific monitoring criteria so that the state can assess the MCO's compliance in using such a definition to determine covered services.

Care Coordination

Specific definitions may vary, but there is universal agreement that care coordination is critical for populations with special needs. Children with special health care needs are a "high touch - high tech" population, and care coordination can make the difference in connecting the providers, the services, and the family. Care coordination usually includes both benefits management and service coordination and, as several symposium participants noted, is most effective when it involves the family. Family Voices, a national grassroots organization of families of CSHCN, conducted a survey of over 2,000 families with children with special needs beginning in March 1998.28 When parents or guardians were asked how many hours they spent in coordinating their child's care per week, 26% reported five hours or more, while 73% spent between one and five hours.


25 Section 1905(r)(5) of the Social Security Act.


28 The Family Survey is a collaborative effort between Family Voices and the Heller School at Brandeis University. It is designed to collect information about the experiences of families of children with special health care needs enrolled in a variety of health care systems. For purposes of the survey, children with special health care needs include those age birth to 18 who have a health or medical problem that is expected to last for at least one year; needs frequent medications or special diets, or medical technology, or assistive devices, or occupational, physical or speech therapy, or personal assistance, needs care from physicians or mental health or other health professionals over and above what is usual for a child of the same age.
Though the federal Medicaid statute does not contain a “care coordination services” category, Medicaid covers services of this type under Early Periodic Screening, Diagnosis and Treatment (EPSDT) services, the optional targeted case management benefit, and through home and community-based services. And HCFA notes in its State Medicaid Manual that “care coordination, including aspects of case management, has always been an integral component of the EPSDT program . . .”29 There are, in fact, three different types of case management defined in the State Medicaid Manual; EPSDT case management, administrative case management, and targeted case management services.30 As discussed in the draft Optional Specifications,31 it is assumed that care coordination services are covered under the State’s Medicaid plan, whether they are characterized as “case management” or as “care coordination” and that they are covered under the MCO as services, not as administrative costs.

Care coordination for CSHCN can encompass a range of functions, from clinical care planning and management to resource identification, scheduling of appointments, and linkages to other supports. The assessment process identifies the appropriate level of care coordination and whether it is necessary on a continuous basis or whether periodic coordination is sufficient. The MCO may identify the child’s primary care physician as the appropriate locus of care coordination or may have staff within the MCO provide that function. In some cases a nonmedical person may be the best coordinator of the individual child’s needs. States have found that it is very important to communicate with both the families and advocates to achieve buy-in for the program and the child’s plan of care. The MCO may be well-served by hiring someone who can be a liaison with the community.

Care coordination may represent a new function for a MCO, particularly for children with special health care needs. MCOs do not necessarily have the experience or capacity to address the range of service and resource needs that CSHCN have. Symposium participants emphasized the importance of states working with their MCOs to develop a care coordination system for this population. The MCOs may need training about the diverse service needs of these children and the variety of providers and agencies that may already be providing case management services for them. One state Medicaid agency has contracted with an advocacy organization to work with the MCOs to help them understand the complex needs and the available community resources for the populations with special needs.

Care coordination can be fraught with complications for the MCO and the family when other providers, programs, and agencies are providing case management services for some component of the child’s care. A child may, in fact, have multiple case managers through the fee-for-service

29 HCFA State Medicaid Manual, Section 4302.2H.

30 Ibid.

31 Optional Specifications: Purchasing Medicaid Managed Care for Children with Special Health Care Needs, in draft. Section 102(b).
system and, from the family’s perspective, they don’t want or need another. Such duplication simply adds to the logistical challenges that families face in navigating the system. This becomes an important consideration for the state Medicaid agency and the MCO in developing policies and procedures for care coordination under managed care. The MCO can play a critical role in coordinating the child’s care across the various case management systems.

- New Jersey has taken a proactive approach to care coordination in incorporating the ABD population in managed care. It has framed care coordination as the centerpiece of managed care for these enrollees and is developing protocols for how to provide this component with the input of providers, public programs, and child advocates.

- CalOPTIMA, a managed health system in California, holds monthly meetings with its participating MCOs, the care coordinators and community-based organizations serving the special needs populations to discuss coordination issues among them.

One of the challenges of providing care to Medicaid beneficiaries is the episodic nature of certain categories of eligibility. Those enrollees whose eligibility is based on their financial eligibility, alone, may cycle on and off Medicaid due to fluctuations in their income. Periods of ineligibility, whether one month or several, are detrimental to the continuity of care and very frustrating to states, MCOs, and providers who are trying to provide that continuity. Ultimately, the care loses both its medical effectiveness and cost effectiveness.

States have the option, under Medicaid rules, of lengthening the eligibility period from the traditional 6 month period to 12 months. Increasingly, states are adopting the guaranteed eligibility provision so that enrollees can continue to receive benefits for a period of time after they lose their Medicaid eligibility.32 This step can stabilize the managed care membership and lessen their disruption of care.

Continued access to benefits can also be facilitated through coordination agreements between State Medicaid agencies and Title V agencies. As noted previously, federal regulations require such interagency agreements. The Title V program complements Medicaid in its provision of services; it can provide wraparound services and access to certain care during periods of ineligibility. States are also establishing linkages with their Children’s Health Insurance Programs (CHIP). Coordination between these programs is important so that children can be followed regardless of eligibility status.

