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# ACHIEVING SERVICE INTEGRATION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: AN ASSESSMENT OF ALTERNATIVE MEDICAID MANAGED CARE MODELS\*

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## I. INTRODUCTION 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.<sup>1</sup> In addition, policy-makers, researchers, and advocates generally 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. These systems include not only the medical care system, but also those providing early intervention, special education, mental health, and a host of

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1. Merle McPherson et al., *A New Definition of Children with Special Health Care Needs*, 102 PEDIATRICS 137, 138 (1998).

other family support services.<sup>2</sup> 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. However, integrating these diverse services into a coherent system that supports high-quality care has been a major challenge.<sup>3</sup>

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.<sup>4</sup> According to the federal Health Care Financing Administration,<sup>5</sup> (HCFA) almost half (48%) 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.<sup>6</sup> 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.<sup>7</sup> In 1998, 36 states enrolled at least some of their Medicaid/SSI beneficiaries into managed care,<sup>8</sup> accounting for roughly 1.6 million individuals,<sup>9</sup> or one-fourth of Medicaid's non-elderly disabled enrollees.<sup>10</sup> 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.<sup>11</sup>

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2. Ruth E.K. Stein et al., *Framework for Identifying Children Who Have Chronic Conditions: The Case for a New Definition*, 122 THE J. OF PEDIATRICS 342, 343-44 (1993).

3. JAMES M. PERRIN ET AL., HOME AND COMMUNITY CARE FOR CHRONICALLY ILL CHILDREN 123-29 (1993).

4. See NEVA KAYE, NATIONAL ACADEMY FOR STATE HEALTH POLICY, MEDICAID MANAGED CARE: A GUIDE FOR THE STATES, VOLUME III: INNOVATIONS IN PAYMENT STRATEGIES TO IMPROVE PLAN PERFORMANCE 111-14 (4th ed. 1999).

5. Subsequent to this study, the Health Care Financing Administration was renamed the Center for Medicare and Medicaid Services (CMS).

6. HEALTH CARE FINANCING ADMINISTRATION, NATIONAL SUMMARY OF MEDICAID MANAGED CARE PROGRAMS AND ENROLLMENT, <http://www.hcfa.gov/medicaid/trends97.pdf> (June 30, 1997) (on file with the Journal of Health Care Law and Policy).

7. Marsha Regenstein & Christy Schroer, *Medicaid Managed Care for Persons with Disabilities: State Profiles*, 6-7, 26, <http://www.kkf.org/content/archive/2114/Disabilities.pdf> (Dec. 1998) (on file with the Journal of Health Care Law and Policy).

8. *Id.* at 2.

9. *Id.* at 3.

10. *Id.* at 6.

11. *See id.* at 9.

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,<sup>12</sup> 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.<sup>13</sup> Many questions have been raised regarding the capacity of managed care organizations (MCOs) to provide appropriate access to high-quality care for this population. Concerns most often center 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.<sup>14</sup> 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,<sup>15</sup> 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. For example, 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

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12. Sheila Leatherman & Douglas McCarthy, *Opportunities and Challenges for Promoting Children's Health in Managed Care Organizations*, in HEALTH CARE FOR CHILDREN: WHAT'S RIGHT, WHAT'S WRONG, WHAT'S NEXT 199 (Ruth E.K. Stein ed., 1997).

13. *Id.* at 218.

14. *See id.* at 205-09; Committee on Children with Disabilities, American Academy of Pediatrics, *Managed Care and Children with Special Health Care Needs: A Subject Review*, 102 PEDIATRICS 657, 657-59 (1998); BETH ZIMMERMAN ET AL., HEALTH SYSTEMS RESEARCH, INC., CRITICAL ISSUES IN DESIGNING CONTRACTS FOR MANAGED CARE ORGANIZATIONS SERVING CHILDREN WITH SPECIAL HEALTH CARE NEEDS, (1996); Jenifer D.C. Cartland & Beth K. Yudkowsky, *Barriers to Pediatric Referral in Managed Care Systems*, 89 PEDIATRICS 183, 186-88 (1992).

