

# Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models

---

## Volume I: Synthesis of Study Results

Prepared by:

Ian Hill, Renee Schwalberg, Beth Zimmerman, and Wilma Tilson  
Health Systems Research, Inc.  
Washington, DC

Prepared for:

The Division of Children with Special Health Care Needs  
Maternal and Child Health Bureau  
Health Resources and Services Administration  
Rockville, MD  
Cooperative Agreement No.: 93-110-C



July 1999

# Table of Contents

---

I.	Background and Purpose of the Study .....	1
	A. Defining Service Integration .....	3
	B. Study Design and Methods .....	4
	C. Organization of Report .....	6
II.	Medicaid Managed Care Models and the Study States .....	6
III.	Service Integration Under Alternative Medicaid Managed Care Models .....	12
	A. Eligibility, Identification, and Enrollment of CSHCN .....	12
	B. Primary Care .....	16
	C. Specialty Medical Care .....	17
	D. Links to Mental Health, Early Intervention, Special Education, and Other Support Services .....	21
	E. Case Management/Care Coordination .....	25
	F. Financing .....	28
	G. Family Involvement in System Planning, Implementation, and Oversight .....	31
	H. State-Level Collaboration .....	33
IV.	Conclusions .....	35
	A. The False Security Offered by the Fee-for-Service “System” .....	35
	B. The Limitations of Mainstream Managed Care and “Carve Outs” .....	36
	C. The Promise of Specialty Managed Care Systems for CSHCN .....	38

# I. Background and Purpose of the Study

Children with special health care needs (CSHCN) are generally considered as having one or more chronic physical, developmental, behavioral, or emotional conditions that affect their ability to function (McPherson, et al., 1998; Stein et al., 1993). While precise definitions of the population vary, policymakers, researchers, and advocates agree that CSHCN often exhibit multiple and complex needs for services beyond those required by children generally, and often must rely on a large number of systems to address these needs, including not only the medical care system, but also those providing early intervention, special education, mental health, and a host of other family support services. Because of these factors, the need for coordinated and integrated service delivery is perhaps greater for CSHCN and the families that care for them than for the population at large. Without strong mechanisms and structures to link these various systems together, parents are left with the burden of navigating disparate and fragmented systems on their own and orchestrating the diverse care needed by their children.

Recent years have witnessed dramatic changes in our nation's health care financing and delivery systems that may hold implications for the goal of building more integrated systems of care for CSHCN. Mirroring trends in the private sector, state Medicaid programs across the country are increasingly enrolling their beneficiaries into managed care. According to the federal Health Care Financing Administration (HCFA), almost half (48 percent) of all Medicaid recipients—15.3 million individuals—received their health care services through managed care arrangements in 1997, representing a greater than five-fold increase since 1991 (Regenstein and Schroer, 1998). Of particular note, most states are also increasingly enrolling their Medicaid beneficiaries with disabilities into managed care, as well. Once a population that could routinely be expected to be “carved out” of managed care, persons receiving Medicaid by virtue of their eligibility for Supplemental Security Income (SSI) are now, more often than not, included in states' managed care initiatives. In 1998, 36 states enrolled at least some of their Medicaid/SSI beneficiaries into managed care, accounting for roughly 1.6 million individuals, or one-fourth of Medicaid's non-elderly disabled enrollees (Regenstein and Schroer, 1998). As the SSI program

employs rather narrow eligibility criteria, these numbers do not represent the total number of beneficiaries with disabilities who are enrolled in Medicaid managed care.

As children comprise a large proportion of this SSI/disabled population, this latter trend has raised issues among those concerned with CSHCN. While managed care, in theory, holds promise for improved organization and accountability through the use of integrated networks of providers, traditional managed care systems have been designed to provide primary and acute medical care to a generally healthy population and have tended not to be targeted to disadvantaged groups such as CSHCN. Many questions have been raised regarding the capacity of managed care organizations (MCOs) to provide appropriate access to high-quality care for this population, with concerns most often centering around the breadth and adequacy of MCOs' networks, financial incentives that may cause MCOs to limit access to needed but expensive services, MCOs' general lack of awareness of the complex and diverse needs of these children, and inadequate links between MCOs and the multiple health-related, educational, and community-based support systems that families with CSHCN rely on in caring for their children (Committee on Children with Disabilities, 1998; Zimmerman, et al., 1996; Cartland and Yudkowsky, 1992). The fact that children on SSI represent just a portion of the overall population of children with chronic illnesses and disabilities, and that the population of CSHCN has been enrolled in Medicaid managed care for years, simply exacerbates concerns over whether or not public managed care systems are up to the task of caring for these children with special needs.

Addressing these concerns is complicated by the fact that no single model of "Medicaid managed care" exists. Rather, a multitude of program designs have emerged over the years that employ numerous variations on the typical fully-capitated, partially-capitated, and managed fee-for-service/primary care case management approaches used by states: some rely on commercial "mainstream" health plans, while others utilize Medicaid-only plans that draw extensively on safety net providers more experienced with serving low-income families; some place responsibility for all services with the MCO, while others "carve out" clusters of services to be delivered by separate systems; and most serve all Medicaid populations, while a few are specifically designed to serve narrower target populations.

To gain a more complete understanding of the effects of managed care on service delivery for CSHCN, the *National Policy Center for Children with Special Health Care Needs* studied eight states with different Medicaid managed care models and, using qualitative evaluation methods, examined the extent to which the alternative models supported effective, cross-system service integration for CSHCN. This report contains the results of this analysis.

## A. Defining Service Integration

As a first step in our analysis, the *Center* conducted a review of the literature on service integration and, from it, developed a definition of the concept. For the purposes of this study, we defined service integration as: *an ongoing process of combining resources across medical, health, mental health, social, and education systems to support and assure a high quality program of care for the child and the family.* The key components of this definition are discussed in more detail below.

- The phrase “ongoing process” recognizes that the needs of children and families evolve over time, resulting in a continuing challenge to integrate new services or discontinue unnecessary ones.
- The term “combining” refers to policies or structures that facilitate (or inhibit) the blending of resources.
- “Resources” include finances, specific interventions or programs, personnel, and other goods and services.
- The terms “support” and “assure” convey an active, goal-directed process that includes developing systems for monitoring and evaluation by the combined efforts of parents, providers, and staff of an MCO or public agency.
- “Program of care” refers to a plan that includes short- and long-term objectives and specifies how different services contribute to the achievement of these objectives.

Throughout the design and conduct of our study, we employed this definition as a framework for considering whether or not managed systems of care were promoting or undermining the goals of service integration. As will be discussed in more detail below, the definition was also

used to guide our development of interview protocols and, by extension, our discussions with state and local officials, providers, and family members.

## B. Study Design and Methods

This study represents a qualitative evaluation of the effects on service integration for CSHCN of alternative Medicaid managed care models. It is based on an in-depth analysis of programs in place in eight states. In developing our study, we followed a number of steps consistent with well accepted qualitative research methods, as described below.

- A sample of eight states was identified and recruited based on their alternative approaches to serving CSHCN under Medicaid managed care. Models of interest included fully-capitated mainstream and specialty managed care systems, PCCM systems, and traditional fee-for-service systems.<sup>1</sup>
- A series of structured interview protocols was developed to permit investigators to collect consistent information across sites. Separate protocols were developed for the various key informants we planned to interview, including officials and individuals representing Medicaid agencies; Title V/Maternal and Child Health agencies; state agencies responsible for mental health, early intervention, and special education, and other programs serving CSHCN; managed care organizations; local providers of care, including primary care physicians, pediatric specialists, and various community-based providers such as local health department staff; and parents of CSHCN. In each of these protocols, we included a consistent series of questions exploring such critical issues as:
  - Eligibility, identification, and enrollment policies and practices;
  - Primary and specialty medical care service systems;
  - Links with other systems of care, including mental health, early intervention, special education, and community-based support services;
  - Systems for case management and care coordination;
  - Quality assurance and monitoring strategies;

---

<sup>1</sup>The eight states studied, and the models of managed care they use, are discussed in detail in the next section.