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Table 2: Selected Services Within Contract to Facilitate Care for CSHCN in Symposium States

The data in this table reflects MCO contract provisions in general, not just those for CSHCN. The data is based on NASHP’s 1999 Guidebook and input from individual states.

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Assessing MCO Capacity

Serving children with special health care needs represents a significant departure from normal practice for many MCOs. Those MCOS that have elected to participate in Medicaid managed care for populations with special needs find themselves on a fairly steep learning curve. They have to become familiar with the needs of a different population and incorporate components of care that are not usually part of their commercial benefit package. As emphasized previously, it is important for states to be as explicit as possible in communicating to the MCO what to expect with this population and with Medicaid. Symposium participants agreed that contracts between the state Medicaid agency and the MCO need to spell out the expectations of the MCO so that there are no questions or problems about financing, providing, or coordinating the care that is described in the contract.

Network Development

The composition of the MCO’s provider network is key to providing benefits to children with special health care needs because it determines the extent of enrollee choice and the degree of access to appropriate services. The MCO must recruit the appropriate providers for the network and then develop a system that links the various players together. States can take an active role in working with their MCOs to make sure they have a comprehensive network of primary care providers, specialists, ancillary service providers, equipment vendors, mental health providers, and community-based supports. They can also require each MCO to conduct a network analysis, to assess whether there are sufficient and varied providers to serve a population with complex needs. If a MCO is unable to assemble a network that includes all necessary specialists for the
covered population, a state may require the MCO to pay for some care outside of the network so that the enrollee has access to a particular provider.

Some states encourage MCOs to recruit traditional providers into their networks and a few actually require MCOs to subcontract with certain public program providers that have been providing specific services to CSHCN. Though this may be beneficial for the child, participants noted that MCOs are often reluctant to include these providers in their networks because they do not necessarily meet the MCO’s credentialing requirements. MCOs are concerned that they will risk their NCQA accreditation by incorporating them into their networks. States and the MCOs may need to consider some additional training for these providers so that they understand the requirements for their participation.

The individual providers in the network also need to know what to expect in serving Medicaid-eligible children with special health care needs and what is required of them in order to participate. Their understanding of the MCO’s performance expectations will influence the amount and quality of the services that they provide. One of the means of evaluating the capacity of the MCO to serve CSHCN is to look at how they support their providers. Physicians, in particular, have been given an extraordinary amount of responsibility with the transition to managed care. What kind of education does the MCO provide to its network? How does it support linkages between primary care physicians and specialists? Is there a care coordination system in place on which the physician can rely for resources and support?

Access to Care

Access to specialty care is critically important to CSHCN. In fact, in some cases, a specialty physician may be more appropriate as the child’s PCP than a generalist. The Family Voices survey found that 48% of the respondents reported that their child’s primary care provider (PCP) is a specialist, and 50% use a generalist, including pediatricians.33 Children with special needs may need evaluation and management by pediatric specialists who are experts in identifying and treating certain medical conditions, they may need complex medical and surgical interventions, or they may need special care such as renal dialysis, extensive therapies, or high-tech appliances. One participant commented that who provides the benefit is as important as making the benefit available.

It is important for states to assure that adequate specialty care is available, whether through the MCO’s network or through fee-for-service and that there are mechanisms to link primary care providers and the appropriate pediatric specialists for each child. Burdensome protocols and standard authorization requirements may hinder access to care for this population. States and MCOs can evaluate their necessity and appropriateness based on the particular needs of the covered populations. MCOs can extend the authorization periodicity, for example, for services provided for a chronic condition. In situations where the individual’s condition is not going to

change, it may be counterproductive for providers and the MCO to require authorization as frequently as with acute conditions. New Mexico requires its MCOs to honor all prior approvals of drugs, DME, institutional and professional services that overlap the enrollment period so that continuity and access can be maintained.

Michigan has developed some innovative approaches to promoting access to specialists and linkages between the primary care provider and specialty care. One of its contracted MCOs uses telemedicine to link the primary care provider of a child with special needs in rural upstate Michigan with a particular specialist at a metropolitan teaching hospital. This results in better care for the child at greater convenience for the family. It also provides education to the primary care provider not only about the individual child’s medical condition but also about how to facilitate the child’s care. As described in a previous section, Michigan has also addressed some of the coordination difficulties between primary care and specialty care by creating “specialty MCOs” for children with special needs, predominantly in the state’s major urban areas. These entities were developed in response to families’ concern that they don’t have adequate input into the care for their child with special needs and that the PCP and the specialist don’t work together. Their intent is to focus the specialty care on the family and provide a much stronger link among the participating providers. In an effort to encourage continuity of care and communication among providers, Michigan providers developed a technology network among hospitals in the state’s rural upper peninsula. Through this technology, providers can share an individual’s medical record, and the PCP can be involved in all aspects of the patient’s care.