15. *See supra*, note 4, at 111-19.

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.<sup>16</sup>

To gain a more complete understanding of the effects of managed care on service delivery for CSHCN, during late 1998 and early 1999, we 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*

We define 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. This definition is drawn from several reports and policy statements pertaining to children’s care in general,<sup>17</sup> services for persons with particular conditions,<sup>18</sup> and mental health systems.<sup>19</sup> Our concern focused particularly on the question of how selected models of care supported or inhibited the process of combining resources from different systems. Included in this perspective are concepts of service coordination, case management, transitions from tertiary care to community care (an example of “vertical integration”) and links among services within a community (“horizontal integration”).

### B. *Study Design and Methods*

This study is a qualitative evaluation of the effects on service integration for CSHCN of alternative Medicaid managed care models. In developing our study, we followed a number of steps consistent with well accepted qualitative research methods.

First, we identified and recruited a sample of eight states based on their alternative approaches to serving children with special health

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16. *See id.*

17. *See* Committee on Children with Disabilities, *supra* note 14, at 657.

18. *See* Lawrence C. Wolfe, *A Model System: Integration of Services for Cancer Treatment*, 72 *CANCER* 3525, 3527-28 (1993).

19. *See* Michael A. Hoge & Richard A. Howenstein, *Administrative Update: Organizational Development Strategies for Integrating Mental Health Services*, 33 *COMMUNITY MENTAL HEALTH J.* 175, 178-86 (1997).

care needs under Medicaid managed care.<sup>20</sup> Second, we designed a series of structured interview protocols to permit investigators to collect consistent information across sites from a broad range of key informants, including state Medicaid officials; state Title V/Maternal and Child Health officials; state staff responsible for mental health, early intervention, and special education, and other programs serving children with special health care needs; managed care organization's administrators; local providers of care, including primary care physicians, pediatric specialists, and various community-based providers such as local health department staff; and parents of children with special health care needs. 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; and financing and payment policies.

We obtained and reviewed Medicaid managed care contracts and other descriptive materials for each of the study states and extracted information from them regarding the principal design characteristics of their managed care models. We conducted two initial in-depth telephone interviews with officials in each study state, one with the Medicaid director and one with the Title V official responsible for the children with special health care needs component of the Maternal and Child Health 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.

We then conducted multi-day site visits 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 children with special health care needs in each state.

Finally, as a means for creating a forum for collaborative discussion of service integration challenges and strategies, we conducted a concluding focus group of all key informants at the end of each site visit whenever possible.<sup>21</sup>

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20. The eight study states are identified and discussed in detail below. See *infra* Part I.C.

21. Extensive written documentation of interviews and analytic procedures are available from the authors.

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

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; fully-capitated programs that “carve out” certain types of care that are commonly used by CSHCN, such as mental health; fully-capitated programs that are specially designed to meet the needs of children with special health care needs; and primary care case management programs that use a managed fee-for-service structure to care for CSHCN. Finally, as a comparison to these models, we also included a state that has chosen to exempt 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 criteria, we selected our sample of eight states, whose models are summarized briefly below.

**Arizona**<sup>22</sup> 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 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 (ALTC) provides comprehensive services for adults and children with developmental and physical disabilities who are at risk of institutionalization.

**District of Columbia**<sup>23</sup> 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. Under the program, children on SSI have the option of enrolling in the new health plan or remaining in the

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22. IAN HILL ET AL., DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACHIEVING SERVICE INTEGRATION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: AN ASSESSMENT OF ALTERNATIVE MEDICAID MANAGED CARE MODELS, VOLUME II: CASE STUDIES 2-25 (1999); see also, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=AZ](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=AZ) (providing copies of Arizona’s Medicaid state plan).

23. HILL ET AL., *supra* note 22, at 32-45; see also, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=DC](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=DC) (providing copies of the District of Columbia’s Medicaid state plan).

traditional fee-for-service system. The District has implemented the waiver through a contract with Health Services for Children with Special Needs, Inc. (HSCSN), a private, non-profit managed care plan that 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**<sup>24</sup> Building on its state Title V/Children's Medical Services (CMS) system and tradition 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 CSHCN operated by the state's CMS program. 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 services are coordinated with services provided through other public systems, including mental health, early intervention, and special education.

