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A Critical Analysis of Care Coordination Strategies for Children With Special Health Care Needs

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

To bring the broadest range of experts into the development of evidence reports and health technology assessments, AHRQ encourages the EPCs to form partnerships and enter into collaborations with other medical and research organizations. The EPCs work with these partner organizations to ensure that the evidence reports and technology assessments they produce will become building blocks for health care quality improvement projects throughout the Nation. The reports undergo peer review prior to their release.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

We welcome comments on this report. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by e-mail to **epc@ahrq.gov.**

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Structured Abstract

Objectives: The goal of this technical review is to critically examine the issue of care coordination for children with special health care needs (CSHCN). Of particular interest is the knowledge base relating to those aspects of care coordination for CSHCN that are of greatest importance to current practice and policy challenges.

Review Methods: A structured search and review of the literature was conducted to address the following issues: (1) analytic approaches and definitions used for care coordination strategies for CSHCN; (2) evidence for best practices of care coordination for CSHCN; and (3) evidence for the impact of managed care for CSHCN enrolled in Medicaid.

Results: Among the principal findings are: (1) despite considerable progress in defining care coordination and CSHCN, there remains considerable variation in current analytic approaches and definitions; (2) some progress has been made in developing care coordination strategies for CSHCN; (3) there is a major need to evaluate the impact of these strategies on health outcomes and costs; (4) continued progress in care coordination for CSHCN may depend upon the replication and evaluation of promising strategies in different practice settings and under different reimbursement policies; (5) the constructive assessment of enhanced care coordination programs in managed care systems would be facilitated by new, more focused metrics and performance measures; (6) there is little evidence regarding the impact of managed care systems on CSHCN enrolled in Medicaid.

Recommendations: Among the principal recommendations are: (1) increase support for efforts to identify in a standard manner CSHCN in large administrative or clinical datasets; (2) expand efforts to evaluate care coordination interventions for CSHCN, particularly in managed care settings; (3) develop capacity and performance standards of direct relevance for CSHCN for managed care plans; (4) link development of care coordination programs for CSHCN to emerging practice and health system reforms.

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Chapter 1. Introduction

Goals and Objectives

The goal of this technical review is to examine critical issues of care coordination for children with special health care needs. It is intended to supplement the more comprehensive Evidence-based Practice Center (EPC) report on care coordination currently under preparation. Unlike the EPC report, the intention of this technical review is not comprehensiveness but rather strategic guidance regarding critical aspects of care coordination for this special group of children. While this more focused purview is mandated by the reduced scope of the technical review format, it also reflects the need to elevate selected issues of particularly urgent concern for practice or policy.

Experts in the field such as Perrin and colleagues[1] and Stein[2] have described in detail the requirements for providing coordinated care for children with complex medical needs. In addition, professional organizations such as the American Academy of Pediatrics and a variety of advocacy groups and service programs for families with children with special health care needs have developed care coordination strategies and developed very useful guidance materials regarding this issue.[3, 4] These sources, while embracing general principles of care coordination that are relevant for all populations and age groups, emphasize those elements of care that are of particular importance for children with special health care needs. Although quite varied, they tend to be due to (1) the dependence of children on parents or other adult caretakers; (2) the distinct epidemiology of childhood and its implications for the organization of health services; (3) the developmental nature of child health problems and the need to link care with educational institutions; and (4) the special financial basis for child health and related services. The inherent dependence of children on adults acting on their behalf adds a level of complexity to care coordination efforts in that the facilitation, monitoring, and at times the enforcement of this proxy function must always be incorporated into coordinative programs for children. The most important distinctive characteristic of the epidemiology of childhood is that unlike in the elderly, serious chronic illness is relatively rare. This requires that specialized services for children with such disorders are heavily dependent on regional referral centers, programs that maintain the expertise, volume of patients, and resource commitment to address these serious but relatively rare disorders. The developmental nature of childhood implies that the problems and service needs of children will be highly dynamic over time and involve developmental support services, such as early intervention programs, as well as school-based interactions. Because children are the poorest segment of our population, poverty and means-tested public programs, such as Medicaid, are of particular concern in developing and evaluating care coordination efforts for children.

What has generally been lacking is an assessment of the evidence regarding the actual impact of care coordination efforts on outcomes for children with special health care needs. In response, this technical review is directed at the evaluative literature, those published reports that attempt to assess the experience of children with special health care needs and their families in response to purposeful care coordination efforts.

In general, these efforts for improving the coordination of care for children with special health care needs have taken two forms:

- **Specialized care coordination interventions for selected clinical populations.** These include the use of case managers, the establishment of a medical home, or home care strategies.
- **The structural organization of health care services**. The dominant current approach is managed care.

Specialized care coordination interventions have been the primary focus of the clinical literature. Here, efforts have been directed at shaping clinical practice procedures and adding coordinative services in direct care delivery programs. Despite the many prescriptive articles concerned with care coordination for children with special health care needs, there has not been a recent review of the evaluative evidence base for assessing such approaches in actual populations of children.

Care coordination is also a focal point for concerns regarding the utility of larger organizational structures of health care delivery, which in the context of children with special health care needs, has almost exclusively been on the impact of managed care. Of special concern for current policy deliberations has been the impact of managed care on children with special health care needs enrolled in public insurance programs, particularly Medicaid. Although the general issue of managed care for children with special health care requires continued attention, the sheer numbers of children affected by Medicaid managed care initiatives, the special vulnerability of poor children to uncoordinated care, and the growing importance of chronic disease to social disparities in child health outcomes, have only underscored the urgency of this issue in the policy arena. This technical review, therefore, attempts to inform discussions of this issue by focusing on the impact of structural influences on care coordination for poor children enrolled in Medicaid managed care (M-MC).

Accordingly, the strategy utilized by this technical review is directed at the evaluative evidence base for both the specialized interventions and structural organization arenas of care coordination. Specifically, the technical review addresses the following objectives:

1. To identify and critically examine studies that empirically evaluate models of care coordination interventions for children with special health care needs.
2. To identify and critically examine studies that empirically evaluate the impact of managed care on children with special health care needs, particularly those enrolled in Medicaid.
3. To develop recommendations for future research and the evidence related to potential ameliorative action.

The emphasis of this technical review, therefore, is on direct, empirical evaluation. Non-evaluative papers documenting associations between elements of practice and indicators of care coordination were examined for possible relevant references; however, these were not included for detailed review. Similarly, articles outlining prescriptions for improving care coordination but without presenting new, evaluative data were reviewed for references only and not included in this review. Finally, the literature searches for the technical review were focused and less extensive than those conducted for a full systematic review, in line with the more limited objectives and designated resources of a technical review.

Technical Review Structure

This technical review is organized into the following chapters:

- **Chapter 1. Introduction**. This chapter presents the goals, objectives, background and general analytic approach of the technical review.
- **Chapter 2. Review of Analytic Approaches and Definitions**. This chapter critically reviews conceptual framings and definitions used by prior reviews and prescriptive papers concerned with care coordination and CSHCN.
- **Chapter 3. Assessment of Evidence for Best Practices of Care Coordination for CSHCN**. This chapter examines critically peer-reviewed evaluations of interventions designed to improve care coordination for CSHCN.
- **Chapter 4. Evidence for the Impact of Managed Care for CSHCN Enrolled in Medicaid**. This chapter presents a systematic review of the literature documenting the impact of placing CSHCN enrolled in Medicaid into managed care systems. The specific focus on this issue reflects two considerations: 1) the importance of this strategy in shaping the potential opportunities and obstacles for care coordination for the most vulnerable CSHCN and 2) the need to assess the available evidence base for guiding programmatic and policy deliberation of Medicaid-managed care strategies and their specific components.
- **Chapter 5. Summary and Recommendations**

Background

National survey data suggest that more than 30 percent of all children are reported to have some form of chronic health condition.[5] However, there is considerable variation in the nature and severity of chronic illnesses in children. The most common serious chronic condition is asthma with some 12 percent of children having received a diagnosis of asthma at some time in their lives. Approximately 6 percent of children are reported to have a diagnosis of attention-deficit/hyperactivity disorder. Although overweight is not usually considered a chronic health condition, almost 17 percent of all children aged six through 19 have a body mass index above the 95th percentile.[6] Reliable national figures for depressive disorders in children are not currently available; however one large study suggested prevalence among nine to 16 year olds of approximately three percent.[7]

These current prevalence figures represent a substantial increase in childhood chronic illness over the past several decades.[5, 8] For example, while approximately two percent of children were reported to have a chronic health condition that limited their activities in 1960, by 2003 the comparable figure reached eight percent. Although the increase in childhood chronic illness is likely due in part to changes in survey methodologies, improvements in diagnosis, and expanded public awareness of behavioral and developmental disorders, there is strong evidence that the prevalence of certain important chronic child health conditions has increased.[9] There are also data that suggest that chronic illness is contributing more profoundly to social disparities in child health.[5]