**Table 3: Strategies for Assuring Access for CSHCN in Symposium States**

*The data in this table reflects MCO contract provisions in general, not just those for CSHCN. The data is based on NASHP’s 1999 Guidebook and input from individual states.*

<table>
<thead>
<tr>
<th>Allow specialist as PCP</th>
<th>DE</th>
<th>FL</th>
<th>MA</th>
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<th>NM</th>
<th>OK</th>
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</thead>
<tbody>
<tr>
<td>Allow standing referral</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Require continuity of provider after enrollment</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td>Review of primary care networks</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>Yes</td>
</tr>
<tr>
<td>Review of specialty networks</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>Yes</td>
</tr>
</tbody>
</table>
MCOs can and do vary greatly; ‘a plan is not a plan is not a plan.’ States note that adequate access can only be determined by looking at the actual networks and the composition of primary care physicians, pediatric specialists, and other providers. Provider-patient ratios have negligible value in judging access. In general, states have found those MCOs that establish coordination relationships and develop capacity at the local level are more successful in meeting the needs of their enrollees. States may want to encourage MCOs to solicit the participation of community-based constituencies and advocacy organizations in preparing their applications and developing their programs, as New Mexico has done. Though not necessarily an indication of provider capacity, it can demonstrate the MCO’s understanding of the particular issues concerning populations with special needs.

Summary

States have found that, though incorporating CSHCN in managed care presents some challenges in crafting a suitable benefit package, the advantages of managed care over fee-for-service far outweigh the disadvantages. Even with the concerns for interpretation of medical necessity, managed care offers a flexibility that fee-for-service doesn’t have. Symposium participants were in agreement that managed care for CSHCN needs to strike a balance between customary medical benefits and the flexibility necessary to provide other services so that the care can match the individual’s needs. For example, if an MCO identifies child care as key to a child’s health and functioning, it can include that service as a benefit. Or a MCO can send a child to camp if that is the most appropriate venue for maintaining his or her well-being and optimum level of functioning. States urge HCFA to refrain from defining specific benefits that states must require of MCOs so that this flexibility can continue.

Though various constituencies worry that managed care limits access to specialists and services, state representatives at the symposium feel that children are now getting services that fee-for-service could not provide. All felt that the key to pulling it all together for children with special health care needs is care coordination, as discussed above. Care coordination ensures that the services and supports identified in the child’s treatment plan are both available and provided.

FINANCING

As states transition children with special health care needs to risk-based managed care, they have had to take a careful look at the costs of this population and how those costs are reflected in their contracts with MCOs. States, MCOs, provider organizations, and family advocates all express concern that MCOs be paid adequate rates to cover the costs of the population and that, overall, there is enough money in the system to make it work. Further, they don’t want to see MCOs trying to avoid enrolling people with disabilities or limiting services because of high costs that aren’t incorporated in the capitation payment. The costs of care can vary greatly within the CSHCN population; some children may have high medical costs because of their extensive health care needs while others may be more similar to the general population. Data from
Washington’s Medicaid program illustrates this. In 1993, the state Medicaid program spent on average:

- $14,377 for a child with cystic fibrosis
- $16,684 for a child with muscular dystrophy
- $14,637 for a child with a malignant neoplasm
- $2,584 for a child with asthma

However, the total spending for all children provides a different picture:

- $37 million for all children with asthma
- $8.4 million for all children with malignant neoplasms
- $2.9 million for all children with cystic fibrosis
- $2.8 million for all children with cerebral palsy

The variation in per capita spending by diagnosis, as seen in the above data, demonstrates that traditional rate-setting approaches that base capitation rates on average costs for large population groups may not be the most appropriate for CSHCN.

**Risk Adjustment**

States that have included CSHCN in their managed care programs emphasize the importance of actuarially sound rates that represent the costs of caring for this population. It is advisable to have enough rate cells so that the variations are reflected, though not so many that they dilute the actuarial certainty of the rates. New Mexico, for example, has 29 rate cells, including one for foster care children and several for Katie Beckett eligibles, based on the age and gender of the individual. Increasingly, states are using risk-adjustment beyond the traditional demographic factors of age, sex, and eligibility category when calculating the rates to be paid to the MCOs. They are looking at health status as a way to set rates that more accurately reflect the population’s varying needs for care.

States that perform this type of rate setting must first have the data to develop the rates and the capacity to analyze them. They must be able to draw the information from their fee-for-service claims data or be confident that the encounter data that they are collecting from the MCOs are complete and accurate. According to some State representatives, there are persistent problems with the level of accuracy of the encounter data being submitted, which makes rate setting very difficult. Participants also noted that, if the risk adjustment is to be based on the diagnosis, one must account for the fact that a diagnosis represents only a point in time. Further, diagnoses can be particularly challenging to identify; they are not always available through claims data, nor are they easily obtained from the Social Security Administration for those enrollees who are eligible

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through SSI. States emphasize that the data on which the rates are based must be auditable. There needs to be a clear link between the data and the resulting rate to discourage upcoding an enrollee’s diagnosis and, thereby, enhancing payment to the MCO.

Risk adjustment is an imperfect science at best and only in its infancy in terms of states’ experience. There will be wide variation in rates, producing “winners” and “losers.” In the aggregate, risk adjustment is likely to result in more predictable costs and less cost over time, but it will take time to achieve this result. With these caveats, risk adjustment does make sense from the MCOs’ perspective. Since enrollment differs from MCO to MCO, the MCO can feel more confident that it is being capitated for the particular constellation of its membership. Risk adjustment can provide incentives to MCOs to develop more responsive delivery systems for their beneficiaries.

**State Approaches**

States take various approaches in contracting with MCOs. Among the states participating in the symposium, the following practices were described.