- Financing and payment policies;
  - Family involvement with program design, implementation, and oversight; and
  - State-level and public/private collaboration.
- Medicaid managed care contracts and other descriptive materials were obtained for each of the study states and information was extracted from them regarding the principal design characteristics of their managed care models.
  - Two in-depth telephone interviews were conducted for each study state, one with the Medicaid director and one with the Title V official responsible for the CSHCN component of the block grant. These interviews served to establish our baseline understanding of the managed care model in place in each state, and allowed us to obtain two perspectives on the strengths and weaknesses of those models with regard to service integration. In addition, during these interviews, we asked state officials for recommendations regarding specific key informants we should meet with during our site visits to the state. Finally, we also requested that state officials forward to us, in advance of our visits, any written background information, documents, and data that would help us develop a fuller understanding of the design, experiences, and impacts of the Medicaid managed care systems.
  - Based on the input received from state Medicaid and MCH officials, we contacted and scheduled appointments with a broad range of public- and private-sector officials and providers, as well as the director of the state chapter of *Family Voices*, a national grass-roots organization comprising parents of CSHCN who work at the federal, state, and local levels to promote the development of high-quality systems of care for their children.
  - Multi-day site visits were conducted in seven of our eight study states; for the eighth state, all interviews were conducted by telephone. Using our interview protocols, we conducted individual interviews with each of the key informants identified above. In addition, we arranged and conducted a focus group of parents of CSHCN in each state. Finally, as a means for creating a forum for collaborative discussion of service integration challenges and strategies, we attempted to conduct a concluding focus group of all key informants at the end of each site visit, where possible.
  - Following our site visits, individual state case study reports were developed using a consistent outline and format. In addition, this synthesis chapter was developed to highlight cross-cutting issues, observations, and lessons learned from the analysis.

## C. Organization of Report

The remainder of this chapter contains a summary of the results of our study. Section II provides an overview of the types of managed care models commonly used by state Medicaid programs, as well as brief summaries of models in place in each of the study states. Section III describes how these programs structure and integrate their service delivery to CSHCN, with particular emphasis on policies and practices related to eligibility, identification, and enrollment; primary and specialty medical care; links to other systems; systems for care coordination; financing and payment policies; quality assurance and monitoring; family involvement with system planning, implementation, and oversight; and state-level collaboration and the role of Title V programs. Finally, Section IV presents overarching conclusions and lessons learned regarding the strengths and weaknesses of alternative models of managed care and their ability to provide integrated services to CSHCN and their families.

## II. Medicaid Managed Care Models and the Study States

Three basic models of managed care have been employed by state Medicaid programs.

Typically, using statutory waiver authority under Sections 1115(a) and 1915(b) of Title XIX of the Social Security Act, states have implemented:

- Fully-capitated programs, through which contracted health plans receive a fixed monthly fee per enrollee in return for accepting full risk for the delivery of a comprehensive range of benefits;
- Partially-capitated programs, through which plans contract and are at risk for a more limited scope of services (e.g., ambulatory care only) and Medicaid provides fee-for-service reimbursement for care not included in the capitation;<sup>2</sup> and
- Primary Care Case Management (PCCM) systems, in which a primary care physician agrees to provide and arrange all of a patient’s care, serving as a “gatekeeper” to approve and monitor all service provision. These physicians do not accept any financial risk; rather, they are paid on a fee-for-service basis for

---

<sup>2</sup>While popular among states in the 1980s, fewer states are today operating partially-capitated managed care programs.

the services they render and accept an additional per-patient-per-month management fee.

As stated in Section I of this report, states have designed and implemented numerous variations on these three models. To study the effects of alternative models on service integration for CSHCN, we were particularly interested in identifying and studying states that enrolled these children into:

- Fully-capitated “mainstream” plans that serve the general Medicaid population (to observe the extent to which they incorporated any special designs or provisions aimed at improving the coordination, integration, and quality of care for CSHCN);
- Fully-capitated programs that “carve out” certain types of care that are commonly used by CSHCN, such as mental health (to observe how these explicit divisions of responsibility among systems either improved or hindered cross-system integration);
- Fully-capitated programs that are specially designed to meet the needs of CSHCN (to permit a detailed comparison with “mainstream” plans); and
- Primary care case management programs that use a managed fee-for-service structure to provide for the needs of CSHCN.

Finally, as a comparison to these models, we also included a state that has chosen to exclude CSHCN from managed care arrangements, under the assumption that doing so would allow these children and their families to maintain existing provider relationships in the fee-for-service “system.”

Based on these goals, we selected a sample of eight states: Arizona, the District of Columbia, Florida, Maryland, Michigan, Minnesota, Oregon, and Tennessee. Brief summaries of these states’ models and how they fit the above schema are provided below.

- **Arizona.** Arizona’s Medicaid program, the Arizona Health Care Cost Containment System (AHCCCS), began on October 1, 1982 under a 1115(a) research and demonstration waiver approved by the federal Health Care Financing Administration (HCFA). The AHCCCS model mandates that all Medicaid-eligible children, including CSHCN—defined as those eligible for SSI

or Children’s Rehabilitative Services (CRS) under the state’s Title V program—enroll in AHCCCS’ capitated health plans. AHCCCS health plans are responsible for providing all primary and acute care services, while specialty care related to qualifying CRS conditions and mental health services are “carved out” to the CRS and Regional Behavioral Health Authority (RBHA) systems, respectively. In addition, a separate managed care program called the Arizona Long Term Care System (ALTCS) provides comprehensive services for adults and children with developmental and physical disabilities who are at risk of institutionalization.

- **District of Columbia.** In late 1995, the District of Columbia received approval from HCFA of a waiver permitting the Medicaid program to implement a special managed care program designed specifically for children enrolled in SSI.<sup>3</sup> Under the program, children on SSI have the option of enrolling in the new health plan or remaining in the traditional fee-for-service system. The District has implemented the waiver through a contract with one private non-profit managed care plan, Health Services for Children with Special Needs, Inc. (HSCSN), which provides a comprehensive array of services for enrolled children, including primary and specialty medical care, mental health, and a broad range of ancillary and support services, in return for capitated fees. HSCSN, in turn, contracts with a broad array of providers to deliver services to plan enrollees, while outreach and case management services are provided by in-house staff of HSCSN.
  
- **Florida.** Building on its strong state Title V/Children’s Medical Services (CMS) system and history of serving Medicaid recipients through managed care arrangements, the State of Florida launched the CMS Network in 1996. At the time of this study, the CMS Network was a PCCM program for Medicaid-eligible children with special health care needs operated by the state’s CMS program.<sup>4</sup> Children eligible for the CMS Network receive their care from a special network of primary care and specialty physicians (and other hospital-based providers) credentialed by and included within the state’s Title V/CMS system. All enrolled children are linked with a primary care provider who is responsible for providing all preventive and primary care services, as well as managing referrals for specialty and ancillary care. Primary care physicians are reimbursed on a fee-for-service basis for the care they render and paid a monthly administrative fee for care management. Specialty providers are likewise reimbursed on a fee-for-service basis for the care they provide. Intensive case management services are provided by local area CMS nurses who assist clients in receiving needed services in an integrated manner and work to ensure that CMS

---

<sup>3</sup>The original waiver was approved for a three-year period—from December 1995 to November 1998—although a one-year extension through November 1999 was recently granted.

<sup>4</sup>In July 1999, the CMS Network will be converted to a full-risk capitated model available to both Medicaid- and Title XXI-eligible CSHCN, with the state CMS agency to serve as the risk-bearing entity.

services are coordinated with services provided through other public systems, including mental health, early intervention, and special education.

- **Maryland.** In January 1997, Maryland launched its Medicaid managed care system—HealthChoice—under a Section 1115 waiver from HCFA. HealthChoice is a modified mainstream managed care model; that is, but for a few narrowly-defined population groups, all Medicaid recipients are required to enroll with one of eight private managed care organizations (MCOs) that receive risk-adjusted capitations in return for providing comprehensive services. Among those “carved out” of HealthChoice MCOs’ responsibility are persons with selected chronic, complex medical conditions whose care is very expensive; these individuals are eligible to enroll in the state’s new Rare and Expensive Case Management (REM) program, which provides services on a traditional fee-for-service basis, along with intensive case management. A Medical Review Panel makes recommendations to the Department of Health and Mental Hygiene regarding which diagnoses to include as REM-eligible conditions and periodically reviews this list, which is made up primarily of pediatric diagnoses. In addition to this population carve-out, the state has also explicitly carved out certain services from the responsibility of HealthChoice MCOs, including specialty mental health services and services specified in children’s Individualized Education Plans (IEPs) or Individualized Family Service Plans (IFSP) (under the Special Education and Part C/Early Intervention programs, respectively) that are delivered in the schools or by Title V/Children’s Medical Services community-based providers. To better accommodate CSHCN who are enrolled in managed care, the state requires HealthChoice plans to designate a Special Needs Coordinator to serve as the plan’s point of contact for enrollees with special needs. Furthermore, HealthChoice MCOs are required to provide case management services to enrollees who fall into one of the seven special population groups identified by the state as needing this extra level of support including, explicitly, CSHCN.
  