Although the nature and impact of chronic illness in childhood is heterogeneous, there are important considerations that are common to virtually all such conditions regardless of their specific diagnosis.[1, 2] The care required by children with serious chronic illnesses is almost

always associated with enhanced financial costs. Children with serious chronic disorders usually require intense clinical management both in community and hospital settings. Close surveillance of disease progression, symptoms and functioning, and adverse medication effects, will often necessitate frequent communication and office visits. Managing hospital admissions and discharge planning may also prove complex and involve a variety of clinicians and community resources. In addition, an uncoordinated approach to the multitude of required clinical visits can prove highly burdensome and can undermine even the most committed family's attempts to adhere to clinical recommendations. Although most children with chronic illness will experience the same level of psychological and behavioral issues as other children their age, the presence of a chronic illness does elevate the likelihood that they will experience such a disorder. The presence of a chronic illness can also add extra burdens to families which can be expressed in a variety of psychological, social, and financial manners.[1, 2]

Chapter 2. Review of Analytic Approaches and Definitions

Defining Children with Special Health Care Needs

The designation of children with special health care needs has long been characterized by a lack of standard definition. The definition recommended by the Federal Maternal and Child Health Bureau (MCHB) and accepted by the Academy of Pediatrics as well as a variety of advocacy groups is as follows:

> *Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*[10]

The development of this definition was the result of a longstanding frustration with the difficulties inherent in interpreting studies using different definitions as well as the practical concern that many CSHCN were not being identified.[11, 12]

Although the MCHB definition is widely recognized as an important step forward in providing the field with a standard definition, the actual implementation of this definition in large health programs remains highly variable. All state programs rely on some definition of children with serious, chronic conditions. These are used for eligibility criteria in a variety of medical, early intervention, and educational programs. Most of these draw at least some of their funding from Federal sources which in turn have definitional guidelines regarding disabling or chronic conditions in children. In addition, a growing number of Federal health and educational surveys are attempting to capture the prevalence and severity of chronic health problems in children. All of these considerations have underscored the utility of clarifying definitional issues, if not agreeing on a universal definition. In part, this variation is due to the difficulties inherent in translating this definition into variable sets that are generally available in extant administrative or other databases.[13] State-administered programs such as Medicaid, for example, may rely on information sources that do not possess the requisite data to assess an "increased risk for chronic physical, developmental, behavioral, or emotional condition" or enhanced requirements for services.[14] Even when such data might be available in collected data sets, the bureaucratic mechanisms to utilize these data to make judgments regarding each individual child may not be in place. Therefore, proxy variables or variable clusters are often employed by a variety of child health programs to define CSHCN. Among the most prominent definition strategies include:

- Categorical definitions based upon diagnoses or clinical conditions perceived to convey a significant risk for morbidity or mortality.
- Service definitions based upon elevated patterns of service utilization.
- Functional status definitions based upon the inability of the child to perform expected, age-appropriate functions or activities.

- Programmatic definitions based upon enrollment in specific programs.
- Cost definitions based upon elevated health care and other service costs.

The utility of each of these strategies depends upon the specific objectives for which they are designed to address. In general, identification systems that depend upon administrative data will tend to employ programmatic or categorical approaches.[15-18] Efforts to identify CSHCN based upon parental survey data will tend to emphasize functional definitions.[19-21] However, the inclusion of survey derived functional status information in administrative data sets may be feasible in some settings.[22] Moreover, these approaches often blur distinctions between definitions of CSHCN and those for disability, which pertain directly to reduced function or impairment.[23, 24]

Also of concern is that the MCHB definition captures a highly heterogeneous group of children with a variety of conditions and severity. While this is an inherent strength of the definition in linking the functional needs of a large group of children, it also can obscure the special character of embedded subgroups of children. It can also undermine the MCHB definition's utility as a means of identifying selected groups, including the neediest, of children. Many programs, therefore, have used more restricted definitions because of programmatic or policy-based eligibility regulations.

There are no recent assessments of how states or other large health care programs are identifying CSHCN. However, based on cursory review of available state Medicaid program information, there remain a variety of definitions being utilized, including lists of diagnoses considered severe and chronic and participation in programs such as the Supplemental Security Income (SSI).

Defining Care Coordination for Children with Special Health Care Needs

There remains no standard definition of care coordination which in many ways, reflects a lack of a widely accepted theoretical base for care coordination.[25] This lack of a standard definition has been largely due to the different purposes for which care coordination efforts have been designed. Even within the relatively limited arena of child health care there has been no consensus on what specifically care coordination actually means. Moreover, there was a tendency to approach care coordination not by proposing a general definition but rather by listing its most important objectives or requirements.

A useful foundation for considering the definition of care coordination for children is provided by the Academy of Pediatrics (AAP) in the1999 statement by its Committee on Children with Disabilities, "Care Coordination: Integrating Health and Related Systems of Care for Children with Special Health Care Needs," suggested that

> Care coordination occurs when a specified care plan is implemented by a variety of service providers and programs in an organized fashion.[26]

The statement references only two empirical studies in support of care coordination; one was published some 16 years earlier[27] and the other was confined to a relatively small sample of severely affected children.[28] The statement goes on to present the goals of care coordination as being to:

- Gain access to and integrate services and resources
- Link service systems with the family
- Avoid duplication and unnecessary cost
- Advocate for improved individual outcomes

The procedures to accomplish these goals are less clearly stated, however. In part, this reflects the position of the Committee that the respective responsibilities and mechanisms of coordination are dynamic and may need to be tailored for different families or geographic settings. Nevertheless, the statement suggests that care coordination must address four domains: the health care system; the educational system; the social service and public health systems; and the home setting. Significantly, the statement suggests that the leader of care coordination for the child be a family member, with pediatricians and other professionals assisting as needed. Professionals would assume primary responsibility for care coordination only when family members could not perform this function. The statement underscores that even in this circumstance it is essential to involve the child and family members in all care coordination planning and implementation.

Subsequent to the 1999 AAP statement, most definitions of care coordination for children are in some way linked to a particular model of care provision, the "medical home". Although the concept of the medical home is not inherently confined to child health, it has, nevertheless, been embraced far more fully in the pediatric arena as the basis for care coordination. The importance of the medical home as an organizing framework for pediatric care coordination is reflected in its adoption in Healthy People 2010 which calls for "an increase in the proportion of children with special health care needs who have access to a medical home."[29] Indeed, most recent discussions of care coordination in the pediatric literature have been framed by the requirements of the medical home. Therefore, given the intent of this section to review the definition and elements of care coordination specifically for children with special health care needs, it is necessary to examine the coordinative elements of the medical home framework.

The concept of the medical home is not new. It has its roots in the services provided by the settlement houses in Chicago and New York at the turn of the century and was broadly outlined in the American Academy of Pediatrics' *Standards of Child Health Care* published in 1976.[30] However, in 1992 an ad hoc task force of the AAP attempted to provide a more detailed definition of the medical home.[31] Although no unifying definition was presented, the essential elements of the medical home were outlined and included:

- Provision of preventive care
- Assurance of ambulatory and inpatient care at all times
- Assurance of continuity of care
- Appropriate referral and transfer of necessary information to consultants and families
- Interaction with school and community agencies
- Maintenance of a central record and data base

Interestingly, care coordination was not listed among the requisite elements, although continuity of care is considered by some to relate to care coordination.[25] Rather, the statement was more concerned with providing a clear standard of comprehensive responsibility for physicians providing care for children. The statement, therefore, defined the medical home as

falling under the leadership of physicians, suggesting even that directing physicians should be "well-trained in primary pediatric medicine, preferably pediatricians."

In 2002, this general approach to the medical home was reaffirmed by the AAP in a policy statement[32] developed as part of a strengthened medical home initiative.[33] However, this statement provided a far more detailed description of the essential components of the medical home than that published in 1992. As in the earlier statement, the medical home was directly embedded in physician-led, primary care practices, although there was no longer an expressed preference for pediatricians specifically. However, unlike the earlier statement, this report explicitly argued that care coordination is an essential component of the medical home. Specifically, it listed this coordinative component of the medical home as consisting in turn of the following eight elements:

1. A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient.
2. Care among multiple providers is coordinated through the medical home.
3. A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice.
4. The medical home physician shares information among the child or youth, family and consultant and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
5. Families are linked to family support groups, parent to parent groups, and other family resources.
6. When a child or youth is referred for a consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues.
7. The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.
8. The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

However, while these care coordination elements were clearly applicable to all children, including those with special health care needs, it is important to recognize that the medical home framework as outlined above was not specifically directed at children with complex health problems. Indeed, while the AAP's 1999 description of care coordination for CSHCN and its 2002 statement on the medical home clearly shared general goals and values, a comparison of these two approaches to care coordination does suggest important differences in emphasis if not content.

As noted above, the care coordination document[32] while strongly recommending collaboration between families and professionals, does clearly suggest that the family and not the physician serve as the primary locus of care coordination in most instances. The role of the physician is largely facilitative. The medical home definition, on the other hand, identifies a primary care physician as the individual principally responsible for care coordination. As a consequence of this distinction between the two approaches, a focus on CSHCN tends to emphasize coordination of specialty care, home care services, special educational programs, and social services, while the medical home tends to emphasize the role of primary care.