- Delaware pays 100% of fee-for-service costs and puts the MCO at full risk. The state began with 14 rate cells and has moved to 28, due to demographic adjustments. It will be transitioning to risk-adjusted rates in early 2000. The state monitors the medical-loss ratios of its MCOs, which currently range from 74% to 117%, and anticipates that risk adjustment will result in greater equality among them.

- Michigan initially chose not to put its specialty MCOs at risk, although noting that an element of risk in contracting is useful in getting the providers to change their behaviors. With its managed care program for children with special health care needs it has developed an integrated health system, combining Title XIX and Title V funding in its contracts with the MCOs. The contracts with the MCOs serving children with special needs include risk-sharing provisions with the state, through very narrow risk corridors. The rates for the ‘special needs’ MCOs are risk adjusted, with 14 rate cells. The maximum monthly rate is $13,000. Michigan is testing its rates by using a “shadow capitation” to determine what the state would have paid without risk adjustment. Since initiating its specialized managed care program the state agency has discovered that many families choose to keep their child in the regular MCO. Therefore the state is adjusting its payment system to these MCOs as well, to accommodate the higher costs.

- Florida’s managed care contract for children with special health care needs is with Florida Children’s Medical Services (CMS), the state Title V CSHCN program. CMS is

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35 With risk corridors, the state agrees to cover a portion of the MCO’s loss if the total loss exceeds a predetermined percentage of the total paid through capitation payments. In this model, the MCO also frequently agrees to turn back to the state a portion of any profit exceeding a predetermined amount.

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functioning as a risk-bearing entity. The state uses Medicaid rates, based on historical expenditures for children with chronic illnesses. The Title V participant from Florida noted that this payment system allows little flexibility for incorporating new and more expensive services such as new technologies that become available for CSHCN.

- Oklahoma uses selective risk adjustment for enrollees with behavioral health needs. The MCO submits a completed assessment tool (developed by the state) to the state and, if approved, the enrollee is designated as an individual with Special Behavioral Health Needs (SBHN). A separate higher capitation rate is paid, depending on whether the individual is a child or an adult. Oklahoma also uses selective risk-adjustment in its stop-loss arrangements for aged, blind, and disabled (ABD) enrollees in managed care. It has established a significantly lower threshold for children with hemophilia-related ICD-9 codes and a higher threshold for all other ABD enrollees.

**Table 4: Rate Setting Components in Symposium States**

*The data in this table reflects MCO contract provisions in general, not just those for CSHCN. The data is based on NASHP’s 1999 Guidebook and input from individual states.*

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<td>Yes</td>
<td>Yes</td>
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<td>Yes</td>
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<td><strong>Sex</strong></td>
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<td>No</td>
<td>No (SSI)</td>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td><strong>Specific risk adjustment for certain conditions</strong></td>
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<td>Yes</td>
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<td>No</td>
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<td>No</td>
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<tr>
<td><strong>Comprehensive risk adjustment</strong></td>
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<td>No</td>
<td>No</td>
<td>No</td>
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</table>

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Payment to Providers

How MCOs pay their providers may have little correlation to the capitation payments that they receive from the state. In many instances the state may be imposing risk upon the MCO, but the MCO pays its physicians on a fee-for-service basis, providing little incentive to make any changes in the physician’s practice. Alternatively, the state may pay adjusted rates to the MCO, yet the MCO continues to pay a flat capitation to its providers instead of passing along the adjustment. States are advised to pay close attention to the MCO’s arrangements with its physicians, to determine who and what is being funded, and how is it being done. Oklahoma conducts onsite monitoring of the PHOs and larger medical groups in the MCOs’ networks. State staff noted that this process allows them to learn what information and instructions providers receive from the MCO and what information providers are lacking, as well as to find out information about providers of which the MCOs aren’t even aware.

MCO representatives and provider organizations at the symposium reminded states that there are increased demands on physicians in managed care with the addition of populations with special needs and that they need to be paid accordingly. If fees are kept low while adding more responsibilities, MCOs will lose physicians, leading to similar access problems as there were in fee-for-service. Though reasonable to ask physicians to share in the risk, there also need to be limitations to that risk and mechanisms to ensure that they have the resources to provide the care that they do. States were advised to review the rates that their contracted MCOs pay to providers as part of the state’s oversight activities. As one participant noted, a MCO is only as good as its physicians. In recognition of the increased responsibilities placed on physicians, CalOPTIMA’s contracted MCOs have increased their fee-for-service payments to physicians who see children with special needs.

Payment for Services that have been Provided by Other Public Programs

Another aspect of financing care for children with special health care needs is the interrelationship between the MCO and the several public programs that have been serving these children, such as Title V, Special Education, Early Intervention, Children’s Mental Health Services Program, and Title IV-B Child Welfare Services. Prior to managed care each of these programs relied heavily on Medicaid fee-for-service to finance their specialized health services for Medicaid-eligible children. State Medicaid agencies and these other state agencies developed reimbursement systems for a wide range of providers, including public health providers, schools, special education and rehabilitative providers, clinics, case managers, mental health providers, and child welfare workers. Now as CSHCN are transitioning to managed care, the state Medicaid agency must determine how to structure its contracts with the MCOs with respect to the services that these public programs have provided. Though there are certain advantages to providing these services as carve-outs, there is also the danger that the costs associated with these services will increase if left out of the package of managed benefits. A state participant commented that states need to pay attention to the potential for cost-shifting. Moreover, the
coordination difficulties increase as additional services are carved out. Too many carve outs can lead back to fee-for-service fragmentation.