**Maryland**<sup>25</sup> 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 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

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24. HILL ET AL., *supra* note 22, at 55-73; *see also*, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=FL](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=FL) (providing copies of Florida's Medicaid state plan).

25. HILL ET AL., *supra* note 22, at 82-101; *see also*, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=MD](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=MD) (providing copies of Maryland's Medicaid state plan).



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 (IFSPs), 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*<sup>26</sup> 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 Early and Periodic Screening, Diagnosis, and Treatment (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 administra-

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26. HILL ET AL., *supra* note 22, at 112-24; *see also*, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=MI](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=MI) (providing copies of Michigan's Medicaid state plan).

tive 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**<sup>27</sup> Minnesota's Medicaid managed care program, the Pre-paid 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<sup>28</sup> (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**<sup>29</sup> Oregon implemented its Medicaid managed care program, the Oregon Health Plan (OHP), in early 1994 under a Section 1115

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27. HILL ET AL., *supra* note 22, at 133-46; *see also*, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=MN](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=MN) (providing copies of Minnesota's Medicaid state plan).

28. Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, 96 Stat. 324 (1982).

29. HILL ET AL., *supra* note 22, at 151-68; *see also*, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=OR](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=OR) (providing copies of Oregon's Medicaid state plan).

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,<sup>30</sup> 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 policy-makers 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 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*<sup>31</sup> 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 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

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30. 42 U.S.C. §§ 601-603(a) (Supp. V 1999).

31. HILL ET AL., *supra* note 22, at 177-89; *see also*, [www.hcfa.gov/medicaid/stateplan/toc.asp?state=TN](http://www.hcfa.gov/medicaid/stateplan/toc.asp?state=TN) (providing copies of Tennessee's Medicaid state plan).

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.

## II. FINDINGS AND ANALYSIS: SERVICE INTEGRATION UNDER ALTERNATIVE MANAGED CARE MODELS

The findings from our site visits to the eight states<sup>32</sup> allowed us to analyze, in depth, how alternative Medicaid managed care models either supported or hindered the delivery of integrated services to children with special health care needs. During our interviews and focus groups, we discussed each model's 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.

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

Ideally, an integrated system of care for children with special health care needs can identify these children and assure that their needs are assessed, planned for, and met.<sup>33</sup> This process would require that children with special health care needs be assigned to providers who are trained and experienced in caring for children with complex needs. Alternative Medicaid managed care models appear to vary in their capacity to effectively identify, enroll, and plan for the needs of CSHCN, as described below.

At one end of the spectrum, the model 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, Minnesota's 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

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32. These site visits were conducted between Fall, 1998 and Spring, 1999.

33. Edwin Fonner, Jr., *Milestones for Developing Integrated Delivery Systems*, 23 J. HEALTH CARE FIN. 1 (1996).

“carved out” SSI population with any special assistance in finding or choosing providers who are skilled in serving them.

The mainstream managed care models we studied also generally lacked the ability to routinely identify CSHCN and link them with appropriate providers of 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. More fundamental is the fact that mainstream managed care systems are intended to promote free and open competition among participating health plans and actually build in safeguards to ensure that no plans experience systematic adverse selection, such as receiving a disproportionate share of high-cost children.<sup>34</sup> Therefore, while state or local enrollment staff (in Arizona, Oregon, and Tennessee) or contracted enrollment brokers (in Maryland) provide 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 and none steered such children, if they were identified, to particular health plans with special capacity to meet their needs. Indeed, the health plans we interviewed in states with mainstream models did not generally have systems for screening new enrollees for special health care needs, and key informants in these states were concerned that such plans had little or no idea how many children with special health care needs were among their enrolled population, nor any way of planning for their care. It is noteworthy that two States have created a mechanism to mitigate the negative potential of these circumstances.