These tensions in the respective strategies for care coordination have been generally addressed by a gradual formulation of a middle ground: care coordination for CSHCN has increasingly embraced the medical home as an important potential strategy and the medical home has in many ways become more open to a greater leadership role for the family and alternative health care professionals. This middle ground was constructively articulated in a cogent review by Cooley and McAllister which presented a care coordination model that was attentive to the requirements of both the medical home and care coordination principles for CSHCN.[34] Using the experience of actual pediatric practices, they suggest that ongoing family inclusion in the development and implementation of the medical home for CSHCN is essential as is the role of a designated practice-based care coordinator. This same integrated approach is represented by a 2005 AAP policy statement, entitled "Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs".[35] Once again, care coordination is not explicitly defined here but rather

> …occurs when care plans are implemented by a variety of service providers and programs in an organized fashion. Care coordination is multifaceted. It involves needs identification, assessment, prioritizing and monitoring.

As in the Cooley and McAllister paper, this most recent AAP statement embeds the medical home as a component of care coordination but does not assign to it a specific set of coordinative responsibilities. Rather, it suggests that

> …its role is not fixed or determined by a defined set of tasks. Instead, it is a dynamic process driven by the health status and developmental progress of the child, the specific needs of the child and family, the primary care physician's expertise with children with special health care needs, and the ability of the family and/or other professionals to participate in care coordination.

This lack of a defined role for clinicians and medical practices respects the heterogeneity of patient and family needs, local resources, and clinical capacities. This in turn implies that the appropriate coordinative role of clinicians and practices in care coordination for CSHCN must rely on intensive and ongoing interaction between patients and their families, primary care clinicians, and virtually all service providers involved in the child's care. The lack of a defined role implies continuous or at least regular assessment and reassessment of the quality of care coordination in order to know whether alterations in roles or contributions to the care plan are required. Although accountability for assuring that these assessments occur and are responded to remains vague, it is generally implied in the various approaches that clinicians and clinical practices have some basic responsibility for these requirements.

In response, a series of instruments and suggested procedures have been developed for primary care practices to assess the adequacy of care coordination. The Medical Home Index provides standard items for assessing the quality of the medical home, including care coordination components, including continuity of care, appropriate use of subspecialty consultation, interaction with school and community agencies, and a central, accessible medical record.[36] In addition, practice-based tool kits for the development and evaluation of medical home care characteristics for CSHCN have been developed and are being used in a variety of states.[22, 37]

Chapter 3. Assessing the Impact of Care Coordination for CSHCN

Search Criteria

A search of the literature was conducted using the following databases and search terms. The PubMed database, the *Social Sciences & Humanities Index*, and the Social Services Abstracts databases were searched (1988 – February 2006; includes HealthSTAR since 2000). For these databases, a broad search was conducted using MeSH headings and terms:

- "Disabled children" or "Chronic illness[Multi]" or "Chronic disease" or "Catastrophic illness" or "Special health care needs" or "Special needs" or "Activity limitations."
- In conjunction with: "infant" or "child" or "child, preschool" or "adolescent."
- In conjunction with "Care coordination" or "Case management" or "Medical home" or "Family" or "Parents."

These search criteria were designed to reflect the scope of this technical review and to capture articles that were likely to most directly relate to the definitions of CSHCN and care coordination used in this review. (For an assessment of a more comprehensive definition of care coordination, see the review by McDonald and colleagues.[25]) Of the generated references, those considered for detailed review also had to be empirical evaluations of care coordination programs that involved more than one diagnostic group. These criteria were chosen because of the expressed focus on empirical evaluation. All evaluation studies regardless of study outcomes (including utilization, costs and health outcomes) were included in the detailed review. Articles concerned with interventions directed at only one diagnostic group (e.g. asthma) were not included in the review. The concern here was that such experiences may be too narrow and not reflect appropriately the needs of a diverse population of children with special health care needs, the central focus of this review. For example, asthma is of far higher prevalence, often of lower severity, and generally requires fewer services than many of the other conditions of concern in assessing care coordination for children with special health care needs. In addition, a forthcoming systematic review addresses comprehensively quality improvement strategies for asthma care, including those that improve care coordination. In contrast, there has not been a recent review of generic care coordination programs designed to address the needs of children with a variety of clinical disorders. The articles generated by the search criteria above were examined to identify those that were specifically evaluative in nature. These studies and their relevant references were reviewed by one of the authors (PHW).

Recently, West and colleagues described a suggested approach to rating the quality and strength of empirical studies.[38] The authors presented a selected set of scales and checklists that clinicians, policymakers, and researchers can use to assess study quality and the strength of scientific evidence. We used these assessment methods to review the identified studies.[39] (See Appendix A for review criteria).

Review Findings

Despite considerable efforts to describe and prescribe care coordination initiatives for CSHCN, there is a striking paucity of empirical evidence regarding its ultimate impact. For example, the 1999 AAP statement on care coordination cited only 2 evaluative studies in support of its recommended strategies; only one had been published in the prior 15 years. The 2005 AAP policy statement cited only three studies that included children with special health care needs.

Our review identified seven studies published in the past 15 years that evaluated the impact of care coordination interventions on health care utilization, costs, or health outcomes.[28, 38-42] The nature of the coordination programs, the study designs, the health status and social status of the children served, and the outcomes measured varied considerably. A summary of these programmatic and evaluative elements are presented in Table 1. A summary of the study quality characteristics of the reviewed studies are presented in Table 2.

Criscione and colleagues using a randomized control trial evaluated a coordinated care model on hospital admissions for a population of people (primarily adolescents and adults) with developmental disabilities.[40] Individuals in the coordinated care group had shorter average lengths of stay and lower hospital charges than did the group receiving standard care, especially when charges were adjusted for case mix. The authors calculated substantial savings associated with this reduced use of hospitalization services.

A study by Fields et al. described the experience of a coordination model for 28 technology-dependent children living at home.[28] The coordination of care was intensive and was led by care coordinators from a community-based home care agency. Although a longitudinal case-series design, the number of children studied was inadequate to ascertain the impact of care coordination on utilization, costs, or health outcomes. However, parents did report a high level of satisfaction with care coordination to the extent that it allowed their children to be cared for at home, an important consideration in the care of these seriously disabled children.

Liptak et al. reported a descriptive study of a hospital-based care coordination program in Rochester, New York.[41] The authors compared hospitalization patterns among children with chronic illness admitted to the major tertiary pediatric hospital in Rochester with those of a group of other tertiary pediatric hospitals in other areas of the country and with national data. The study reported that hospital length-of-stay and associated costs were lower in Rochester than in the comparison groups. Approximately, half of the costs of the coordination program could not be recovered from standard charges to insurance plans. Rather, supplemental funds were obtained from a capitation agreement with local insurers to support the care coordination program. The authors calculate that the savings from reduced hospital charges far exceeded the costs associated with the coordination program. The authors do not account for the fact that hospitalization rates for children in Rochester appear to be significantly lower in general than other studied cities.[42]

Perhaps, the most instructive study regarding the impact of care coordination for CSHCN was performed by Palfrey and colleagues, reporting on the results of the Pediatric Alliance for Coordinated Care (PACC) model.[43] Using a pre/post survey of parents, the authors assessed

Table 1. Characteristics of evaluations of care coordination interventions for children with special health care needs

Article	Study design	N	Sample Definition or Eligibility	Coordination Program Components	Measured Outcomes Categories
Fields et al.[28]	Prospective cohort	28	Technology-dependent children	Home-based care via consortium of community services and medical facilities; set minimal standards for discharge planning.	Parent satisfaction, technology dependence, death, care use, cost
Criscione et al.[40]	Randomized Control Trial	115	Adolescents and young adults with developmental disabilities	Nurse practitioner clinical care; referral and accompanying to specialty services; active involvement in hospitalization and discharge planning.	Hospital admissions, length of stay, charges
Liptak et al.[41]	Retrospective descriptive	10,715	Children with ICD-defined chronic illness	Case management and wraparound services in specialty care clinics.	Hospital admissions, length of stay, charges
Palfrey et al.[43]	Prospective cohort	150	Children with clinically assessed serious chronic diseases	Nurse practitioners in pediatric care; assignment of local parents of CSHCN; modification of pediatric office routine; individualized health plan; expedited referrals and communication with specialists.	Parent satisfaction, parent work days missed, care use, costs
Farmer et al.[44]	Pre-post treatment	51	Children with clinically assessed serious chronic diseases	Nurse practitioners in pediatric care; assignment of local parents of CSHCN; modification of pediatric office routine; individualized health plan; expedited referrals and communication with specialists; home visit.	Parental satisfaction, family needs, caregiver strain, parents' missed work days, children's school absences, and utilization
Chernoff RG et al.[45]	Randomized, prospective clinical trial	136	Children with diabetes, sickle cell anemia, cystic fibrosis, asthma	Assignment of local parents of CSHCN; child life specialists; telephone, visits, family-based events.	Adjustment and mental health problems
Pless IB et al.[46]	Randomized, prospective clinical trial	332	Care received in specialty clinics	Nurses assigned as case managers and family support facilitators; referral coordination; school communication.	Psychosocial functioning

an intervention model which relied on nurse coordinators based in a consortium of primary care practices in the Boston area. The intervention model was a medical home strategy that relied on six components:

1. The services of a designated pediatric nurse practitioner.
2. Consultation from a local parent of a child with special health care needs.
3. Modification of office routines.
4. Implementation of an individualized health plan (IHP).
5. Regularly scheduled continuing medical and nursing education.
6. Expedited referrals and communication with specialists and hospital-based personnel.