The Upper Payment Limit

One of the challenges of Medicaid managed care is the federal requirement to demonstrate savings and keep costs within the upper payment limit (UPL).\textsuperscript{36} Though savings beyond short-term shifts in costs can be achieved, it is a long-term process. One needs to improve the care delivery system first in order to get improved health outcomes that result in reduced costs. The UPL has become a constraint for states in developing their managed care programs. MCOs either are reluctant to participate or are terminating their contracts because of the limitations of the UPL. Because the UPL is a fixed number it does not allow flexibility in payment, such as paying more in the first year of a managed care contract to produce savings in later years. Nor does it recognize the possibility that new enrollees may enter managed care with “pent up” demand, such that the MCO may need to cover more services than originally predicted in the rate. States are unable to compensate MCOs for this situation, under the current UPL system. And the UPL has become increasingly difficult to calculate for those population groups that have been covered by managed care for years and therefore have no fee-for-service data to evaluate. In response to these concerns, HCFA, the Office of Management and the Budget (OMB), and selected states have formed a workgroup to examine how the UPL can be redefined.

ENSURING QUALITY OF CARE FOR CSHCN

Quality of care is a significant concern in any managed care delivery system. Consumers, providers, states and the federal government all want to be assured that the care provided under managed care is adequate and appropriate for the populations it serves. This becomes a sensitive issue for Medicaid when Congress hears anecdotal reports from national provider associations and advocacy organizations that care has been denied or there has been a lack of due process for enrollees. HCFA is continually looking for ways in which it can track and validate both the positive and negative experiences of CSHCN in Medicaid managed care and demonstrate specific outcomes from a statistically reliable data base.

States and MCOs were in agreement that a selected set of tools could be adopted for judging MCO and program performance in serving CSHCN and that it would be most productive if those tools were used for a long enough period of time to test their utility. There was some frustration among the participants that there are too many tools being introduced and promoted and too

\textsuperscript{36} Under a risk contract, Medicaid payments to the contractor, for a defined scope of services to be furnished to a defined number of recipients, may not exceed the cost to the agency of providing those same services on a fee-for-service basis, to an actuarially equivalent nonenrolled population group (42 CFR 447.361).
much “switching of gears” as states and MCOs are instructed to change from one tool to another. They agreed that they could, and would, implement HEDIS measures and administer an enrollee survey, such as CAHPS, for the CSHCN population as a means of standardizing the quality assurance process.

**HEDIS**

HEDIS\(^{37}\) is an important quality improvement tool for measuring plan performance, and it is an instrument that MCOs pay attention to. Though HEDIS has now been adapted for Medicaid managed care, it would benefit from selected additional measures for children with special needs. Participants suggested that both asthma and diabetes were two key clinical areas of importance and that care coordination could also be incorporated as an area to assess. Standard measures such as immunization rates and well-child visits are also important barometers of MCO performance for CSHCN and can be stratified to reflect CSHCN data specifically. Other clinical practices and outcomes remain more difficult to assess because of the variability among the population and the lack of consensus as to what services should be provided to CSHCN. Though it is important to measure outcomes to know if the care is producing improvement, it may not be advisable to mandate specific criteria for each diagnosis. Outcome measurements also need to be adjusted for the intermittent eligibility of many of the Medicaid population, particularly those children who receive Medicaid because of their TANF eligibility.

**Consumer Surveys**

Participants felt that a single survey instrument for the consumer would be preferable to multiple tools and that beneficiaries should be surveyed no more than once a year. Several states are using the CAHPS survey\(^ {38}\), which has been adapted for children with special health care needs, to assess consumer satisfaction and perception of the care they receive. Representatives from consumer and provider advocacy organizations stressed the importance of states and MCOs making an explicit commitment to evaluate the particular service, access, and coordination issues that affect this population. General oversight of MCOs, like that in place for other Medicaid populations, is not sufficient for children with special needs. The National Association of Children’s Hospitals feels strongly that consumer satisfaction surveys should either oversample for CSHCN or be designed explicitly for this population.

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\(^{37}\) The Health Plan Employer Data Information Set (HEDIS) consists of measures which are used in evaluating a health plan’s performance in areas of access, clinical effectiveness, cost, and satisfaction. It is an initiative of the National Committee for Quality Assurance (NCQA).

\(^{38}\) The Consumer Assessment of Health Plans Survey (CAHPS) is a project of the Agency for Health Care Policy and Research (AHCPR) to compile comparative information on beneficiary satisfaction with managed care plans. It includes sets of survey questions specifically designed for Medicaid populations.

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Other Quality Improvement Mechanisms

One child advocate emphasized that there need to be other mechanisms for consumers to express their concerns about managed care. In fee-for-service, consumers could vote with their feet and change to another provider, but in managed care that freedom is restricted. Most states have implemented enrollee “hotlines” so that individual members can call with questions, concerns, or complaints. States have also established linkages with advocacy organizations and consumer groups that provide an ongoing forum for raising issues and concerns about the managed care system. New Mexico contracts with certain advocacy groups for technical assistance and looks to them for the first warning of potential problems in an MCO. This state also holds periodic meetings around the state to get feedback on the consumers’ experiences with the managed care program.