In Maryland, a *Health Risk Assessment Form* 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 required to follow-up within 15 days, confirm whether the child has special needs and, if so, to refer them to special case management services.

In Oregon, SSI recipients are never “auto assigned” to a health plan if they fail to make an active choice of a plan; rather, they are to receive counseling from social services caseworkers to help them select a plan that can meet their needs. In addition, disabled individuals who wish to maintain an ongoing relationship with a provider who

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34. Stephanie Rifkinson-Mann, M.D., Note, *The Impact of Managed Care Payer Contracts on the Subspecialty Medical Provider: Policy Implications that Impact on the Care of Disabled Children*, 27 *FORDHAM URB. L.J.* 1943 (2000).

does not participate in any of the participating health plans may "opt out" of enrollment into the managed care system.

By definition, the Medicaid managed care systems that are explicitly designed to serve children with disabilities or chronic conditions do not need a system for identifying children with special health care needs among their enrollees. They do, however, need outreach systems to make families of these children 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. For example, in Florida, public health nurses routinely conduct outreach in hospitals and with physicians to publicize the availability of Children's Medical Services, talk to parents about the availability of this option, and work closely with all enrolled families to assess children's needs and link them with appropriate providers.

In the District of Columbia, the specialty health plan is permitted to conduct direct marketing to families of SSI-eligible children to counsel them regarding the availability of the capitated option.

### *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, a high quality "medical home" also represents an essential component of a comprehensive system of care for CSHCN.<sup>35</sup> A consistent finding in seven of the eight states we studied was that the use of managed care under Medicaid has succeeded in assigning its enrollees, including CSHCN, a primary care medical home. Key informants of all types 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 use fairly consistent processes for linking new eligibles with primary care providers at the time of enrollment; most also permitted pediatric specialists to serve as the primary coordinating physician for CSHCN who desired such an arrangement. Each of the states also included language in their contracts with MCOs requiring plans to adhere to Medicaid's EPSDT rules regarding

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35. See Ad Hoc Task Force on Definition of Medical Home, American Academy of Pediatrics, *The Medical Home*, 90 PEDIATRICS 774 (1992).

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.

It is important to note, however, that in order for a "medical home" to be of high quality for a child with special needs, the primary care physician should possess some degree of experience and comfort with serving this population.<sup>36</sup> In all of the states we studied, however, the supply of such physicians was described by key informants as insufficient. Furthermore, the financial incentives inherent in capitated systems tended to discourage primary care physicians from actually providing all of the services subsumed under the concept of a "medical home." According to many physicians we interviewed, health plans typically use the same fees for visits with a typical child as they do 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. Florida's CMS program has addressed part of this problem by requiring each of its local offices to develop a plan for recruiting, credentialing, and enrolling primary care providers with expertise in serving CSHCN, but the payment levels for these providers are not adjusted for the complexity or intensity of their services.

### 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.<sup>37</sup> To meet these complex needs, a provider network of appropriate breadth and depth is a critical feature of any managed care model intending to serve CSHCN.

Theoretically, the Medicaid statute guarantees that children are covered for any service they need to address a condition identified through an EPSDT screen.<sup>38</sup> In a managed care environment, how-

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36. See *id.* at 774.

37. See E. Wehr & E. Jameson, *Beyond Benefits: The Importance of a Pediatric Standard in Private Insurance Contracts to Ensuring Health Care Access for Children*, 4 THE FUTURE OF CHILD. 115, 119-120 (1994).

38. See 42 U.S.C. § 1397cc (Supp. V 1999).

ever, such access is determined less by which services are nominally covered than by such factors as health plans' rules for obtaining prior authorization, processes for determining medical necessity, and the quality of MCOs' provider networks.<sup>39</sup> Each of these factors, in turn, is highly dependent on the policies, regulations, and contracting rules set by each state.<sup>40</sup> We observed highly variable practices among the states we studied in terms of their provision of specialty care. Children's access to that care was significantly influenced by the managed care model used by each state.