- **Michigan.** Medicaid eligibles in Michigan, including SSI recipients, have been required to enroll in some form of managed care since 1994, although children enrolled in Children’s Special Health Care Services (CSHCS), the state Title V CSHCN program, were exempt from enrolling in capitated plans. In 1998, however, Michigan implemented a separate capitated program designed specially for children enrolled in CSHCS, whether or not they were also eligible for Medicaid. The program, which is currently implemented in six counties, is voluntary; families may choose between a capitated HMO (known as a Special Health Plan) and the existing fee-for-service system. If they choose a Special Health Plan, they may enroll their child in one of two plans, depending on their county. Children eligible for Medicaid receive the full package of Medicaid and EPSDT services, while those eligible solely for CSHCS receive specialty services related to their qualifying diagnosis as well as well-child care and immunizations. The Special Health Plans are responsible for all physical health care services and a limited amount of mental health care. Each plan has as part of its

administrative staff a Family Centered Care Coordinator who works to ensure that plan policies and services are responsive to the needs of families with CSHCN. At the service delivery level, case management is provided through affiliated community-based care coordinators in local health departments and other agencies, and all care is delivered according to an Individualized Health Care Plan developed jointly by the enrollees' Principal Coordinating Doctor and families. The plans receive capitation payments that are adjusted for each enrollee's diagnosis, insurance and Medicaid coverage status, and geographic location.

- **Minnesota.** Minnesota's Medicaid managed care program, the Prepaid Medical Assistance Program (PMAP), exempts from enrollment anyone who is eligible for SSI, along with several other categories of children with special health care needs, such as those served under the Tax Equity and Fiscal Responsibility Act (TEFRA) home-based care program. As such, the state serves as the study's "control" group. These children are served through the traditional fee-for-service Medicaid program. Like many fee-for-service Medicaid systems, this program does not guarantee access to primary care or specialty providers, does not offer case management for CSHCN, and does not monitor the amount or quality of care that children receive.

Importantly, other Medicaid-eligible children with chronic conditions or disabilities who do not meet the eligibility standards for SSI or TEFRA are enrolled in PMAP, although this system is not designed to meet their needs and includes no special provisions for their care. Some individual plans and providers have taken steps to identify CSHCN retrospectively in their encounter databases and do provide comprehensive care coordination to these children.

Finally, the state has begun to develop model Medicaid managed care systems for people with disabilities in two areas of the state. These models, known as the Disability Pilots, are designed by local work groups including consumers, family members, and providers, and are to include an extensive service coordination component. The pilot projects will not begin enrollment until early 2000.

- **Oregon.** Oregon implemented its Medicaid managed care program—the Oregon Health Plan (OHP)—in early 1994 under a Section 1115 waiver. The first phase of the program, which enrolled only mothers and children eligible for Medicaid receiving Aid to Families with Dependent Children (AFDC) benefits, received significant national attention for its use of a limited benefit package based on a "Prioritized List" of covered services and treatments chosen by a multi-disciplinary panel of health care providers, researchers, and policymakers based on their effectiveness, cost effectiveness, and perceived value to the community. Under Phase II, implemented in January 1995, OHP became one of the first statewide Medicaid managed care programs to mandatorily enroll the Supplemental Security Income (SSI) disabled population. Today, the program represents a model through which virtually all Medicaid populations, including

CSHCN, are enrolled into mainstream managed care organizations that are responsible for meeting all of the acute and ambulatory health care needs of their enrollees for a fixed, capitated fee. The only significant service categories “carved out” of the responsibility of MCOs are mental health and dental services; Medicaid’s delivery and financing of these services have also recently been organized within fully-capitated arrangements with managed behavioral health organizations and dental plans. Of note, the planning process for Phase II did result in the creation of several provisions designed to safeguard SSI populations under managed care, including a requirement that plans provide for Exceptional Needs Care Coordinators to support individuals with particular needs in service coordination.

- **Tennessee.** Tennessee’s Medicaid managed care program, TennCare, is a mainstream, fully capitated model that requires all beneficiaries, including SSI-eligible and other CSHCN, to enroll in managed care plans. The program was implemented in January 1994 under a Section 1115(a) waiver. In addition to serving the Medicaid population, TennCare is available to uninsured residents including those whose medical condition makes them uninsurable. Medical services for TennCare recipients are provided under contract with nine health maintenance organizations (HMOs) for a fixed capitated amount per recipient per month. The HMOs in turn contract with a network of providers, including Federally Qualified Health Centers (FQHCs), to offer acute and specialty care services to all recipients. TennCare also contracts with 20 local health departments to provide access to health care services in some of the more rural areas of the state. In addition to acute and specialty care services, TennCare provides behavioral health services to Medicaid-eligible individuals through a service “carve out” with the TennCare Partners Program. TennCare Partners offers a comprehensive package of behavioral health services, including mental health and substance abuse treatment, to all eligible recipients through a contract with two Behavioral Health Organizations (BHOs). The state contracts with the BHOs to deliver mental health services to assigned enrollees based on a set capitation rate. The two BHOs operate statewide and are each aligned with a set of health plans.

### III. Service Integration Under Alternative Medicaid Managed Care Models

The case studies of the eight states were designed to permit an in-depth analysis of how alternative Medicaid managed care models either supported or hindered the delivery of integrated services to children with special health care needs. Interview and focus group protocols specifically addressed the models’ policies, structures, mechanisms, and experiences

related to eligibility, identification, and enrollment; primary and specialty medical care service delivery; links to other systems, including mental health, early intervention, and special education; systems for care coordination/case management; financing and payment; quality assurance and monitoring; family involvement with system planning, implementation, and oversight; and state-level collaboration and the role of Title V programs. Findings in each of these areas are described below.

## A. Eligibility, Identification, and Enrollment of CSHCN

A critical element of an integrated system of care for CSHCN is the ability of that system to identify these children and assure that their needs are assessed, planned for, and met. Part of this process involves assuring that CSHCN are assigned to providers who are trained and experienced in caring for children with complex needs. Without mechanisms for systematically identifying CSHCN and assessing their needs, systems of care are crippled in their ability to anticipate and provide these children and their families with the numerous and diverse services they often need to achieve optimal functioning. This study has revealed that alternative Medicaid managed care models possess widely varying capacity to effectively identify, enroll, and plan for the needs of CSHCN, as described below.

At one end of the spectrum, the system that appeared to have the least capacity to identify CSHCN and assist them with finding an appropriate provider was the fee-for-service system in Minnesota. Like all fee-for-service systems, the one in Minnesota leaves Medicaid eligibles on their own to choose among any available provider who will accept Medicaid. The Department of Human Services does not provide the “carved out” SSI population with any special assistance in finding or choosing providers who are skilled in serving CSHCN.

The mainstream managed care models we studied also generally lacked the ability to routinely identify CSHCN and link them with appropriate providers and/or care. Part of this problem related to the lack of a commonly agreed-upon definition of the population and a screening tool for operationalizing the definition. But more fundamental to this problem, in terms of its relevance to managed care, is the fact that mainstream systems are designed, a priori, with the

intent of promoting free and open competition among participating health plans, and actually build in safeguards to ensure that no plans experience systematic adverse selection (by receiving a disproportionate number of high-cost children). Therefore, while state or local enrollment staff (in Arizona, Oregon, and Tennessee), or contracted enrollment brokers (in Maryland), provided newly eligible families with information packets and varying levels of hands-on assistance in choosing health plans, none explicitly screened for the presence of special needs among children for the purpose of steering these children, if they were identified, to particular health plans with special capacity to meet their needs. Furthermore, our study generally found that health plans involved with mainstream Medicaid programs did not have their own systems for screening new enrollees for special health care needs. Therefore, key informants interviewed for our study were particularly concerned that the majority of such plans had little or no idea how many CSHCN were among their enrolled population, nor any way of planning for their care. State officials in Maryland and Oregon deserve mention for creating certain mechanisms designed to mitigate the negative potential of these circumstances, as described below.

- In Maryland, since all HealthChoice plans are required to provide case management services to CSHCN, the state has designed two mechanisms by which CSHCN can come to attention of plan administrators and providers. First, the state created a Health Risk Assessment Form which is included in the packets provided to newly eligible families. This simple, eight-item questionnaire is to be filled out by all families and forwarded to the system's enrollment broker. For persons who identify themselves as having a high risk condition, HealthChoice plans are next required to conduct a follow-up Initial Health Visit within 15 days to confirm whether the individual has special needs. If they do, then they are referred to case management.
- Under the Oregon Health Plan, SSI recipients are provided the same information as all other new Medicaid eligibles about available health plans. However, during the managed care enrollment process, if SSI recipients indicate any problems or disruptions that might occur as a result of their enrollment into managed care, social services caseworkers are instructed to counsel them more closely on the selection of a plan that might meet their needs. Furthermore, SSI recipients are never "auto assigned" to a health plan if they fail to make an active choice of a plan. Finally, OHP includes an "opt out" provision for disabled individuals who wish to maintain an ongoing relationship with a provider who does not participate in any of the networks of available health plans.