Provider impressions and experience are an important component of the assessment of managed care performance. Participants suggested that a provider survey be incorporated into the quality assurance process to obtain their viewpoint as to how the managed care system is working. Providers can also provide some insight into the grievance and appeals process. Virginia has found that grievances alone may not contain sufficient information to identify a problem. The state also looks at provider appeals; the provider may be able to fill in the blanks as to what it took to get the care delivered.

States use a variety of other measures to monitor MCO performance as well. Those include access standards such as waiting times for appointments and travel distances and times to primary care providers and specialists. They also monitor the MCO’s responsiveness to enrollee phone calls and processing time for authorization requests.

Summary

As states incorporate appropriate quality indicators for CSHCN, they would like a toolbox of standarized measures from which to select, such as additional HEDIS requirements and an enhanced CAHPS survey. Since individual programs and contracts with MCOs vary from state to state, they caution against overly prescriptive requirements beyond some brief standardized instruments. Instead, states feel that they can benefit from a review of “best practices” that have been successful with certain contracts, programs, and populations.

Managed care has been cast by some as the solution to the problems of the health care delivery system, and the expectations of it are high. Though many of those system flaws are beyond the scope and power of managed care to address, state participants agreed that it can offer significant improvement over the fee-for-service system in Medicaid. Managed care offers a system that is measurable, whereas fee-for-service provides few opportunities to measure outcomes. The most important caveat in assessing quality improvement in managed care is to recognize that change takes time. The outcome results of a managed care delivery system cannot be measured.
immediately. Further, though one can expect continual improvement over fee-for-service from a managed care system, it is important not to raise the bar too quickly.

Table 5: Selected Quality Improvement Activities in Symposium States
The data in this table reflect MCO contract provisions in general, not just those for CSHCN. The data is based on NASHP’s 1999 Guidebook and input from individual states.

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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>Enrollee survey/focus group</td>
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<td>Yes</td>
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</tr>
<tr>
<td>Provider survey/focus group</td>
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<td>Enrollee hotline</td>
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<td>Yes</td>
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<tr>
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<td>No</td>
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* P = Plan, S = State, I = Independent

**EFFECTIVE LINKAGES**

Linkages are an important component of a managed care program for children with special needs. Whether formal or informal, they are the relationships that both the Medicaid agency and the MCO establish with other entities that serve CSHCN. Linkages can form the basis for care coordination agreements, service delivery systems, or quality oversight. When crafted successfully, they determine the respective responsibilities of each participant, their means of communication, and accountability.

Those agencies and groups that states and MCOs find are most critical to work with are those that have had a role in delivering care to children with special needs. Often referred to as ‘safety-net’ providers, they include Title V agencies, early intervention providers, special education providers, community-based agencies, children’s hospitals, mental health agencies, foster care agencies, and other private community groups. In many instances they have a knowledge base and expertise that can be invaluable to the MCO, particularly in the early stages of implementing a delivery system for CSHCN. One symposium participant remarked that states and MCOs need to develop these relationships carefully, with a sensitivity to the enormous adjustment that some of these entities must make with the advent of managed care. While their commitment to CSHCN does not necessarily change, the role of these agencies and providers in the delivery
system can change dramatically. They may be faced with redefining their mission and responsibilities. Their identity as a provider may no longer be appropriate, and they may be struggling to determine whether they should step in as a coordinator, an overseer, and/or an advocate.

Linkages can take one of several forms. The state or MCO may develop a Memorandum of Understanding (MOU) with an agency or organization to establish boundaries between the two and accountability for specific activities and services. Or it may develop a subcontract for a prescribed set of tasks and/or services, in return for payment. Finally, the linkage can be simply a liaison with another individual or organization that facilitates the delivery of care. If any of these linkages involve the sharing of data, the cooperating agencies need to have a clear agreement as to how that exchange will occur and how they will satisfy relevant confidentiality requirements.

Regardless of the form that the linkage takes, it is critical to develop an understanding of the other’s approach to the identified problem. There are cultural differences between the various agencies and programs that cannot be underestimated. One of the biggest issues reported between Medicaid and Title V, for example, is simply a lack of understanding as to what each program does and how it approaches a given situation or responsibility. States, MCOs, and constituency organizations all stressed the importance of taking the time to understand and overcome those cultural barriers.

**Memorandums of Understanding**

A memorandum of understanding (MOU) can be merely a piece of paper between the state or the MCO and a particular agency, or it can represent an agreement that has been put in practice. MOUs can often represent an evolving relationship. Initially, the document may detail the outcome of a series of discussions and agreement on how the two or more entities intend to work together. Over time, as the program develops experience, the MOU develops more substance; it delineates the policies that are created to resolve specific problems and issues that the organizations encounter. As outlined in the draft *Optional Specifications*, there may be several possible elements of an MOU between the MCO and other state and local agencies, including:

- respective responsibilities of the contractor and of the agency for providing and paying for services: those that are in the contract, those that have been routinely provided by the agency, and those that are not covered in the contract;
- responsibility for the identification of enrolled children with special health care needs;
- arrangements for reciprocal referrals of enrolled children;
- exchange of data and information related to items and services furnished to enrolled children; and
- designation of individuals responsible for coordinating the implementation of the MOU.