A total of 150 children with a variety of major health problems were recruited in six pediatric practices. Although this group was derived from a total of 222 referred families, it was unclear what portion of the 72 families not enrolled in the study resulted from exclusion criteria or refusal to participate, an important distinction in assessing the potential for selection bias. Families were administered surveys prior to the intervention and two years after the intervention was initiated. Thirty-three of the original 150 families were not available for the follow-up survey, leaving 117 for analysis. The study found that parent satisfaction with pediatric primary care improved subsequent to the medical home intervention. Specifically, there was improvement in being able to speak with the same nurse by phone, ease in obtaining letters of medical necessity, receiving resources, obtaining acute medical care as well as specialty referral, receiving prescriptions, understanding the child's condition and setting goals for care, and improving the relationship with the child's physician. These improvements were noted to be greatest for children with the most severe conditions. However, overall satisfaction with their primary care source did not change as satisfaction levels were high prior to the intervention. Emergency room visits and school days missed did not change significantly over the study period. Parents reported a reduction in days they missed work and in their child's need for hospitalization. However, given the study pre/post design, the authors could not assess the extent to which these findings were due to the child growing older rather than program effects. The authors estimated that the care coordination program cost approximately $400 annually for each child enrolled. This figure did not include any estimate of savings or additional expenditures due to possible changes in utilization resulting from care coordination activities. Although the studied children were generally quite severely affected by their conditions, this study represents the first community practice-based trial of a medical home model for children with special health care needs.

Farmer and colleagues utilized the PACC medical home model developed by Palfrey et al. to improve care coordination among CSHCN in three university-affiliated primary care practices in the rural Midwest.[44] A total of 51 children were studied via a pre/post parental survey; this represented approximately one-third of the children eligible for the study as the remaining two-thirds declined participation or could not be reached for the follow-up survey. Post intervention, parents reported reduced caregiver strain, parents' missed work days, their children's school absences, and ambulatory care visits. Hospitalizations did not decrease. Parental satisfaction with care coordination and access to mental health services improved but satisfaction with overall primary care fell slightly subsequent to the intervention. No cost data were provided. Two studies evaluated the impact of coordinative interventions on the mental health outcomes for CSHCN. A study by Chernoff et al.[45] utilized organized linkages to "experienced mothers"

and child life specialists to provide support and logistical expertise to families engaged in the program. Although not specifically directed at care coordination, the nature of the intervention included guidance and support for coordinating care elements. In direct response to calls for more rigorous evaluation of coordinative and mental health interventions for CSHCN, this study used a randomized, controlled trial design to assess the impact of a 15 month program. The measured outcomes were focused on four areas: adjustment and role skills; depression; anxiety, and self-perception. Overall, the intervention had modest results. In part, this may have been due to the relatively small number of children who entered the trial with highly abnormal scores on the administered tests. The intervention seemed to have its greatest positive effects in children initially found to be at highest risk for the examined psychosocial outcomes.

A similar study was conducted by Pless et al.[46] which evaluated the impact of a nursing intervention program to improve the adjustment of children with chronic disorders. Children recruited from a variety of specialty clinics were randomized to a program utilizing nurses to address parental stress, parental competency and overall family functioning. Control families received standard nursing care from the specialty clinics. In an effort to restrict substantial nursing involvement to the program group, families to be entered into the program group were recruited from clinics without standard nursing involvement. However, this strategy yielded too few recruitments and was abandoned. The portion of the control and program groups derived from clinics with preexisting and ongoing nursing involvement was not provided. Outcomes were generally positive although somewhat mixed, particularly among different age groups. This complex set of findings may have been due in part to the varied utility of the measures used for different developmental ages and underlying disabling conditions.

Although not a trial of care coordination per se, a study by Antonelli and Antonelli provided important insight into the costs associated with care coordination for CSHCN in primary care practice.[47] The authors documented in detail all care coordination activities performed in a primary care pediatric practice over a 95 day period. Assessed activities included telephone discussions, contacts with consultants, form processing for schools, camps, etc, meetings, written reports for SSI or other agencies, letters, chart reviews, and patient-focused research. Costs were calculated on the basis of time spent on the care coordination elements multiplied by the average salary of the office personnel performing the service. Over the study period, 774 encounters on 444 separate patients were logged. Half of the encounters were considered related to issues not traditionally considered medical, such as processing referrals, consulting with schools, and oversight for psychosocial problems. Based on national salary data, the annual cost of the care coordination activities in this care model for the studied CSHCN ranged between a 25th percentile of $22,809 and a 75th percentile of $33,048, which per child averaged $51 and $71, respectively. The authors concluded that these costs while considerable were not prohibitive for their practice setting. However, the study also underscored the relatively large costs associated with care coordination that are not directly reimbursable under current payment mechanisms. The cost figures in this study were substantially lower than those estimated by Palfrey et al. for the PACC model. However, the children entered into the PACC program were a more severely affected group than those in the Antonelli and Antonelli study, which included children with the kind of broad range of severities usually found in general pediatric practices.

Table 2. Summary of Quality Elements of Reviewed Studies

Article	Study Question	Study Population	Comparability of Subjects	Exposure to Intervention	Outcomes	Statistics	Results	Discussion	Funding
Criscione et al.[40]	●	●	●	◒	●	●	●	◒	●
Chernoff RG et al.[45]	●	●	●	○	●	○	◒	◒	●
Farmer JE et al.[44]	●	●	○	◒	●	◒	◒	◒	●
Fields AI et al.[28]	◒	●	◒	○	●	○	◒	◒	●
Liptak GS et al.[41]	●	◒	◒	○	●	○	◒	◒	○
Palfrey J et al.[43]	●	●	◒	○	●	●	◒	●	●
Pless IB et al.[46]	◒	●	●	○	●	○	◒	●	●

●=addressed domain fully ◒=addressed domain in part ○=did not address domain

Chapter 4. Systematic Review of the Impact of Managed Care on Children With Special Health Care Needs: A Special Focus on Medicaid

Beyond specific intervention programs, efforts to enhance care coordination for CSHCN have relied on changes in the overall organization of services, primarily through some form of managed care. In a recent review of the literature regarding insurance coverage and CSHCN, Jeffrey and Newacheck detailed the published evidence to date regarding the experience of CSHCN under different insurance systems.[48] This cogent review suggested that the few studies assessing the impact of managed care on CSHCN revealed mixed effects on health care utilization and satisfaction. Among their most important findings was a troubling lack of research regarding the actual health outcomes of chronically ill children in relation to different insurance coverage profiles.

This review is intended to extend the findings of the Jeffrey and Newacheck review by offering a more detailed examination of published reports regarding the impact of managed care on a particular group of CSHCN: those enrolled in Medicaid. The focus on this group is based on several considerations. First, poor children are more likely to be particularly vulnerable to any deleterious effects of structural changes in care delivery.[49] Second, they also appear to be in greatest need of improvements in the coordination of care.[50] Third, over the last two decades, legislative and regulatory action by state governments has resulted in US states moving large number of children from Medicaid fee for service (M-FFS) into Medicaid managed care (M-MC) programs,[51] a shift whose effects have taken on a variety of forms.[52, 53] Current policy trends will likely extend this shift in delivery structure to a growing number of CSHCN.[54] Because Medicaid provides health insurance for the single largest group of CSHCN in the country, the prospective shift from M-FFS to M-MC for these children represents the most critical, potential change in the structure of health care delivery for CSHCN currently being deliberated at the state and national level.

Background

Despite recurring calls for data,[55-58] the effects of the movement from M-FFS to M-MC for CSHCN remain unclear.[59, 60] The potential utility and uncertainties related to poor children served by Medicaid managed care were voiced as early as 1990[60, 61] and included concerns about access, utilization, and health outcomes. Over the subsequent fifteen years, others have revisited these concerns, particularly for CSHCN.[62-65] When articulated, the justification for the shift of CSHCN from M-FFS to M-MC usually includes one of three objectives. A central objective is to enhance access to a primary care provider as well as appropriate specialty care, with improved service utilization mix.[66] A second objective is to improve expressly the coordination of services. Such coordination can occur by providing one usual place of care with an emphasis on providing preventive services.[67] It also can occur by making services more readily available with improved record-keeping and without duplication. A third objective is to reduce costs through more cost-effective prescription practices,[68] preventing hospitalization and emergency department use and, reducing direct and indirect overhead costs.[69]

In large part, this rationale for moving CSHCN into M-MC is based on experiences with adults and generally healthy children. However, CSHCN are more likely than other children to be enrolled in Medicaid[70] and the implementation of managed care has varied.[71, 72]

Review Methods

To identify published peer-reviewed research related to the effect of M-MC on CSHCN, we conducted a literature search and sought further information from existing bibliographies and expert colleagues. For the purposes of this review, we excluded 'gray literature' -- materials that are found in recorded, written, or electronic form that are not traditionally well indexed, readily available, or peer-reviewed (e.g., conference papers, white papers, technical reports, electronic theses and dissertations, online documents, and oral presentations/abstracts).