By definition, the Medicaid managed care systems that are explicitly designed to serve children with disabilities and/or chronic conditions do not need a system for identifying CSHCN among their enrollees. They do, however, need outreach systems to make families with CSHCN aware of the availability of the special plans, as well as mechanisms to assess particular needs and identify providers who are equipped to meet those needs. It does appear, based on our analysis, that these “specialty” managed care models do possess greater capacity and more explicit systems for identifying the needs of their enrollees and planning the appropriate delivery of their care. Examples of this capacity are provided below.

- In Florida, CMS nurses routinely conduct outreach in area hospitals and with area physicians to publicize the availability of the CMS Network and to talk to parents of children with disabilities about their option to enroll in the plan. Once enrolled, CMS nurse case managers then work closely with families to fully assess their children’s needs and to link them with appropriate providers.
- In the District of Columbia, HSCSN, Inc. is permitted to conduct direct marketing to families with SSI-eligible children to counsel them regarding the availability of the special health plan. The plan’s outreach workers have succeeded in raising the rate of voluntary choice of the plan among eligible families from below 20 percent in the program’s first year to greater than 80 percent at the time of this study.
- In Arizona’s ALTCS system, potentially eligible children undergo a thorough financial and medical eligibility review that results in a detailed assessment of needs. This assessment is used by the program’s case managers to develop a plan of care and organize subsequent receipt of services through the plan.

Of course, the effectiveness of these programs is often hampered by their lack of an inclusive definition of CSHCN—Arizona’s ALTCS systems only serves those children with severe developmental and physical disabilities that are at risk of institutionalization; the system in DC is voluntary only for families with SSI-eligible children; and Michigan’s program only serves those children with CSHCS-eligible conditions. Even Florida, which uses the broad eligibility definition of “children with serious or chronic physical or developmental conditions that require extensive preventive and maintenance care beyond that required by typically healthy children,” is only as successful as its outreach efforts. That is, key informants there admit that the state undoubtedly misses some CSHCN since its Medicaid enrollment broker does not systematically

inquire about children's special needs that might qualify them for the CMS Network, nor even generally offer the CMS Network as an option to new Medicaid eligibles. Thus, children that are missed by CMS outreach may end up in the mainstream system and do not have the opportunity to benefit from the features built into the specialty model.<sup>5</sup>

## B. Primary Care

For children with serious health problems, the need for ongoing specialized medical treatment often overshadows the need for routine primary care. However, as is the case for all children, a high quality "medical home" represents an essential component of a comprehensive system of care for CSHCN.

A consistent and positive finding in seven of the eight states we studied was that the use of managed care under Medicaid has succeeded in providing all enrollees, including CSHCN, with a primary care medical home. Key informants at all levels described this as a critical strength of their systems, an attribute that was clearly absent from their previous fee-for-service systems. All of the states that enrolled CSHCN into managed care arrangements utilize fairly consistent processes for linking new eligibles, at the time of enrollment, with a primary care provider. Most also permitted pediatric specialists to serve as the primary coordinating physician for CSHCN who desired such an arrangement, and each of the states also included language in their contracts with MCOs requiring plans to adhere to EPSDT rules regarding coverage, periodicity of well-child visits and, in states like Maryland, the EPSDT statute's broad and inclusive definition of medical necessity. Notably, all of these safeguards were absent from the fee-for-service system in Minnesota; CSHCN who are exempt from enrollment into managed care are provided no guarantee of a primary care medical home, nor does any mechanism exist for assuring that CSHCN receive routine EPSDT screens under the fee-for-service system.

---

<sup>5</sup>Since the time that key informant interviews were conducted for this study, Medicaid has significantly reduced the likelihood that CSHCN will be enrolled in mainstream HMOs with improvements in its enrollment procedure. In late 1998, the state revised the script used by its enrollment broker (Benova) to include a query about any special health care needs of child enrollees and, as appropriate, discuss the CMS Network as an enrollment option.

It is important to note, however, that in order for a “medical home” to be of optimally high quality for a child with special needs, the primary care physician should possess some degree of experience and comfort with serving this population. Unfortunately, in all of the states we studied, the supply of such physicians was described as insufficient. Furthermore, the financial incentives inherent in capitated systems tended to discourage primary care physicians from serving CSHCN in their practices. According to many physicians we interviewed, health plans typically use the same (relatively low) fees for visits with a “healthy” child as they do one with a child with disabilities. Given the extra time and effort involved with treating CSHCN, these physicians said it was economically unfeasible to serve large numbers of these children in their practices. One of the states we studied has taken important steps to address these related challenges, as described below.

- In Florida, the CMS program has always placed heavy emphasis on primary care as part of its continuum of care for CSHCN. When the CMS Network became part of Medicaid’s *MediPass* PCCM program, the state required each local area CMS office to develop a plan for recruiting, credentialing, and enrolling primary care providers with expertise in serving CSHCN. To be credentialed in the CMS Network, physicians must (1) be board certified in pediatrics or family medicine; and (2) have hospital privileges at a designated CMS facility, or have arrangements in place with the local CMS program to admit patients to these facilities. Despite Medicaid’s low payment rates, CMS officials reported success in their recruitment efforts, due in large part to the strong case management support that is provided to physicians by CMS nurses (to be discussed in more detail below).

### C. Specialty Medical Care

Access to a broad range of specialty services and ancillary therapies, from hospital care to physical therapy to durable medical equipment, is essential to providing appropriate care, promoting development, and supporting the functioning of CSHCN. Given the complex and diverse needs of chronically ill and disabled children, a provider network of appropriate breadth and depth represents one of the most critical features of any managed care model intending to serve CSHCN.

Under the Medicaid statute and, more specifically, EPSDT rules that were bolstered by OBRA-89, children should be covered for any treatment service needed to address a condition identified through an EPSDT screen. Theoretically, therefore, CSHCN covered by Medicaid should enjoy equal and widespread access to all the services they need. In a managed care environment, however, such access is determined less by which services are “covered,” on paper, than by such factors as health plans’ rules for obtaining prior authorization, processes for determining medical necessity, and the quality of MCOs’ provider networks. Each of these factors, in turn, is highly dependent on the policies, regulations, and contracting rules set by each state. Indeed, we observed highly variable practices among the states we studied in terms of their provision of specialty care, and children’s access to that care was significantly influenced by the managed care model used by each state.

Among the mainstream managed care systems we studied, key informants generally reported that children’s access to specialty care, in particular specialty medical care, was good. This was observed to be a natural extension of health plans’ focus on a medical model of care as well as the growth and improvements in quality of many of the MCOs that now contract with state Medicaid programs. This strength was also attributed to effective state policy-making, such as the inclusion in managed care contracts language identical, or at least similar, to the EPSDT “treatment provision,” and safeguards extended in the form of grievance and appeals procedures for families to follow if they believed they were unfairly denied services. While some of these circumstances were a result of external pressure and oversight (such as the EPSDT consent decree in Tennessee which forced the state to bolster its contracts with MCOs), other states, such as Maryland, proactively established rules that led to the development of high-quality networks with capacity to serve CSHCN, as summarized below.

- Prior to implementing the HealthChoice program, Maryland policymakers engaged providers, plans, and advocates in a lengthy deliberative process to consider strategies for making the managed care system responsive to the needs of special populations. The CSHCN workgroup, in particular, focused on criteria for provider networks, and rules surrounding access and medical necessity. Specifically, RFPs stipulated that the state would not contract with any MCO that couldn’t demonstrate its inclusion of an extensive array of pediatric subspecialty providers and tertiary facilities to care for CSHCN. This provision reportedly spurred the development of new relationships between

health plans and such traditional providers as the Johns Hopkins University Hospital, the Kennedy-Krieger Institute, Mt. Washington Hospital, and many providers traditionally involved with the state Title V/Children's Medical Services program. Furthermore, Maryland's contracts with MCOs require plans to use a definition of medical necessity that mirrors the EPSDT statute's; that is, they are required to deliver any services "necessary to prevent, treat, or ameliorate physical, mental, or developmental problems or conditions identified by an EPSDT-certified provider or other health care professional."

Unfortunately, despite such safeguards, mainstream models were consistently reported to be much less effective in providing easy access to other specialty care, especially habilitative and rehabilitative therapies, durable medical equipment and supplies, and other support services. These types of care, falling outside of the medical model most familiar to mainstream plans, tended to receive considerably more scrutiny by plan "gatekeepers" and were often denied on the grounds that they were not "medically necessary," according to many of the families we interviewed in states such as Tennessee, Maryland, and Oregon.

The use of an explicit "carve out" for specialty care in Arizona, a unique policy among the states we studied, caused considerable confusion among families and providers, as well as contentious debate among state policymakers. Designed to preserve the longstanding and highly respected multidisciplinary model of care rendered through the Title V/Children's Rehabilitative Services (CRS) program, the "carve out" requires AHCCCS health plans to refer to CRS any services required to treat a child's CRS-eligible condition; these services are, in turn, delivered and paid for through the separate CRS system. Many AHCCCS officials and health plan administrators, however, contend that this policy fragments care, creates "boundary" disputes over which system is responsible for various components of care, and tends to undermine integration as a result of cumbersome and ineffective information flow between systems of care. (As will be discussed further in the next section, such problems were commonly identified and associated with service "carve outs" included within mainstream managed care models.)