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39 *Optional Specifications: Purchasing Medicaid Managed Care for Children with Special Health Care Needs*, in draft. Section 206(b).
Relationships between state-level agencies can either help or hinder those that are fostered between the MCO and community-based organizations at the local level. From one MCO’s perspective, agreements are most effective at the community level between entities that have accountability to a particular population. That local cooperation can be thwarted, however, if state level agencies are unable to overcome their differences about turf and policy.

Subcontracts

The linkage takes a somewhat different character when it is established through a subcontract. Subcontracts, unlike MOUs, imply payment. MCOs may develop contracts with those entities that have been providing certain services to children with special health care needs in the fee-for-service system. This may be helpful to the MCO, at least initially, if it doesn’t have the expertise internally. One symposium participant cautions states and MCOs to be mindful of potential difficulties with these contractual relationships, however. Some publicly funded programs have become dependent on Title XIX for their financial survival and assume that they will be incorporated in the funded benefit package of the MCO. The MCO may find that, expertise aside, it doesn’t want to buy those services at the price that Title XIX has been paying. And when does a financial linkage become a cost shift? Some traditional providers may be using their Medicaid funds, whether through the fee-for-service system or managed care, to subsidize the services they provide to other populations.

Other Relationships

The delivery of care for CSHCN is also dependent on relationships outside of any subcontract or MOU. These linkages can be some of the most delicate and the most critical to continuity of care. For example, a child court judge has the authority to decide the service needs for a particular child with special needs, yet doesn’t understand the managed care system, the contracts and agreements that are in place, or the definition of medical necessity. It is incumbent upon the state, in this situation, to bring the various parties together and to provide education to those who may not understand the managed care delivery system and to clarify each party’s role. It is also important to determine where the financing comes from to deliver the care. Are state mandates for specific services linked to funding? In another example, New Mexico mandates that the MCO establish liaisons with case managers in other systems like child protective or juvenile justice, any program from which the child might be receiving services, regardless of whether they are strictly health related. This linkage helps clarify the respective responsibilities and expectations of each of the players.

Summary

MCO representatives caution states that they must be absolutely clear in the contract as to what the MCO’s responsibilities are and that they cannot hold MCOs accountable for what is not in the contract. If a MCO is expected to establish linkages with certain entities, those expectations
need to be spelled out in the agreement. The MCOs also need to understand the differences between the various agencies in how they deliver care; some operate on the principle of entitlement, like Medicaid, and others administer “non-entitlement” programs. This means that a referral for care does not necessarily result in the care being provided if there is not enough funding to cover it. Though MCOs understand that a Medicaid contract expands the scope of their usual care delivery system, they do not want to see “mission creep,” such that they are expected to broker relationships and establish agreements that were not made clear to them and that they are not paid to do. Once again, training for the MCO and its providers is extremely important so that all parties understand the complex nature of Medicaid and of providing care for children with special health care needs.

States appreciate the importance and necessity of coordinating with other entities to provide comprehensive care to CSHCN, but they prefer that specific linkages not be mandated by HCFA. Instead, they suggest that one look at how the state works with various organizations and how the MCO proposes to deliver care, and then evaluate whether the linkages and relationships are sufficient. In New Mexico’s most recent Request for Proposals, it asked the MCOs to describe how they would deliver care under specific scenarios. They wanted to know how access to care would be assured, the delivery implemented, and the care monitored across health, social services, education, and justice systems. For example, when a child is put in state custody, how does the care follow? Or, how will the responsible parties work together when a child is in a detention center? Because of the varying needs and situations of children with special health care needs, it is difficult to define the specific linkages that should be developed or set one standard approach for these relationships.

**Stakeholder Involvement**

Just as linkages with multiple agencies and providers are key to the delivery of care to CSHCN, it is also important for states to seek the input of a variety of constituencies during the design and implementation of their managed care programs. These stakeholders can be anyone who identifies themselves as such: families, consumers, advocacy groups, providers, community organizations, or other state agencies. They may differ from state to state or region to region within a state, depending on the particular design of the managed care program or the nature of the stakeholders’ concerns.

The state Medicaid agency can take the initiative in identifying who needs to be involved and in organizing a variety of mechanisms by which stakeholders can provide their input. Symposium participants emphasize that the state needs to be aggressive in this effort and go beyond the “usual suspects” in order to bring together the appropriate constituencies for children with special health care needs. It is too easy to simply contact the organized advocacy groups and bypass the families, who are the actual care givers that experience the delivery system first-hand. States and advocacy organizations agree that families are critical to the development of Medicaid managed care for their children. Though it may not be necessary to have a separate forum for CSHCN, it is important to create a very clear vehicle for their stakeholders to have input. And CSHCN
require more than a single representative for their concerns because of the diversity of their medical conditions.

Soliciting input can have the advantage of creating a two-way education process. In one example, representatives from an advocacy organization for hearing-impaired people had the opportunity to provide education to MCOs about caring for hearing-impaired enrollees. As a result, they became informed about how the managed care system works and how to deal with the MCO. They, in turn, were able to convey this information to their constituencies.