The PubMed database was searched (1988 – February 2006; includes HealthSTAR since 2000). For this database, a broad search was conducted using MeSH headings and terms:

- "Disabled children" or "Chronic illness[Multi]" or "Chronic Disease" or "Catastrophic illness" or "special health care needs" or "special needs."
- In conjunction with: "infant" or "child" or "child, preschool" or "adolescent."
- In conjunction with: "Medicaid" and "Managed Care Programs" or "Medicaid" and "HMO."

We also searched the Cochrane Controlled Trials Register database and the Cochrane Collaboration's Specialized Register of Effective Practice and Organization of Care (EPOC). For this database, a free text search strategy was applied, using the following terms (* indicates wild card symbol):

- Special health care needs* or disabil* or chronic*.
- In conjunction with: infant or child or preschool* or adolesc*.
- In conjunction with: Managed care* and Medicaid* or Medicaid* and HMO*.

Finally, the reference lists of located papers were scanned for studies of children with special health care needs in Medicaid managed care and relevant articles were retrieved. We compiled the results from all searches into an EndNote bibliographic database, removing all duplicate records. Through this process, we identified 99 publications.

Inclusion and exclusion criteria were determined. Inclusion criteria stated that the article must be written in English and must: (1) be empirical; and, (2) address children, special health care needs (broadly considered), health care services as provided by Medicaid managed care, as well as patient experiences and outcomes (broadly considered). The exclusion criteria stated that articles would be excluded if: (1) representing opinions, commentaries, reviews; (2) addressing behavioral or mental health issues exclusively; or, (3) focusing on state children's insurance programs (SCHIP) -- within Federal guidelines, each state establishes the design and administrative/operating procedures of its SCHIP program; thus, not all SCHIP programs are extensions of Medicaid.

Two persons (LH and GB) independently examined the titles and abstracts of the 99 publications. From this set, 59 publications were excluded (the two reviewers agreed that articles did not meet inclusion/exclusion criteria). Thus, there were 40 publications that were put forward

for full review. The two reviewers independently reviewed the full text of the 40 articles. Of these, an additional 24 were excluded because of one of the following: (1) editorial, comment, or letter; (2) not relevant for specific reason (i.e., discussion of design or methodological issues, opinion/commentary/description, or review or overview).

The remaining 16 articles were the subject of our efforts concerning the quality of studies, strength of evidence, and summary of findings. For the quality of studies assessment, the two reviewers completed and compared their abstractions; disagreements were settled by discussion and additional review of disputed articles.

Results

Characteristics and Quality of Individual Studies

Sixteen articles addressed the impact of Medicaid Managed Care on health services delivery to children with special health care needs (see Table 3). There was one randomized trial.[73] The remaining 15 articles represented observational studies: one was a prospective cohort design,[74] seven were retrospective cohort designs,[75-81] one was a time series design,[82] four were before-and-after designs,[83-86] one was a cross-sectional design,[87] and one was a case series.[70]

Table 3. Summary of Characteristics of Reviewed Studies

Article	Study design and State	End of data collection	Sample size for CSHCN	Special Health Care Needs: Definition or Eligibility	Measured Outcomes Categories
Chan and Vanderberg[76]	Retrospective cohort MN	12/01/95	374	Katie Beckett Option: <18 meeting SSI definition of disability and not living in hospital or intermediate care but needing that level of care	Health Care Utilization Health; Care Expenditures
Finkelstein et al.[77]	Retrospective cohort MA	09/30/96	1928	Children with diagnosis of asthma	Health Care Utilization ; Use of Effective Medication; Equity of Use of Effective Medication
Fox et al.[83]	Before-after 39 states	12/31/97	0	Not addressed	Other (Medicaid financing for EI services)
Gadomsky et al.[82]	Time series MD	11/30/93	3160	Children eligible for SSI[1] or MA (AFDC-related assistance to disabled children)	Health Care Utilization
Grossman et al.[85]	Before-after OH	06/30/96	38	Children eligible for SSI	Health Care Utilization; Satisfaction with Care; Health Care Expenditures
Lieu et al.[74]	Prospective cohort CA, DC, MA	10/01/00	1633	Children (2 – 16 years old) with diagnosis of asthma confirmed by utilization data and parent report	Health Care Utilization; Use of Effective Medication; Satisfaction with Care; Asthma Status Survey
Mauldon et al.[73]	Randomized trial 1 state	12/31/92	2078	Children with major disabling conditions (i.e., blindness, diabetes, cerebral palsy, mental retardation, cancer, missing limbs) Children with nondisabling chronic conditions (i.e., eczema, asthma, hay fever, other allergies)	Health Care Utilization

[1] Supplemental Security Income (SSI): medically determined physical or mental impairment that results in severe functional limitations, can be expected to result in death, or has lasted >12 months.

Table 3. Summary of Characteristics of Reviewed Studies (continued)

Article	Study design and State	End of data collection	Sample size for CSHCN	Special Health Care Needs: Definition or Eligibility	Measured Outcomes Categories
Mele and Flowers[70]	Case series AL, OH, TN	02/01/96	0	Title V, state criteria[2]	Satisfaction with Care
Millar et al.[87]	Cross-sectional OK	12/31/99	750	Children eligible for SSI	Satisfaction with Care
Mitchell and Gaskin[81]	Retrospective cohort DC	12/30/02	644	Children eligible for SSI	Access to Care
Mitchell et al.[78]	Retrospective cohort OR	10/31/98	615	Children eligible for SSI Children with asthma	Access to Care; Health Care Utilization; Satisfaction with Care
Roberto et al.[86]	Before-after DC	08/01/03	644	Children eligible for SSI	Access to Care
Shatin et al.[75]	Retrospective cohort 2 Midwest states	12/31/93	3839	Children with specific high-prevalence conditions (i.e., asthma, ADHD, diabetes, epilepsy, sickle cell anemia)	Health Care Utilization
Valet et al.[80]	Retrospective cohort TN	08/30/02	399	Children with chronic conditions - determined by 5-item CSHCN Screener,	Access to Care

[2] Title V Alabama: Any child with a special health care need (see list of eligible conditions) is eligible for services based on individual needs and the availability of the service within the agency (http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-May-2003/Alabama_2003.pdf).
Title V Ohio: A medically handicapped child is one who suffers from a chronic organic disease, defect, or congenital or acquired physically handicapping and associated condition that may hinder achievement of normal growth and development (http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-May-2003/Ohio_2002.pdf).
Title V Tennessee: Eligible child must have a covered condition or be chronically handicapped by any reason of physical infirmity, whether congenital or acquired, as a result of accident or disease which requires medical, surgical, or dental treatment and rehabilitation, and be totally or partially incapacitated for receipt of normal education or support (http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-May-2003/Tennessee_2002.pdf).

The study quality criteria suggested by West et al. (see Appendix A) were used in the review. Table 4 presents the summary of these ratings. Of the 16 articles, two fully addressed all domains.[73, 82] Three other articles addressed most of the domains, omitting only information about subject comparability,[77] exposure to managed care,[74] or results.[86] The remaining 11 articles partially or entirely overlooked two domains,[75, 79-81] three domains,[78, 79, 83-85] or four or more domains.[70, 76, 87]

All of the articles described a research question that was clearly focused and appropriate, depicted the study population, and delineated the outcomes. Most articles (n=14) also included information about the exposure of the study population to Medicaid managed care (the intervention under examination). Only a few articles (n=5) included a measure of effect size (e.g., odds ratio, absolute or relative risk reduction, number needed to treat). Similarly, only six fully addressed the issue of subject comparability (e.g., defining special health care needs, noting specific inclusion/exclusion criteria, establishing comparability of groups at baseline).

Subject comparability is important in these studies as there can be notable between-group variation at the start of a new program. In the case of M-MC and children with special health care needs, such variation may include child demographics (with significant proportions of children in Medicaid who are poor, minority, or in single-parent households), child epidemiology (with low overall prevalence of disease made up of mainly rare conditions, though asthma, diabetes, epilepsy, and sickle cell anemia are exceptions) and adverse selection (children who are less healthy tending to join one plan or another).