In the mainstream managed care systems, key informants (including state officials, providers, and parents of CSHCN) generally reported that children's access to specialty care, in particular specialty medical care, was good. That is, most children in need of specialty care were able to receive it in a timely fashion from qualified providers within the managed care networks. This ability 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 of language nearly identical 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 an 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 children with special health care needs.

Despite such safeguards, mainstream models were consistently described by key informants as ineffective 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 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 con-

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39. See Wehr & Jameson, *supra* note 37, at 116-118.

40. *Id.* at 117-118.



fusion among families and providers, as well as contentious debate among state policy-makers. The “carve out” was designed to preserve the longstanding and highly respected multidisciplinary model of care rendered through the Title V/Children’s Rehabilitative Services (CRS) program. This policy 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 state officials and health plan administrators, however, contend that this policy fragments care, creates 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.

The specialty managed care models we studied appeared to excel in providing comprehensive specialty care in a manner that was integrated with other systems of care. While operating under the same basic authority of the Medicaid statute, these programs more explicitly focused on the needs of children with special health care needs and crafted their networks and policies to be directly responsive to their needs. For example, Michigan’s Special Health Plans use an Individualized Health Care Plan for each enrolled child as a standing authorization for all services the child is expected to need for a year, thus eliminating the need for time-consuming prior authorization processes. In addition, the state’s policy-makers solicited the input of a wide range of providers, plans, and family advocates in drafting its specifications for the specialty managed care system, resulting in rigorous standards for participating MCOs.

Once again, the weakest system we observed was the traditional fee-for-service system in Minnesota. Without a centralized entity to hold accountable (such as an MCO), state officials admitted they had little ability to exert control over variations in practice among the state’s thousands of pediatric providers, no systems through which to enforce EPSDT rules of coverage, and still required families to obtain prior authorization for the receipt of physical, occupational, and speech therapy over certain limits, 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 when compared to the managed care models we examined.

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

A large proportion of children with special health care needs also need and use services from a number of other systems of care, includ-

ing mental health, Part C/Early Intervention, and special education.<sup>41</sup> In each of the mainstream managed care systems we studied, “carve out” arrangements were established for mental health, Early Intervention, and special education services (that is, these services were not included within the responsibility of the health plans with whom the state contracted). 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 policy-makers 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, into the operations of health plans.

With regard to mental health, system designers in these states determined that these services should be delivered through managed care arrangements, and they designed and implemented capitated managed behavioral health systems (with either private organizations or state mental health agencies) that operate separately from health plans. 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. However, key informants were just as consistent in describing the integration problems that surround these “carve outs.”

In Oregon, for example, health plans have no responsibility for the behavioral health needs of their enrollees, and Medicaid recipients can access mental health services without a referral from their primary care provider. This system was praised for enhancing access, but simultaneously criticized as undermining the effective flow of information between primary care and mental health systems. 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 Hyperactivity Disorder. State officials acknowledged that health plans have financial incentives to refer all mental health-related care to behavioral health systems, yet primary care physicians often feel they should manage and oversee medications.

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41. See GENERAL ACCOUNTING OFFICE, *MEDICAID MANAGED CARE: STATES’ SAFEGUARDS FOR CHILDREN WITH SPECIAL NEEDS VARY SIGNIFICANTLY* 24 (2000) [hereinafter *STATES’ SAFEGUARDS*].

In Maryland, the division of responsibility between the health and behavioral health systems is perhaps even less clear. Here, HealthChoice plans are paid for, and responsible for delivering, “primary” mental health care, but are required to refer enrollees with more significant needs to the state mental health agency. Under this arrangement, providers and plans have contested 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 this care.

In all 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. 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. 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. Parents appear to be especially affected by these disconnects; family focus group participants reported that they felt like the only ones bridging the systems and keeping each system’s providers informed about the care that was being provided to their children.

We observed cross-system integration to be equally challenging, but somewhat more successful, in the specialty health plans. Because of their specific focus on children with special health care needs, these plans were described as being more aware of these children’s need for mental health, Early Intervention, and special education services. Some plans had implemented specific processes for integrating these services with those provided by health providers in the network. For example, Florida’s CMS program systematically integrates Part C Early Intervention services, for which CMS is also the lead agency. CMS nurses performing outreach in neonatal intensive care units also serve a case-finding role for both CMS and Early Intervention. Each program accepts the other’s evaluations, and each local CMS program has a case manager funded by Early Intervention who coordinates care for dually-enrolled children.