Physicians are also important stakeholders, whose input and participation is critical to the success of the managed care program. Provider groups note that physicians have become frustrated by their limited input into managed care plans, so states would be well-advised to create an opportunity to hear their concerns. Pediatricians see the majority of Medicaid children and therefore are the physician group that should be contacted. Other physician associations may also be key stakeholders in a given state, depending upon the involvement of the particular discipline.

Regardless of the selected population for managed care, symposium participants emphasized the importance of creating ongoing opportunities for stakeholder input. Holding occasional meetings, alone, does not institutionalize the process; stakeholders need a feedback loop and confirmation that their input is being considered. The state agency and MCOs can benefit from this input throughout the administration of the program, whether it be about care coordination, access to services, the quality of care delivered or member services. Participants identified several strategies that can be used to create an effective stakeholder process, including:

- hold informational meetings that are convenient to the target audience, i.e., early morning meetings at the hospital for physicians, evening meetings for working parents;
- get on the agenda of already scheduled events: parent groups, physician forums, advocacy organization meetings;
- form a provider advisory committee and a member advisory committee that meet periodically to provide input from their constituencies;
- tape record all meetings that are held;
- document the input of the meetings in writing, what changes were made and what policies were developed in response to the input;
- publicize the results of the meetings; use web sites to keep stakeholders informed;
- provide direct feedback to those individuals who made suggestions, letting them know how their input was incorporated;
- include MCOs in the feedback loop;
- maintain ongoing relationships with stakeholders as the tough issues arise, even if those relationships become somewhat strained;
- rely on credibility with stakeholders when working with the State legislature.
Oklahoma provides a good illustration of a carefully constructed process for informing the public and gaining input from their stakeholders. Prior to implementation of their managed care program for the Aged, Blind, and Disabled populations, the Medicaid agency held town meetings across the state to inform consumers and providers about managed care, including Indian tribal representatives. They issued (for comment) a concept paper about the new initiative, conducted focus groups on their draft enrollment materials, and issued a draft of the Request for Proposals for managed care organizations for comment from MCOs, providers, advocacy groups, and other interested parties. They held informational meetings with legislators and provided written communication to providers and beneficiaries, alerting them to the upcoming changes in Medicaid. Finally, Medicaid staff also developed internal support through agency education programs, written updates, meetings with Medicaid regional staff, and interagency meetings with the Title V agency. All of these efforts have contributed to the strength of the managed care initiative, building trust among constituencies and credibility for the program.

**CONCLUSION**

Several issues emerged from the symposium on Medicaid managed care and children with special health care needs. Participants were in agreement that the transition of CSHCN to managed care poses certain challenges and, at this point, can merely be looked at as a "work in progress." The identification of CSHCN is one of the greatest difficulties. Though the BBA provides a definition of children with special health care needs, it does not solve the problem of actually identifying children through the various federal categorical programs nor is there a tool that states can readily use to identify these children.

States feel that they have made considerable progress in developing appropriate managed care models for CSHCN and would like to continue their efforts. They hope that the current scrutiny by Congress and HCFA does not result in reversing the slow but steady progress that they feel they have made. Provider and children’s advocates expressed reservations about the transition to managed care for CSHCN, however. They feel that the lack of quantifiable results and the volatility of the managed care marketplace are cause for caution in pursuing a managed care delivery system for these children.

The problems that states and MCOs encounter in developing adequate delivery systems for CSHCN are not unique to managed care. They exist in the fee-for-service system as well. These issues include:

- inability to identify CSHCN through eligibility data;
- lack of data collection capabilities so that state or MCO can track and monitor their care;
- difficulty in assembling adequate number of pediatric specialists, like neurology, because of the low supply and their resistance to participating in Medicaid;
- coordination with other public programs that serve CSHCN; and
- adequate financing to support providers who deliver specialized care.
Despite these challenges, state and MCO participants feel that managed care may offer children with special health care needs a better health care system. They see improved access to providers and, even with the difficulties in locating certain sub-specialties, states feel that there are more providers participating in Medicaid managed care than there were in fee-for-service. As states now purchase care for Medicaid beneficiaries from managed care organizations, they can direct how that care should be delivered and make changes as necessary. Through the credentialing process, managed care sets standards of quality and capability for participating providers, where there was little control before.

Most importantly, managed care can offer increased opportunity for coordination and appropriate management of care for the child with special health care needs. When constructed with sensitivity to the child's needs, involvement and empowerment of the family, and the participation of experienced and knowledgeable providers, a managed care delivery system can improve the quality of care for CSHCN. It offers a medical home to both the child and the family as they secure care for their complex medical and social needs.

As states construct their managed care systems for children with special health care needs, they would like the opportunity to try various approaches; they do not want to be locked in to a single model. State participants at the symposium urged HCFA to allow flexibility in the design of these programs because the children's needs are so varied and the options for medical care are constantly changing. A uniform process for identification, care coordination, or delivery of care is not necessarily conducive to the multiple and divergent requirements of CSHCN. As one symposium participant noted, “don't let the perfect be the enemy of the good.” State Medicaid agencies have developed identification and enrollment processes specific to the existing systems within their individual state, and they have shaped care coordination arrangements that recognize the particular needs and dynamics of the individual child and family. Finally, benefit packages for children with special health care needs have been developed to be responsive to the individual child's unique needs and the ever-changing technology of medical care. As the health care market evolves and the ability to identify children with special health care needs improves, states want to be able to respond with innovative models of managed care that meet the needs of the population.
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