Table 4. Summary of Quality Elements of Reviewed Studies

Article	Domains								
	Study question	Study population	Comparability of subjects	Exposure to intervention	Outcomes	Statistics	Results	Discussion	Funding
Chan and Vanderberg[76]	●	●	◒	●	●	○	○	○	○
Cooper et al.[84]	●	●	◒	●	●	●	●	○	○
Finkelstein et al.[77]	●	●	◒	●	●	●	●	●	●
Fox et al.[83]	●	●	○	●	●	○	○	●	●
Gadomsky et al.[82]	●	●	●	●	●	●	●	●	●
Grossman et al.[85]	●	●	◒	●	●	●	○	●	○
Lieu et al.[74]	●	●	●	○	●	●	●	●	●
Mauldon et al.[73]	●	●	●	●	●	●	●	●	●
Mele and Flowers[70]	●	●	○	●	●	○	○	●	○
Millar et al.[87]	●	●	●	○	●	○	○	○	○
Mitchell and Gaskin[81]	●	●	◒	●	●	●	○	●	●
Mitchell and Gaskin[79]	●	●	●	●	●	○	○	●	●
Mitchell et al.[78]	●	●	◒	●	●	●	○	○	●
Roberto et al.[86]	●	●	●	●	●	●	○	●	●
Shatin et al.[75]	●	●	◒	●	●	●	○	●	●
Valet et al.[80]	●	●	◒	●	●	●	○	●	●

●=addressed domain fully ◒=addressed domain in part ○=did not address domain

Evidence of Program Effects

In this section, we distill the results of the 16 identified studies. We apply the strategy of Newacheck and colleagues[56] for categorizing these outcomes. Briefly, there are seven outcomes categories that are salient for CSHCN. While one involves care coordination directly, the other elements also reflect elements of care coordination more generally, including satisfaction, access and family impact. Moreover, unlike specific care coordination interventions, M-MC is structural and organizational system whose coordinative effects can touch virtually all aspects of these care indicators:

1. *Access to Care*, with indicators reflecting convenience and physical access, travel and waiting time, provider choice, coverage of services, and availability of services (frequently denoted in measures of unmet need).
2. *Health Care Utilization*, with indicators reflecting use and volume of primary medical care, specialized medical care, specialized therapies (e.g., physical therapy, mental health therapy, home health services), family support services, equipment and supplies, and related services (e.g., early intervention, special education).
3. *Quality of Care*, with indicators reflecting case finding and service coordination, provider training and supply, medical necessity, clinical quality (e.g., quality of care standards, quality improvement system), and grievance procedures.
4. *Satisfaction with Care*, with indicators reflecting family and practitioner satisfaction;
5. *Health Care Expenditures*, with indicators reflecting expenditures for care (including out-of-plan services), indirect costs incurred by families, degree to which other funding provides financing (e.g., Title V, EPSDT), and degree to which savings are achieved by managed care.
6. *Health Outcomes*, with indicators reflecting global health as well as cognitive, physical, social, and emotional functional status.
7. *Family Impact*, with indicators reflecting sibling and parent health status, parent financial burden, parent knowledge of special health care needs, and managed care plan-provided family support.

The general findings of the reviewed studies were highly varied and did not present a clear message as to the general utility of M-MC for CSHCN. Eight studies reported utilization findings; five access findings; four quality findings; four satisfaction findings; and one expenditure finding. None of the reviewed studies reported direct health outcomes measures or family functioning but did report parental survey data on child health.

Access to Care. There was no consistent set of findings regarding access to care. Fox et al.[83] reported that after the introduction of M-MC, care programs experienced reduced financing for most early intervention services for CSHCN but enhanced financial support for vision and enabling services. Mitchell and Gaskin[79, 81] similarly reported mixed access findings. CSHCN in M-MC had similar rates as their M-FFS counterparts of unmet needs for physician/hospital care, mental health, home health and therapy services. However, the children in M-MC had fewer unmet needs for dental care, medical equipment and prescription drugs. Roberto et al.[86] reported children in M-MC had fewer problems accessing primary, specialty, emergency and hospital care. However, Valet et al.[80] found that parents of CSHCN in M-MC experienced high levels of care denial and that these levels were higher than children without special health care

needs. In sum, two of the examined studies reported reduced access in M-MC, 4 improved access in M-MC, and two mixed access findings.

Utilization. As was found for access to care, utilization findings were decidedly mixed. Cooper et al.[84] found that the proportion of children hospitalized with chronic conditions were similar during the periods before and after the introduction of a M-MC system. Finkelstein and colleagues[77] reported that children with asthma in M-MC were more likely to receive care in emergency departments and were hospitalized more often than those in commercial managed care plans. However, both groups of children had similar rates of nonurgent and urgent ambulatory visits. Similar mixed findings were reported by Gadomsky et al.[82] with CSHCN in M-MC eligible for SSI having higher emergency department use, hospitalization and ambulatory-sensitive hospitalizations but also a slight increase in preventive care than non-MC counterparts. Shatin et al.[75] reported that children with chronic illness in M-MC had increased service use compared with commercial-MC counterparts. Grossman et al.[85] reported that after the introduction of M-MC program, CSHCN had no change in emergency department visits but fewer hospitalizations and hospital days. Lieu et al.[74] found that children with asthma in M-MC had greater hospital utilization than those in commercial managed care while Mitchell et al.[78] reported no differences in hospital, physician, dentist and prescription drug services among CSHCN.

In sum, the reviewed studies reported four findings that M-MC was associated with reduced utilization, three improved utilization, and five that showed no difference with the compared populations.

Quality of Care. Two studies reported improved quality of care in M-MS. Cooper et al.[84] reported that there were fewer enrollment gaps among CSHCN after M-MS was instituted. Grossman et al.[85] found that certain groups of CSHCN had improved quality of care indicators in M-MC; however, most of the studied children had similar quality indicators. Lieu et al.[74] found no differences in quality indicators between children with asthma in M-MC and those in commercial managed care. Finkelstein et al.[77] found that children with asthma in M-MC had similar prescriptions written for controller medications but fewer of these were actually dispensed to the children in the M-MC group.

In sum, one study found reduced quality indicators associated with M-MC, two reported improved quality measures in M-MC systems, and three reported no quality differences between M-MC and comparison populations.

Satisfaction. Satisfaction findings were reported in 4 of the examined studies. Mele and Flowers[70] and Millar et al.[87] both reported reduced parental satisfaction among CSHCN enrolled in M-MC. Mitchell and Gaskin[79] however, reported improved parental satisfaction in M-MC, particularly in office visit wait time, office hours, telephone medical advice and specialist care. Grossman et al.[85] and Mitchell et al.[78] reported no differences in parental satisfaction between the compared groups. Thus, two reported worse satisfaction for M-MC, one improved satisfaction and one no difference.

Expenditures. Interestingly, there was no study that indicated that children in M-MC had reduced health care expenditures, although only two addressed this factor. Chan and Vanderberg[76] reported that M-MC was associated with higher costs in general but reduced claims for mental health care than their M-FFS counterparts. Grossman et al.[85] found no difference in costs after M-MC was introduced.

Outcomes. There were no studies that directly assessed health outcomes. However, Lieu et al.[74] assessed reported asthma physical health and found no difference between the M-MC and commercial managed care groups of children with asthma.

Family Functioning. There were no studies that assessed family functioning.

Summary of Review Findings

Despite the fact that large numbers of CSHCN are being moved into managed care programs, there are a relatively small number of peer-reviewed studies documenting the impact of such programs on this vulnerable population of children. In total, the numbers of reviewed articles is 16, representing 14 separate projects. One article describes an RCT, and 15 articles describe non-randomized comparative studies. The samples of children with special health care needs ranged in size from zero (studies where the subjects were the directors of state programs for Infants and Toddlers with Disabilities (ITDP or IDEA, Part C) or other key informants) to 3,839.

Assessing the strength of the body of evidence concerning this research involves judgments of study quality; it also includes how confident one is that a finding is true and whether the same finding has been detected using a range of studies or study participants. In this regard, only two of the sixteen articles fully address all domains that characterize high-quality observational studies. In addition, this is a generally inconsistent body of evidence. This collection of scientific work consists of a small number of lesser quality studies that can be contradictory in their conclusions.

It should be noted that these studies do not explicitly evaluate care coordination directly. However, they do assess attempts to move CSHCN into a structure of care that is expressly justified, at least in part, as a means of improving the coordination of care for these children. Moreover, the outcome measures used in these studies, although far from ideal, are largely representative of the kinds of outcomes expected to respond to coordinative effects.

The basic premise here is that care coordination is sensitive to both structural initiatives and specific programmatic interventions. Particularly given the scale of the M-MC policy initiatives and the number and vulnerability of affected children, any consideration of care coordination for CSHCN in the United States today must address both programmatic and structural pathways of effect.

Chapter 5. Summary and Recommendations

Despite the importance of care coordination for children with special health care needs, there is a relative paucity of evaluative evidence to guide its development and implementation. This observation is not directed at challenging the contention that care coordination is helpful to children with special health care needs and their families. The experience of countless families and providers caring for children with complex medical needs and the face validity of the goals of care coordination provide sufficient justification for maintaining care coordination's central role in shaping both child health practice and policy.