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 edu-

cation systems, leaving 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 children with special health care needs, because it provides a mechanism to organize and link services for individual children.<sup>42</sup> 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.<sup>43</sup> Virtually all of the states we studied placed significant emphasis on case management for children with special health care needs, 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, the fee-for-service system in Minnesota possessed no explicit case management benefit for children with special health care needs, and no targeted case management service is covered for these children under the Medicaid state plan. However, in two of the mainstream managed care plans we studied as well, no explicit effort was observed to implement a centralized case management system for children with special health care needs, nor were particular mechanisms incorporated into managed care systems to bolster their capacity to coordinate care for these children. Rather, both TennCare (in Tennessee) and AHCCCS (in Arizona) have many separate system components that provide some form, albeit limited, of case management, including primary care physicians acting as "gatekeepers" for referrals, health plans performing prior authorization for such referrals, and behavioral health organizations coordinating service delivery within their unique system of care.

In both Maryland and Oregon, however, policy-makers anticipated that traditional managed care organizations would not provide case management of the intensity that CSHCN might need and took explicit steps to strengthen these plans' ability to render appropriate support.

In Maryland, all plans participating in HealthChoice are required to designate Special Needs Coordinators to serve as the plans' point of

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42. See GENERAL ACCOUNTING OFFICE, *MEDICAID MANAGED CARE: SERVING THE DISABLED CHALLENGES STATE PROGRAMS* 40 (1996) [hereinafter *SERVING THE DISABLED*].

43. See *id.*

contact for “special populations,” including children with chronic conditions. In addition, for persons with eligible conditions enrolled in the Rare and Expensive Case Management (REM) program, which is carved out of HealthChoice plans’ responsibility, one of several case management agencies under contract with the state provides intensive support.

In Oregon, the plans must designate Exceptional Needs Care Coordinators to serve as advocates and points of contact for SSI-eligible enrollees and others with special needs. In both cases, these coordinators are generally nurses who are charged with the broad task of assisting their clients in gaining access to both medical and “health-related” services in the community.

However, in both states the number of care coordinators employed by health plans was not large, and the programs only served those who requested assistance, as opposed to proactively seeking out and offering assistance to the entire population that could potentially benefit from their support. Thus, some parents we interviewed in these states were not even aware of the existence of these care coordinators.

Among the Medicaid managed care plans that were specifically designed to serve CSHCN, the likelihood was much higher of finding expansive systems for providing intensive case management support to children and their families. For example: The Arizona Long-Term Care Services (ALTCS) program assigns a case manager from the State’s Developmental Disabilities (DD) agency to every enrolled child based on his or her level of need. This individual is responsible for planning and coordinating all aspects of the enrollee’s care based on the results of the child’s pre-admission screen. A “DD Liaison” in each AHCCCS plan 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 the managed care plan’s in-house staff is composed of professional case management and lay outreach staff who have responsibility for conducting risk assessments, developing plans of care, and coordinating and monitoring referrals.

In contrast to those participating in mainstream managed care plans, parents with children in specialty plans tended to provide more favorable reviews of the quality and intensity of case management they received.

### 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.<sup>44</sup> Without a method of adjusting capitation rates for children's level of risk, plans have financial incentives to minimize the amount of care they provide or shift costs to other systems.<sup>45</sup> In addition to risk-adjusted capitation rates, an integrated financing system might also include the ability to blend funding from across programs to maximize the resources available to families.<sup>46</sup> 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. 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, these study states do not attempt to identify which among their 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 diagnoses, eligibility for Medicaid, access to private insurance, and geographic region. 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 coordination of funding across programs and agencies proved equally complex and daunting in our study states. Categorical rules governing the expenditure of Federal funds represent the clearest barrier to up-front blending of funding streams. In addition, most states had not developed successful systems to bill Medicaid for medically necessary services provided by Early Intervention, mental health, and special education programs.