The specialty managed care models we studied in Florida, Michigan, and the District of Columbia appeared to excel in providing comprehensive specialty care in a manner that was

integrated with other systems of care. Once again, while operating under the same basic authority of the Medicaid statute, these programs more explicitly focused on the needs of CSHCN and crafted their networks and policies to be directly responsive to their needs. For example:

- In Florida, the CMS Network was formed around the state’s well-established network of pediatric specialists and tertiary care centers who provide care using a multidisciplinary model, supported by CMS case managers. This care is provided in centralized, usually hospital-based settings, as well as through a network of satellite clinics held in rural portions of the state. Furthermore, CMS rules encourage participating primary care providers to grant “blanket,” time-limited authorizations of referrals for specialty care to ease the administrative burden on both families and providers.
- In the District of Columbia, a broad network of 2,000 providers has been recruited, most of whom are pediatric specialists, tertiary centers with pediatric capacity, and other ancillary providers that serve children. Also, each enrolled child’s plan of care, developed by HSCSN case managers and signed by plan primary care providers, serves as a standing authorization for specialty referrals for a period of six months. The system was reported to be less burdensome and easier to access for families compared to the District’s mainstream HMO program.
- Special Health Plans in Michigan, too, use the child’s Individualized Health Care Plan as standing authorization for a given set of services. Here, it can remain in place for up to a year. In addition, Michigan policymakers solicited the input of a wide range of providers, plans, and family advocates in drafting its RFPs for the specialty managed care system. These deliberations resulted in rigorous standards for MCOs that wished to participate, requiring that networks possess broad and deep capacity to serve the diverse needs of CSHCN.

Once again, perhaps the weakest system we observed was the traditional fee-for-service system in Minnesota. Without a centralized entity to hold accountable (such as a MCO), state officials admitted little ability to exert control over variations in practice among the state’s thousands of pediatric providers, and no systems upon which to enforce EPSDT rules of coverage. In addition, while fee-for-service is often regarded as more accommodating of children’s need for specialty referrals, the Medicaid agency in Minnesota (as is the case in many states) actually requires families to obtain prior authorization for the receipt of physical, occupational, and speech therapy over certain limits, and the most frequent appeals of denials of coverage

concerned these services, as well as home care and durable medical equipment. Therefore, it does not appear that a fee-for-service system guarantees easier access to specialty care.

#### D. Links to Mental Health, Early Intervention, Special Education, and Other Support Services

Beyond health and medical care, a large proportion of CSHCN also need and use services from a number of other systems of care, including mental health, Part C/Early Intervention, and special education services, among others. Through this study, we observed numerous arrangements between these systems and Medicaid managed care programs, the effectiveness of which held significant implications for whether or not services for CSHCN were considered to be well integrated. The ability of alternative Medicaid managed care systems to effectively integrate with these other systems is discussed below.

For mental health services in particular, the basic system design question appears to be whether or not to exclude these services from managed care plans' responsibility. Proponents of these service "carve-outs" argue that higher-quality care will result if services are offered through systems with expertise and experience providing that care, even if it means doing so outside of the managed care plan. Opponents of "carve-outs" contend that such arrangements, by nature, fragment care and create serious challenges related to the sharing of information across systems, the determination of clear boundaries of responsibility (for service delivery and financing), and financial incentives for shifting responsibility for high-cost cases between systems. These opponents also believe services can be better integrated when a single plan is paid and held accountable for delivering the widest array of services possible. While this study's findings do not resolve this debate, they do lend credence to the argument that, at least for CSHCN, service "carve-outs" cause considerable confusion among providers and families alike and seriously challenge managed care systems' ability to effectively integrate care.

In each of the mainstream managed care systems we studied, "carve-out" arrangements were established for mental health, Early Intervention, and special education. The mainstream systems in Arizona, Maryland, Oregon and Tennessee operate under the broad charge of

addressing the health care needs of all Medicaid recipients; therefore, it is understandable that policymakers chose not to integrate the Early Intervention and special education systems, which serve narrower populations of children with developmental delays and disabilities that affect their ability to learn, with the operations of health plans. With regard to mental health, while system designers in these states determined that these services should be delivered through managed care arrangements, they designed managed behavioral health systems that operate separately from health plans. In recent years, each of these states' Medicaid programs has established contracts with either private behavioral health organizations or state mental health agencies to deliver a wide range of mental health (and often substance abuse treatment) services to Medicaid recipients on a capitated basis. These system development efforts were consistently described by key informants in all four states as having led to significant improvements in public mental health coverage, usually by broadening the network of available providers to include private practitioners, and by increasing the systems' emphasis on children's mental health issues. Unfortunately, key informants were just as consistent in describing the integration problems that surround these "carve-outs."

- In Oregon, where a "clean" carve-out results in health plans not having any responsibility for addressing the behavioral health needs of enrollees, Medicaid recipients can access mental health services without a referral from their primary care provider. While this open access was praised, it was also criticized as undermining the free flow of information between primary care and mental health systems. As these systems are, by design, organizationally separate, key informants admitted that routine channels and mechanisms for sharing information simply do not exist, and described how requests for information by primary care providers are often denied due to the mental health system's concerns over patient confidentiality. Furthermore, providers and health plan administrators described boundary confusions arising over how to handle crisis and emergency care, laboratory tests, and the prescribing of medications for such common childhood behavioral problems as Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD).
- In Maryland, the division of responsibility between the health and behavioral health systems is even less clear. Here, HealthChoice plans are responsible for "primary" mental health care (and enrollees can self-refer to mental health providers for up to 12 visits), and are to formally refer enrollees to the state mental health agency for more significant conditions. Here again, questions have arisen surrounding what constitutes "primary" mental health care (for example, treatment of ADD/ADHD), and key informants pointed out that health plans

have a strong financial incentive to refer all mental health services to the behavioral health system, thereby avoiding the costs associated with their care.

Similar issues were discussed at length in Arizona and Tennessee, where the lack of information exchange between the health and behavioral health systems was described as especially problematic for integrating and coordinating care for children served by each system.

In the states with mainstream managed care models, similar problems were cited with regard to the delivery of “carved out” Early Intervention and special education services. In short, key informants stated that these systems operated quite separately from one another; little or no information flowed between the systems, undermining providers’ ability to understand and coordinate the care each were providing to the same children; and, in the case of ancillary therapy services (including occupational, physical, and speech therapy), financial incentives often led health plans to inappropriately refer families to the schools and early intervention programs for their care.

Focus groups with families in each of these states indicated that parents of CSHCN were often most affected by the negative outcomes of these “carve-out” arrangements. Specifically, since the systems themselves were not sharing information or integrating their activities, parents were left trying to bridge the two systems and keep each system’s providers informed about the care the other was providing to their children.

Cross-system integration was observed to be equally challenging, but somewhat more successfully addressed in the specialty health plans compared to the mainstream systems. By virtue of their design and specific focus on CSHCN, these plans were described as more aware of the needs of CSHCN for mental health, Early Intervention, and special education services, and some had implemented specific processes for integrating these services with those provided by health providers in the network.

- In the District of Columbia, largely due to the flexibility afforded by capitation rates that were described as “generous,” HSCSN, Inc. has assumed responsibility for delivering, managing, and paying for a broad range of services beyond

traditional medical care. Witnessing a high level of need for mental health services among its enrollees, coupled with a sense that DC's public mental health systems were not well equipped to serve children, HSCSN has begun providing and paying for individual and family therapy, day treatment, 24-hour crisis intervention for at-risk youth, and mentors for troubled teens. Early Intervention and some special education services are also arranged and paid for by the plan for children who are dually eligible. Finally, HSCSN appreciates the importance of providing significant support to the parents of CSHCN, and thus provides such services as basic telephone service for families without phones, transportation to appointments, therapeutic day care and camps for CSHCN, and up to 120 hours of respite care every six months.

- In Florida, as the CMS Program is also the lead agency for Early Intervention, these services are especially well integrated with those provided by the CMS Network for dually-eligible children. CMS nurses performing outreach in neonatal intensive care units perform a case-finding role for both CMS and Early Intervention. Each program accepts the other's evaluations, and each local area CMS program has a case manager funded by Part C who handles the coordination of care for CMS children who are also enrolled in Early Intervention.

At this writing, Florida was in the process of revising its approach for handling mental health services for CSHCN. Traditionally, mental health services were delivered separately from health services provided through CMS. Thus, many of the coordination and integration problems described above plagued the systems. However, under a new initiative, responsibility for children's mental health will be folded into the CMS program and its CMS Network. A pilot program will achieve this for the subset of Medicaid-eligible children with Serious Emotional Disturbances, while this arrangement will hold for all children enrolled in the state's new Title XXI/CHIP program.