Rather, the primary challenge generated by this critical review of the relevant literature is whether current approaches to care coordination for CSHCN can substantially improve the quality of care for these children under current practice structures and policies. Framed somewhat differently, the current knowledge base seems inadequate to identify which care coordination strategies are most likely to be useful in any given practice setting.

The following sections summarize the central considerations informing this general assessment. They represent the primary findings of this review, interpreted and organized to help define the outstanding analytic issues concerning care coordination for CSHCN and recommendations for further research.

Analytic Approach and Definitions

This technical review documents that the variety of analytic strategies that have been employed in evaluating care coordination for CSHCN not only reflects diverse practice and policy settings but also a remarkable analytic creativity in addressing this issue with relatively limited available resources. In addition, definitional issues continue to make the comparison of published studies difficult and more importantly, have helped create a confusing context for the assessment of program characteristics and ultimate effects. The most important of these analytic and definitional issues are summarized below, with each followed by a corollary recommendation.

Heterogeneity in Identifying CSHCN

Considerable progress has been made in providing useful methods for defining and identifying CSHCN. However, there remains considerable variation in analytic approaches and definitions in the available literature. In addition, there remains a gap between recommended definitions for CSHCN and datasets with sufficient information to utilize these definitions in large populations of children. This is of particular importance as administrative datasets become available for research, monitoring and evaluation. Also worthy of special note is the observation that when the generally recommended definition of CSHCN is used, the group so defined is highly heterogeneous. Indeed, illness severity and functional impact are inherently continuous variables but the definition is largely used to make categorical yes/no designations. It should not be surprising therefore, that different programs or policies may find alternative or more restrictive definitions better suited to meet their evaluative needs.

Recommendation: Generate Consensus on Definition Use. The literature regarding CSHCN definition has been characterized by a search for a "preeminent" or at least consistent definition. However, it might prove useful to reexamine the growing experience with the MCHB

definition, not to reconsider its content but rather to develop more consistent methodologic strategies to enhance its programmatic and analytic utility. For example, a fuller embrace of the definition as a programmatic screener or survey instrument might be enhanced if it were accompanied by agreed-upon, standard sets of supplementary variables that would be of direct use for programs and researchers concerned with subsets of CSHCN or trends in the epidemiology within the broad CSHCN population.

Parent and Clinician Roles in Coordinating Care

Although there are a variety of approaches to care coordination,[25] in the pediatric literature there are differences in how the respective roles of parents and clinicians are framed and emphasized. In general, the use of the medical home concept has largely emphasized the central role of the clinician, and particularly the pediatrician. Other care coordination strategies have focused on the coordinative capacities of the parent and the utility of programmatic supports that can strengthen this role. While it is clear that any constructive care coordination model for children must include both parents and clinicians, there remain important differences that should be recognized, if not addressed, in shaping care coordination strategies. For example, there is growing interest in expanding reimbursement to clinicians for coordinative activities. This, in turn, may involve a formalization of the clinician's responsibilities for care coordination which, in some instances, may conflict with some care models that elevate and support a primary parental role. Such considerations may also become increasingly important as the practice of pediatrics responds more fundamentally to the challenges of childhood chronic disease in the years to come.[88]

Recommendation: **Integrate More Fully Parental and Clinician Roles in Care Coordination for CSHCN.** Purposeful efforts to integrate the conceptual approaches and the various constituencies together should be strengthened. Clearly, the different coordinative approaches need not be mutually exclusive and the respective roles of parents and clinicians should be expected to vary in different settings or even as a child grows and develops. However, this review of care coordination for CSHCN suggests that important differences in approach exist and that they are best identified and addressed as part of the larger effort to develop coherent and collaborative care coordination strategies for CSHCN.

Assessing the Impact of Care Coordination Interventions for CSHCN

Inadequate Evaluation of Care Coordination Strategies

The number and quality of studies evaluating different care coordination strategies for CSHCN do not provide a strong empirical base for reaching general conclusions or assessing specific programmatic components of care coordination strategies for CSHCN. This assessment is not intended to suggest inaction in developing care coordination initiatives for CSHCN but rather some critical caution in shaping such programs in different practice and policy settings.

Of particular note is the lack of rigorous study design in the reviewed evaluations. In part, this reflects the relatively poor resource base of these studies. However, it may also reflect inadequate disciplinary connections between those focused on the provision of care to CSHCN

and those developing new methods to evaluate clinical programs and improve the quality of health care.

Recommendation: **Expand the Evaluation of Care Coordination Programs for CSHCN.** Support for high quality evaluations of coordination interventions is desperately needed, particularly regarding health outcomes and costs. This enhanced effort should include:

- Greater emphasis on identifying the specific aspects of coordination particularly relevant to CSHCN and clearly describing how the implemented interventions address these discrete components of coordination;
- Mechanisms to enhance disciplinary interaction between care coordination programs and quality improvement methodologists to generate more rigorous evaluative strategies.

Given the growing pressure for greater efficiencies in delivering health care services in general and for the chronically ill in particular, there would seem to be important opportunities to generate an expanded evaluative agenda.

Evaluating Replications of Promising Care Coordination Programs

Only one of the reviewed care coordination programs represented a replication (albeit modified) of a prior care coordination model.[45] Although different programs components are likely to be more useful in different practice settings, there could be some benefit in supporting the critical replication or scaling up of successful coordination models. Of particular note are the approaches reflected in the Pediatric Alliance for Coordinated Care (PACC) developed by Palfrey and colleagues.[44] This program could serve as a useful starting point for such replication efforts since it represents perhaps the most relevant and best evaluated coordination approach for primary care practices.

Recommendation: **Support for the implementation and continued evaluation of PACC and related models should be enhanced.**

Care Coordination and Practice Structure and Policy

One of the basic observations made in this review is that the implemented care coordination efforts varied considerably and were related to different structures of child health care delivery and practice. This point has been made by Shenkman and colleagues[89] and suggests that care coordination interventions will likely need to be adapted for different settings.

Recommendation: **Link Care Coordination Program Development to Practice and Policy Reform.** Given the dynamic nature of health care delivery in the United States, this relationship between care coordination components and practice structures also suggests that the findings of any evaluation of care coordination for CSHCN should be interpreted within its historical context. Careful consideration should be given as to the relevance of the evaluated experience to current practice and policy trends. Therefore, as practice structures undergo change, the challenges and opportunities for coordination programs will change as well. The concern is that longstanding child health practice patterns may be increasingly out of step with the evolving epidemiology of childhood conditions and the growing efficiency demands of health policy reform.[9] This may be particularly true in meeting the enhanced, and often time

consuming needs of CSHCN. Accordingly, efforts to enhance care coordination for CSHCN should be informed by a close consideration of practice and policy requirements.

Managed Care for CSHCN Enrolled in Medicaid

Lack of Child-focused Metrics for Assessing the Performance of Managed Care Systems for Poor CSHCN

Of note, while the reviewed studies utilized a variety of outcome measures, none of these were focused on measuring health outcomes directly.

Recommendation: **Develop Performance Measures of Direct Relevance to CSHCN.** Despite progress in developing performance measures for a variety of mainly adult health conditions, there are no standard performance measures of any meaning for CSHCN being utilized to assess either the capacity or performance of health plans or practices.

Inadequate Information on the Impact of Managed Care for CSHCN

The implementation of managed care programs for CSHCN enrolled in Medicaid is moving forward rapidly despite an extremely weak knowledge base regarding its ultimate impact on the health of enrolled children and costs.

Recommendation: **Urgently Expand the Evaluation of Managed Care for CSHCN.** There is a critical and immediate need to assess the impact, problems, and missed opportunities associated with managed care strategies for CSHCN enrolled in Medicaid and other public programs for poor children. Special attention should be paid to documenting relevant coordinative components of the implemented programs and particularly, their impact on the coordination of care. Great caution should be exercised, therefore, in making broad judgments regarding the problems or benefits associated with this approach.