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44. See *SERVING THE DISABLED*, *supra* note 42, at 12. See also *STATES' SAFEGUARDS*, *supra* note 41, at 9-10.

45. See *SERVING THE DISABLED*, *supra* note 42, at 49.

46. See *id.* at 57.

One example did emerge 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. In Tennessee, the TEACH program, funded by the Department of Education, 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 plans appropriately. Because the plans are paying for the services, this model helps to support coordination between special education and medical care.

### III. CONCLUSIONS AND DISCUSSION

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 discussed in more depth below.

#### A. *The False Security Offered by the Fee-for-Service "System"*

In years past, many state Medicaid programs have exempted persons with disabilities, including CSHCN, from mandatory managed care arrangements<sup>47</sup> under the assumption that managed care was not designed for or equipped to serve these high-need/high-cost individuals,<sup>48</sup> that enrollment into managed care was likely to disrupt existing

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47. See *SERVING THE DISABLED*, *supra* note 42, at 27.

48. See *id.* at 19.

relationships with providers,<sup>49</sup> and that the fee-for-service system “protected” these populations’ open access to high-quality care.<sup>50</sup>

This study found serious faults in this logic. Evidence from our study indicates that the traditional fee-for-service “system” 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; 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; cannot assure access to the broad range of specialty services and ancillary therapies they might need, nor control variations in practice among children’s specialty providers; often include 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 systematic capacity to assist families in linking the various health, mental health, educational, and other systems they need for supporting the effective flow of information among them.

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

In contrast, we found strong qualitative evidence that Medicaid managed care systems, at least in the states we studied, have matured and now have the capacity 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 children 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 children with complex needs. These modifications included 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

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49. *See id.*

50. NEVA KAYE ET AL., NAT’L ACAD. STATE HEALTH POL’Y, CERTAIN CHILDREN WITH SPECIAL HEALTH CARE NEEDS: AN ASSESSMENT OF STATE ACTIVITIES AND THEIR RELATIONSHIP TO HCFA’S INTERIM CRITERIA 109 (2000).



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.

Despite this strength in organizing and delivering primary and specialty medical care, the mainstream managed care models that we studied also had many weaknesses with regard to their ability to integrate essential, but non-medical, services. In most of the states we observed, mainstream managed care plans had poor or nonexistent links with Early Intervention, special education, and other community-based systems that support CSHCN and their families. Particularly distressing, though, were reports we heard of the fragmentation that resulted from “carve outs” of mental health services and specialty clinic services. By their nature, such “carve outs” explicitly divide responsibility among systems for various aspects of enrollees’ care, and these divisions reportedly undermined integration and contributed 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 these kinds of 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. Without a basic ability to identify these children, managed care systems have few means for planning or organizing services to address their needs.

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

As an alternative to these mainstream models, the specialty managed care systems we studied set out to take advantage of the benefits of managed care within a system specifically designed to meet the needs of CSHCN and their families. Our study found that 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 included these models' use of a single, central organization that was accountable for the delivery and financing of all (or nearly all) services needed by children; 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 use of networks of providers with special qualifications to serve CSHCN; mechanisms to facilitate children's receipt of diverse services, including plans of care that serve 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 manner that recognizes families' role as the primary caregivers for their children and values the input of parents in decision-making regarding their children's health services.

This study is limited by the constraints of qualitative methods. Our observations may not be generalizable to other states. In addition, our conclusions are invariably biased by the particular selection of individuals we interviewed. Despite this, the standard procedures we used and the collective review of our extensive documentation support the validity and reliability of our conclusions.

The findings of this study, while qualitative in nature, 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. Future research to attempt to quantify and measure the differences we observed between the alternative managed care models and seek to provide state officials with tools to measure and monitor the extent of service integration within their systems. In the meantime, we hope that this study will help policy-makers, providers, insurers, and families in designing managed care systems that advance the goal of providing our nation's most vulnerable children with the high-quality care they deserve.