Just as parents in states with mainstream managed care systems described the burden of coordinating the care their children received across disparate systems, parents in states with specialty health plans praised the coordination they perceived as occurring across systems.

Finally, it bears mention that the fee-for-service system in Minnesota lacked any formal mechanisms for integrating service delivery across its separate health, mental health, Early Intervention, and special education systems. While key informants praised the individual strengths of some of these systems (in particular, the quality of new Community Mental Health Collaboratives forming in many of Minnesota's counties), they admitted that the fee-for-service

structure within Medicaid left families on their own to access and coordinate services among these different programs.

## E. Case Management/Care Coordination

Case management is an especially critical component of care for CSHCN, as it provides a mechanism to organize and link the wide range of services these children need. Outreach, comprehensive assessment of a child's needs, development of a plan of care, referral to services, and coordination and monitoring of the receipt of care are all essential elements of case management, elements that are often described as the “glue” that holds disparate systems of care together. Virtually all of the states we studied placed significant emphasis on case management for CSHCN yet, once again, we observed considerable variation in the scope and intensity of the service among the alternative managed care models.

As a basis of comparison, it is important to first note that the fee-for-service system in Minnesota held no explicit case management benefit for CSHCN, and no targeted case management service is covered for these children under the Medicaid state plan. As a result, families of CSHCN in Minnesota are largely unsupported in their efforts to obtain access to the various services their children need.

In two of the mainstream managed care plans we studied, no explicit effort was observed to implement a centralized case management system for CSHCN, nor were particular mechanisms incorporated into managed care systems to bolster their capacity to coordinate care for these children. Both TennCare (in Tennessee) and AHCCCS (in Arizona) were characterized by the many systems that provided some form, albeit limited, of case management, including primary care physicians (acting as “gatekeepers” for referral services), health plan case managers (largely focused on prior approval and utilization review processes), Title V/CSHCN programs (providing more intensive support but only to the small number of children eligible for their programs), and behavioral health organizations (with case managers concerned with coordinating service delivery within their unique system of care).

In both Maryland and Oregon, however, policymakers anticipated that traditional managed care organizations would not be likely to provide the intensity of case management that CSHCN (and other special populations) might need and took explicit steps to strengthen these plans' ability to render appropriate support. These efforts are summarized below.

- In Maryland, two systems of case management deserve mention. First, with the implementation of the HealthChoice program, Medicaid required all participating health plans to designate Special Needs Coordinators to serve as the plans' points of contact for persons within each of the seven "special population" groups (including CSHCN) identified by the state. These coordinators, typically nurses, are charged by the state with "assessing, planning, coordinating, monitoring, and arranging the delivery of medically necessary and appropriate health-related services," although MCOs are provided considerable leeway in implementing this charge.

Second, for persons with eligible conditions enrolled in the Rare and Expensive Case Management (REM) program, which falls outside of HealthChoice MCOs' responsibility, one of several case management agencies under contract with the state provides this support. This intensive assistance was explicitly included to address the fragmentation inherent in the fee-for-service system and to assist special populations in arranging and coordinating their care.

- Oregon, like Maryland, requires plans participating in OHP to designate Exceptional Needs Care Coordinators (ENCCs) to serve as advocates and points of contact for SSI-eligible enrollees and others with special needs. Medicaid requires that these ENCCs (again, mostly nurses) respond to requests for assistance within one working day, and their charge entails not only helping enrollees to gain access to needed medical and health-related services within the plan, but also assisting persons in overcoming barriers to care in the community and coordinating their receipt of services in community-based systems.

Despite the noteworthy intentions of these efforts, these plan-based systems contained certain weaknesses in their ability to provide intensive ongoing support to CSHCN, according to many key informants and parents. First, none of the plans we spoke with employed large numbers of Special Needs Coordinators or ENCCs. Thus, the programs had limited reach and could only react to those requesting assistance, as opposed to proactively seeking out and offering assistance to the entire population that could potentially benefit from their support. In attempting to meet demand, plan case managers tended to carry large caseloads, often in excess of 75 to 100 enrollees, at any given time. Finally, as a result of this supply/demand tension,

most coordinators provided assistance by telephone, rather than in person; this indirect contact can hinder a case manager's ability to fully assess clients' needs and/or engage their clients in a meaningful dialogue regarding sensitive needs. In our focus groups, some parents of CSHCN were not even aware of the existence of these special care coordinators. Those parents familiar with the systems appreciated their support, but still felt that the case managers' ability to provide the intensive assistance they often needed was limited. Ultimately, families in these states believed that they were their children's only real case managers, a role that created significant stress. State officials in both Maryland and Oregon are aware of their systems' shortcomings in this area and are taking steps to address them. In Maryland, a Case Management Task Force was formed to analyze alternative approaches that might work better for special populations and its recommendations are now being implemented. In Oregon, Medicaid and Title V officials have spoken of the possibility of expanding the scope and financing for Title V's CaCoon program, a local health department-based case management system that provides a particularly intensive form of case management to CSHCN and their families.

Among the Medicaid managed care plans that were specifically designed to serve CSHCN, there was a much higher likelihood of finding expansive systems for providing intensive case management support to children and their families, as described below.

- In Arizona, the ALTCS program assigns a "DD Case Manager" to every enrolled child based on his or her level of need. This individual, armed with the results of the child's preadmission screen, is responsible for planning and coordinating all aspects of the enrollee's care. That job is facilitated by ALTCS' support of a DD Liaison position in each AHCCCS plan that contracts to provide for the acute care needs of ALTCS enrollees. These DD Liaisons assist DD Case Managers in coordinating the medical care provided through the health plans with the community-based care provided by other components of the ALTCS model.
- In the District of Columbia, most of HSCSN's in-house staff is composed of professional case management and lay outreach staff. These persons, working in teams, have responsibility for conducting risk assessments, developing plans of care, and coordinating and monitoring referrals.

- In Florida, each local area CMS office is staffed with a large number of nurse case managers. All children in the CMS Network are assigned a case manager, based on the outcomes of the program's Family Support Assessment and Family Support Index tools. CMS case managers take responsibility for care plan development, linkage and referrals, coordination and monitoring of the receipt of care, arranging transportation, and ensuring that medical records and other information flows among various system providers. Of particular note, CMS case managers are supported by a cadre of paid Resource Parents who assist families in accessing needed resources and offer peer support to other families dealing with the challenges of raising a child with serious health problems.
- Only in Michigan was it less clear that the Special Health Plan supported intensive, ongoing, community-based care coordination. First, each of the two Special Health Plans possess staff designated as "plan-based care coordinators" but these individuals perform more traditional managed care functions related to prior authorization and utilization monitoring. Second, while enrollees also choose a "local coordinator" from among agencies under contact with the Plan, including local health departments, home health agencies, and CMS clinics, these individuals operate independently and without consistent protocols. Moreover, the provision of care coordination is not supported within the state's capitation rate for plans; rather, funds are set aside by the CSHCS program for this purpose and are paid directly to local agencies. These arrangements conveyed unclear messages to Special Health Plans regarding the emphasis they are to place on comprehensive case management.

In contrast to those participating in mainstream managed care plans, parents with children in specialty plans tended to provide much more favorable reviews of the quality and intensity of case management they received. This assistance was described as significantly reducing the burden, and related stress, felt by parents.

## F. Financing

An essential element of a system of care for CSHCN is a mechanism to assure that providers are appropriately compensated for these children's care. Without a method of adjusting capitation rates for children's level of risk, plans have a financial incentive to minimize the amount of care they provide or to shift costs to other systems. In addition to risk-adjusted capitation rates, an integrated financing system would also include the ability to blend funding from across programs to maximize the resources available to families. In the absence of truly blended

funding systems, agreements between the agencies that operate programs for CSHCN regarding the coordination of payment can help to assure that children have access to the full range of services they need.

Few examples of risk-adjusted or integrated funding mechanisms were evident among our study states. In the area of risk adjustment, while three states—Arizona, Oregon, and Tennessee—maintain separate capitation rates for Medicaid eligibles enrolled in SSI, none of them use separate rates for children within that category. Moreover, the study states do not attempt to identify which among the SSI-eligible children are likely to require more expensive services, nor do they adjust their rates for varying levels of risk among non-SSI-eligible children.

Two states in our sample, Michigan and Maryland, have made significant progress in the development of risk-adjusted capitation rates. In Michigan, the rates used for the specialty managed care model for CSHCN include 48 cells, taking into account children’s diagnosis, eligibility for Medicaid, access to private insurance, and geographic region. This rate structure, which was developed by the Medicaid Working Group under a Special Projects of Regional And National Significance (SPRANS) grant from the MCHB, will be evaluated after the plans have a year of experience to ascertain whether the rates paid were adequate to meet children’s needs. In Maryland, children with chronic conditions who have at least six months of claims in the Medicaid program are assigned to one of nine rate cells based on the number and types of diagnoses reflected in their claims. The state is currently investigating ways to similarly classify those children without a history of fee-for-service Medicaid claims.

The coordination of funding across programs and agencies has proven equally complex and daunting in our study states. Categorical rules dictating the expenditure of federal funds represent the clearest barrier to up-front blending of funding streams. In addition, while the scope of services in Medicaid, Early Intervention, mental health, and special education programs frequently overlap, most states had not developed successful systems to bill Medicaid for medically necessary services provided by these programs and maximize Federal funding. Several types of problems were observed as states attempted to institute these systems, as described below.

- **Reliance on cooperation of personnel.** In Minnesota, the Medicaid managed care program covers both medically and educationally necessary services. Therefore, Early Intervention services should be billable to the managed care plans. However, case managers and Part C care coordinators do not always cooperate with each other, and it is often left to the family to assure that plans reimburse for IFSP services.
- **Limitations on providers.** In Minnesota, schools were required until recently to become Medicaid providers before they could bill for health-related special education services, a requirement that posed a significant barrier to Medicaid payment. (This problem has been ameliorated through the creation of a new Medicaid provider category called “IEP provider” and a billing code for “IEP services.”) Similarly, in Florida, psychologists and family therapists may bill Medicaid only if they are under contract with Community Mental Health Centers.

In some cases where Medicaid does pay for Early Intervention or special education services, payment systems do not support integration of services. In Oregon and Michigan, providers of special education services (and Early Intervention services in Oregon) are able to bill Medicaid for medically necessary services. However, because these providers bill the Medicaid agency directly, not the managed care plan, this arrangement provides an incentive for plans to shift costs to these outside systems wherever possible. Moreover, information regarding the services provided in these systems is not communicated to the managed care plans in which the children are enrolled, so these services are not coordinated with the children’s medical care.

One example of a successful pilot program to assure appropriate Medicaid payment for medically necessary special education services and integration of these services with those provided through managed care plans is Tennessee’s TEACH program, funded by the Department of Education and the Department of Health. The program supports care coordinators in local health departments who can gain access to TennCare’s information systems, identify a child’s plan and primary care provider, determine which special education services are medically necessary and bill the plan appropriately. Because the plans are paying for the services, this model helps to support coordination between special education and medical care.

## G. Family Involvement in System Planning, Implementation, and Oversight

Recent years have witnessed a growing recognition among health system planners and policymakers of the importance of “family-centered” care. Systems that serve CSHCN can be thought of as “family-centered” if they: recognize that family members are the primary caregivers for CSHCN; value and honor the input of parents in decision making regarding the health services for CSHCN; and seek to involve and solicit the input of families of CSHCN in designing, implementing, and monitoring their programs.

In nearly all of the managed care systems studied, we observed an encouraging level of family involvement in system planning, implementation, and oversight. This involvement, in most cases, appeared to have contributed to specific policies and programs that succeeded in making systems more supportive of families and more responsive to their needs. In many cases, state Title V programs played the central role in facilitating and sponsoring this involvement. While families’ direct involvement with the day-to-day operations of managed care systems was most apparent in states with specialized health plans, strong influence and high levels of activity on the part of parents were also observed in states with mainstream plans. Highlights of the study’s findings in this area appear below.

- Michigan’s Title V program has sponsored the Parent Participation Program since 1988, which has carried out a wide array of activities designed to make systems of care family friendly. The Program was instrumental in the design of the Special Health Plans, contributing to the original RFP for the plans, recommending the use of the IHCP as a standing referral for ongoing specialty care, and developing policies regarding the inclusion of a Family-Centered Care Coordinator within each plan. These paid professionals, each parents of a CSHCN, function at the policy and system levels to assure that plans’ services are family-centered and to assure that the plans’ policies meet families’ needs.
- Florida’s Title V/CMS program has had a similar longstanding commitment to involving parents of CSHCN in policy and planning. The state employs two Parent Consultants in the central office, ensuring that parents are “at the table” where policy and programmatic decisions are made. These consultants also participate in reviewing and developing program brochures and materials, a parent newsletter, providing training to advocacy groups on parent issues, and providing peer support to other parents. At the local level, once again, each

CMS office employs Resource Parents who assist CMS case managers with care coordination activities.

- Families' voices, in particular their complaints regarding the difficulty of receiving integrated care for their CSHCN, were the impetus for the design of the HSCSN model in the District of Columbia. Through the Title V program's *Use Your Power* Parent Council, members of which sit on the Medicaid program's Policy Advisory Board, families had direct input in shaping the program, including its use of the child's plan of care as a "blanket" authorization document for specialty referrals. HSCSN, as well, facilitates family involvement by requiring that families are involved with and sign off on the care plans for enrollees. In addition, it routinely conducts parent satisfaction surveys to gauge program effectiveness from the consumer perspective.
- Arizona's Title V/Office of CSHCN also has a long and impressive track record for involving parents in system planning, implementation, and oversight. Through activities such as its Community Development Initiative and Project Tsunami, parents become directly involved with effecting system change at the community level and strengthening family/professional partnerships.
- Maryland extensively involved families and family advocates in its various advisory groups that steered the development of HealthChoice. Of particular import, families were well represented on the Special Needs Children Advisory Council and the Case Management Task Force. In addition, the state has periodically conducted family focus groups as another means of obtaining parents' input and feedback on how well the system is working for them.

## H. State-Level Collaboration

Virtually all of the states included in this study showed an impressive level of interagency collaboration in developing their managed care programs for CSHCN, and most continue to do so as these systems are implemented. It is apparent that such inclusiveness led to the creation of stronger systems than would have otherwise resulted, as the opinions and perspectives of a broad array of stakeholders from both the public and private sectors was brought to bear on the question of how to make managed care systems responsive to the needs of persons with chronic illnesses and disabilities. In some instances, these deliberations directly influenced the fundamental model that emerged. In others, these discussions did not directly influence the state's Medicaid managed care model, but broad-based input did contribute to important modifications in plan design and strengthening the system's ability to serve CSHCN.

Highlights of the state-level collaborative efforts are summarized below.

- The emergence of Minnesota’s PMAP program has been characterized by the cautious and deliberative approach used by state agencies to assure that managed care systems were not implemented until counties were ready for them. The extension of managed care to persons with disabilities has also been a protracted process, begun in the early 1990s. Delays have occurred partly because PMAP was never designed to serve persons with disabilities, so the system includes few of the provisions and protections this population needs. Just as integral to these delays, however, have been the concerns for the viability of local providers who serve these populations who might be displaced by managed care. The result of these deliberations has been the maintenance of the traditional fee-for-service system for CSHCN, and the testing of a series of county-based pilot projects testing the feasibility of managed care for persons with disabilities.
  
- In Oregon, Maryland, and Tennessee, there was never any debate over what kind of approach to managed care would be used; the mainstream model was always the intention of policymakers. However, the Oregon and Maryland Medicaid programs, in particular, engaged in careful deliberative processes with their sister state agencies, key providers in the state, representatives of managed care organizations, consumer advocates, and researchers and other experts in an effort to assess the readiness of managed care systems to serve CSHCN (or persons with disabilities, more broadly), and to identify strategies for fine-tuning these systems so that they would be more responsive to special populations’ needs. Such deliberations during the Phase II preparation process in Oregon resulted in the creation of an Ombudsman Program for SSI recipients unfairly denied access to care, the requirement that health plans designate Exceptional Needs Care Coordinators for the SSI population, and the creation of a Continuity of Care Referral Form to notify health plans of the nature of SSI recipients’ special needs. Similarly, Maryland’s efforts led to the identification of seven special populations to whom health plans would be required to provide special care coordination, and the creation of a special exemption for persons with rare and expensive conditions that were thought to be better served in traditional fee-for-service arrangements. In Tennessee, where TennCare was initially developed on a very fast track and with little interagency input, an executive branch reorganization has moved the TennCare Bureau back into the Department of Health; since that time, communication and collaboration among agencies involved with serving CSHCN, primary Medicaid and Title V, have reportedly improved dramatically.
  
- In Arizona, despite heated debate over the ongoing viability of the CRS “carve-out,” AHCCCS officials and DHS’ Maternal and Child Health officials continue to work closely and effectively together to fine tune and improve the AHCCCS program’s ability to serve CSHCN.

- In each of the states that have implemented specialty managed care plans, particularly Florida and Michigan, extremely strong historical relationships between Medicaid and Title V have facilitated the development of these innovative models. The very close CMS/Medicaid partnership in Florida perhaps began in the early 1990s as the state worked to enhance EPSDT's effectiveness in the wake of OBRA-89, and has further blossomed with the evolution of the CMS Network as the centerpiece of Florida's effort to provide high quality care to Medicaid-eligible CSHCN through managed care. The Medicaid and MCH programs in Michigan have worked closely with one another on programs for women and children since the Medicaid expansions of the mid-1980s. This partnership was further and more formally strengthened during a recent executive branch reorganization that moved the CSHCN portion of Title V into the Medicaid agency. Once again, Title V and Medicaid officials spearheaded a careful and inclusive process to assess the feasibility of a special managed care program for CSHCN, a process that resulted in the creation of the Special Health Plans now in place.

Once again, each of the states included in this study can be credited with valuing the importance of interagency and public/private collaboration in the systems development process. Without exception, key informants we interviewed stated that obtaining the broad-based input, buy-in, and advice of not only state agencies, but providers, managed care organizations, and consumers, as well, helped to create systems of care that are stronger and more integrated than they might have been in the absence of such collaboration.

## IV. Conclusions

This study of alternative Medicaid managed care systems has yielded important qualitative insights and detailed information regarding how different models support or undermine integrated service delivery for children with special health care needs and their families. In short, our findings suggest that:

- Traditional fee-for-service systems offer the least structure and no formal mechanisms for coordinating resources across health, mental health, educational, and other systems families rely on;
- Mainstream managed care systems, while providing an important locus of organization and accountability for the delivery of primary and specialty medical care, often fall short in their ability to identify and serve CSHCN among their

enrolled children, integrate with non-medical systems of care, and provide intensive case management support to CSHCN and their families; and

- Specialized managed care systems, designed specifically to serve children with chronic illnesses and disabilities, hold great promise to more fully address the diverse and complex needs of this population through their unique service delivery and care coordination strategies.

These conclusions are elaborated upon below.

## A. The False Security Offered by the Fee-for-Service “System”

Historically, state Medicaid programs have elected to exempt persons with disabilities, including CSHCN, from mandatory managed care arrangements. These decisions typically grew from reasoning that traditional managed care systems were not designed for or equipped to serve these high-need, high-cost individuals, that enrollment into managed care was likely to disrupt existing relationships with providers, and that the fee-for-service system “protected” these populations’ open access to high-quality care.

This study found serious faults in this logic and concludes that the fee-for-service “system”—which is often not a system at all—offers the least structure and support for the goals of integrated service delivery. According to key informants interviewed for our study, Medicaid fee-for-service arrangements:

- Have limited capacity to systematically identify CSHCN in need of care, and have few systems for assisting families in finding or choosing providers who are skilled in serving these children;
- Provide no guarantee that a child with special health care needs will have a primary care medical home, nor assurance that he or she will receive routine EPSDT screening from a primary care provider;
- Cannot assure that CSHCN have access to the broad range of specialty services and ancillary therapies they might need, nor much control over variations in practice among children’s specialty providers;

- Have no explicit case management component to permit comprehensive assessments of children’s needs, the development of plans of care, nor the coordination of service delivery; and
- Possess little or no capacity to assist families with linking among the various health, mental health, educational, and other systems they need nor supporting the effective flow of information among them.

## B. The Limitations of Mainstream Managed Care and “Carve Outs”

Just as traditional wisdom questioned the readiness of mainstream managed care to effectively serve special populations, this study found strong qualitative evidence that Medicaid managed care systems, at least in the states we studied, have matured, and now tend to provide a high-quality source of care to CSHCN. Key informants we interviewed, including parents, tended to praise managed care systems’ capacity to provide a primary care medical home for CSHCN and to extend appropriate pediatric subspecialty care to them. Careful and deliberate systems planning among state agencies, providers, managed care representatives, and family advocates had, in several states, resulted in important modifications to the mainstream model that improved its responsiveness to CSHCN, including, for example, setting strong standards for network configuration, creating consumer ombudsman programs, instituting special assessment and referral instruments, and requiring plans to designate special care coordinators for persons with disabilities. Perhaps most important, state Medicaid officials were satisfied that managed care now offered them a system through which they could develop and enforce standards for appropriate access and delivery of care, and emphasized that no such accountable entity existed under the fee-for-service system.

However, while strengths were noted regarding mainstream managed care’s ability to organize and deliver primary and specialty medical care, many weaknesses in these systems were also noted with regard to their ability to facilitate access to and integrate with services beyond health systems. In most of the states we observed, mainstream managed care plans had poor, if not nonexistent, links with Early Intervention, special education, and other community-based systems that support CSHCN and their families. Particularly distressing were reports of the fragmentation that resulted from “carve-outs” of mental health services (in three states) and

specialty clinic services (in one state). By their nature, such “carve-outs” explicitly divide responsibility among systems for various aspects of enrollees’ care, and these divisions reportedly undermine integration and contribute to significant confusion, disruption, and inefficiency among providers and families. Common problems cited with “carve-outs” included:

- Poor information flow between the systems serving children;
- Unclear divisions of responsibility between systems for service delivery and financing, leading to frequent boundary disputes; and
- Inappropriate financial incentives for shifting responsibility for care between systems.

Mainstream managed care systems were also hampered in their ability to address such integration challenges due to their lack of strong, intensive case management systems. While the creation of Exceptional Needs Care Coordinators and Special Needs Coordinators in Oregon and Maryland, respectively, represent steps in the right direction, none of the mainstream plans we observed had nearly sufficient capacity to provide families with the intensive support they said they needed.

Finally, a fundamental weakness of these systems was their inability to systematically identify among their enrollee population those children who had special health care needs. This problem stems from the lack of a commonly-accepted definition of this population and an accompanying tool to operationalize the definition and allow systems to screen for CSHCN. Without a basic ability to identify children with special health care needs, managed care systems have no way of planning or organizing care to address their needs.

### C. The Promise of Specialty Managed Care Systems for CSHCN

This study set out to analyze the early experience of emerging specialty managed care systems, designed specifically to serve children with chronic illnesses and disabilities. In the states of Florida and Michigan and in the District of Columbia, policymakers were aware of the weaknesses of their mainstream managed care systems and set out to design alternative systems

that could be more responsive to CSHCN and their families.<sup>6</sup> Based on the findings of this effort, these models hold considerable promise for promoting a more comprehensive, family-centered, and integrated approach to serving these vulnerable children. The strengths that fostered effective service integration that were commonly identified in these systems were:

- A single, central organization that was accountable for the delivery and financing of all (or nearly all) services needed by CSHCN, not just health services;
- Formal links with service systems outside of the managed care system, and mechanisms for sharing patient information and coordinating referrals with those systems;
- A systematic process for assessing the diverse needs of all enrollees and a subsequent process for organizing a plan of care to address those needs;
- The recruitment and utilization of networks of providers with special qualifications to serve CSHCN;
- Mechanisms to facilitate children's receipt of diverse services, including the use of plans of care as standing prior authorization documents, and the enforcement of broad definitions of medical necessity;
- Strong systems of case management that provided every enrollee with support and assistance tailored to the intensity of their needs;
- Coverage of non-medical support services of particular importance to families of CSHCN, such as respite care, family counseling, and transportation; and
- Extensive family involvement with both the design and implementation of the special health plans, to help ensure that services are provided in a family-centered manner.

The findings of this study, while qualitative in nature, are compelling and add a new layer to our understanding of how managed systems of care hold the potential for fostering more integrated service delivery for CSHCN and their families. It will be important for future research to attempt to quantify and measure the differences we observed between the alternative managed care models and to provide state officials with tools to measure and monitor the extent of

---

<sup>6</sup> In Arizona as well, a specialty capitated system—ALTCS—was created to serve developmentally disabled adults and children at risk of institutionalization.

service integration within their systems. In the meantime, it is hoped that this report will help state officials, providers, insurers, and families in designing their managed care systems and further advance the goal of providing our nation's most vulnerable children with the high-quality care they deserve.

## References

Cartland JD and Yudkowsky BK. Barriers to referral in pediatric managed care systems. *Pediatrics* 1992;89:183-192.

Committee on Children with Disabilities, American Academy of Pediatrics. Managed care and children with special health care needs: a subject review. *Pediatrics* 1998;102:657-660.

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics* 1998;102(1):137-140.

Regenstein M and Schroer C. *Medicaid Managed Care for Persons with Disabilities: State Profiles*. Washington, DC: Kaiser Family Foundation, 1998.

Stein REK, Bauman LJ, Westbrook LE, Coupey SM, Ireys HT. Framework for identifying children who have chronic conditions: the case for a new definition. *J Pediatr* 1993;122:342-347.

Zimmerman B, Eisen N, Schwalberg R, Gabor V, and Hill I. *Critical Issues in Designing Contracts for Managed Care Organizations Serving Children with Special Health Care Needs*. Washington, DC: Health Systems Research, Inc. 1996.