References

1. Perrin JM, Shayne MW, Bloom SR. Home and Community Care for Chronically Ill Children. New York: Oxford Press; 1993.
2. Stein R. Caring for Children With Chronic Illness: Issues and Strategies. New York: Springer; 1989.
3. Epstein SG, Taylor AB, Halberg AS. Shared Responsibilities: Ensuring Quality Managed Care for Children with Special Health Care Needs. Boston: New England Serve; 1998.
4. Family Voices. What do Families Say about Health Care for Children with Special Health Care needs in California: Your Voice Counts. Boston: Family Voices at the Federation for Children with Special Health Care Needs. 2000.
5. National Health Interview Survey 2000-2003. National Center for Health Statistics, Centers for Disease Control.
6. Hedley AA, Ogden CL, Johnson CL, Carroll MD, Curtin LR, Flegal KM. Prevalence of overweight and obesity among US children, adolescents, and adults, 1999-2002. Jama. 2004 Jun 16;291(23):2847-50.
7. Costello EJ, Mustillo S, Erkanli A, Keeler G, Angold A. Prevalence and development of psychiatric disorders in childhood and adolescence. Archives of general psychiatry. 2003 Aug;60(8):837-44.
8. Newacheck PW, Halfon N. Prevalence and impact of disabling chronic conditions in childhood. American journal of public health. 1998 Apr;88(4):610-7.
9. Wise PH. The transformation of child health in the United States. Health affairs (Project Hope). 2004 Sep-Oct;23(5):9-25.
10. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. Pediatrics. 1998 Jul;102(1 Pt 1):137-40.
11. Perrin EC, Newacheck P, Pless IB, et al. Issues involved in the definition and classification of chronic health conditions. Pediatrics. 1993;91:787-93.
12. Stein RE, 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 Mar;122(3):342-7.
13. Bethell CD, Read D, Brockwood K. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. Pediatrics. 2004 May;113(5 Suppl):1529-37.
14. Kaye N, Curtis D, Booth M. Certain Children with Special Health Care Needs: An Assessment of State Activities and their Relationship to HCFA's Interim Criteria. Washington, DC: National Academy for State Health Policy; 2000.
15. Ellis RP, Pope GC, Iezzoni L, et al. Diagnosis-based risk adjustment for Medicare capitation payments. Health care financing review. 1996 Spring;17(3):101-28.
16. Kronick R, Dreyfus T, Lee L, Zhou Z. Diagnostic risk adjustment for Medicaid: the disability payment system. Health care financing review. 1996 Spring;17(3):7-33.
17. Neff JM, Sharp VL, Muldoon J, Graham J, Popalisky J, Gay JC. Identifying and classifying children with chronic conditions using administrative data with the clinical risk group classification system. Ambul Pediatr. 2002 Jan-Feb;2(1):71-9.
18. Weiner JP, Tucker AM, Collins AM, et al. The development of a risk-adjusted capitation payment system: the Maryland Medicaid model. The Journal of ambulatory care management. 1998 Oct;21(4):29-52.
19. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. Ambul Pediatr. 2002 Jan-Feb;2(1):38-48.
20. Stein RE, Silver EJ, Bauman LJ. Shortening the questionnaire for identifying children with chronic conditions: what is the consequence? Pediatrics. 2001 Apr;107(4):E61.
21. Stein RE, Westbrook LE, Bauman LJ. The Questionnaire for Identifying Children with Chronic Conditions: a measure based on a noncategorical approach. Pediatrics. 1997 Apr;99(4):513-21.
22. Iezzoni LI, Greenberg MS. Capturing and classifying functional status information in administrative databases. Health care financing review. 2003 Spring;24(3):61-76.
23. Leonardi M, Bickenbach J, Ustun TB, Kostanjsek N, Chatterji S. The definition of disability: what is in a name? Lancet. 2006 Oct 7;368(9543):1219-21.
24. Perrin JM, Thyen U. Chronic illness. In: Levine MD, Carey WB, Crocker AC, editors. Developmental-Behavioral Pediatrics. 3 ed. Philadelphia: WB Saunders; 1999. p. 335-45.
25. McDonald KM, Sundaram V, Bravata DM. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies; In Press.
26. Ziring PR, Brazdziunas D, Cooley WC, et al. American Academy of Pediatrics. Committee on Children With Disabilities. Care coordination: integrating health and related systems of care for children with special health care needs. Pediatrics. 1999 Oct;104(4 Pt 1):978-81.
27. Pierce PM, Freedman SA. The REACH Project: an innovative health delivery model for medically dependent children. Child Health Care. 1983 Fall;12(2):86-9.
28. Fields AI, Coble DH, Pollack MM, Kaufman J. Outcome of home care for technology-dependent children: success of an independent, community-based case management model. Pediatric pulmonology. 1991;11(4):310-7.
29. US Department of Health and Human Services, Health Resources and Services Administration. Healthy People: 2010. Objective 16-22. Washington, DC: Department of Health and Human Services; 1999.
30. American Academy of Pediatrics. Standards of Child Health Care. Elk Grove, Ill: American Academy of Pediatrics; 1976.

31. American Academy of Pediatrics. The medical home. Pediatrics. 1992 Nov;90(5):774.
32. American Academy of Pediatrics. The medical home. Pediatrics. 2002 Jul;110(1 Pt 1):184-6.
33. American Academy of Pediatrics. The National Center of Medical Homes Initiative for Children with Special Needs. [Accessed; Available from: http://www.medicalhomeinfo.org/
34. Cooley WC, McAllister JW. Building medical homes: improvement strategies in primary care for children with special health care needs. Pediatrics. 2004 May;113(5 Suppl):1499-506.
35. American Academy of Pediatrics. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. Pediatrics. 2005 Nov;116(5):1238-44.
36. Cooley WC, McAllister JW, Sherrieb K, Clark RE. The Medical Home Index: development and validation of a new practice-level measure of implementation of the Medical Home model. Ambul Pediatr. 2003 Jul-Aug;3(4):173-80.
37. Center for Medical Home Improvement. Medical Home: Improvement Kit. Lebanon, NH: Hood Center for Children and Families, Children's Hospital at Dartmouth Hitchcock Medical Center; 2001.
38. West S, King V, Lohr K. Systems to rate the strength of scientific evidence. Rockville, MD: Agency for Healthcare Research and Quality; 2002.
39. West S, King V, Lohr K. Systems to rate the strength of scientific evidence: Appendix F. Rockville, MD: Agency for Healthcare Research and Quality; 2002.
40. Criscione T, Walsh KK, Kastner TA. An evaluation of care coordination in controlling inpatient hospital utilization of people with developmental disabilities. Mental retardation. 1995 Dec;33(6):364-73.
41. Liptak GS, Burns CM, Davidson PW, McAnarney ER. Effects of providing comprehensive ambulatory services to children with chronic conditions. Archives of pediatrics & adolescent medicine. 1998 Oct;152(10):1003-8.
42. Perrin JM, Homer CJ, Berwick DM, Woolf AD, Freeman JL, Wennberg JE. Variations in rates of hospitalization of children in three urban communities. The New England journal of medicine. 1989 May 4;320(18):1183-7.
43. Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. Pediatrics. 2004 May;113(5 Suppl):1507-16.
44. Farmer JE, Clark MJ, Sherman A, Marien WE, Selva TJ. Comprehensive primary care for children with special health care needs in rural areas. Pediatrics. 2005 Sep;116(3):649-56.
45. Chernoff RG, Ireys HT, DeVet KA, Kim YJ. A randomized, controlled trial of a community-based support program for families of children with chronic illness: pediatric outcomes. Archives of pediatrics & adolescent medicine. 2002 Jun;156(6):533-9.
46. Pless IB, Feeley N, Gottlieb L, Rowat K, Dougherty G, Willard B. A randomized trial of a nursing intervention to promote the adjustment of children with chronic physical disorders. Pediatrics. 1994 Jul;94(1):70-5.
47. Antonelli RC, Antonelli DM. Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice. Pediatrics. 2004 May;113(5 Suppl):1522-8.
48. Jeffrey AE, Newacheck PW. Role of insurance for children with special health care needs: a synthesis of the evidence. Pediatrics. 2006 Oct;118(4):e1027-38.
49. Galbraith AA, Wong ST, Kim SE, Newacheck PW. Out-of-pocket financial burden for low-income families with children: socioeconomic disparities and effects of insurance. Health services research. 2005 Dec;40(6 Pt 1):1722-36.
50. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. Archives of pediatrics & adolescent medicine. 2004 Sep;158(9):884-90.
51. Kaye N. Medicaid managed care: Looking forward, looking back. Portland, ME: National Academy for State Health Policy; 2005.
52. Backus LI, Bindman AB. Low-income Californians' experiences with health insurance and managed care. Journal of health care for the poor and underserved. 2001 Nov;12(4):446-60.
53. Claxton G, Feder J, Shactman D, Altman S. Public policy issues in nonprofit conversions: an overview. Health affairs (Project Hope). 1997 Mar-Apr;16(2):9-28.
54. Rosenbaum S, Wise PH. Crossing the Medicaid-private insurance divide: the case of EPSDT. Health affairs (Project Hope). 2007 Mar-Apr;26(2):382-93.
55. Bergman DA, Homer CJ. Managed care and the quality of children's health services. The Future of children / Center for the Future of Children, the David and Lucile Packard Foundation. 1998 Summer-Fall;8(2):60-75.
56. Newacheck PW, Stein RE, Walker DK, Gortmaker SL, Kuhlthau K, Perrin JM. Monitoring and evaluating managed care for children with chronic illnesses and disabilities. Pediatrics. 1996 Nov;98(5):952-8.
57. Perrin JM, Kuhlthau K, Walker DK, Stein RE, Newacheck PW, Gortmaker SL. Monitoring health care for children with chronic conditions in a managed care environment. Maternal and child health journal. 1997 Mar;1(1):15-23.
58. RWJF. Chronic Care Initiatives in HMOs. Princeton, NJ: R.W.J. Foundation; 1992.
59. Berman S. The brave new bipartisan world of health care reform: how will low-income families with children with special health care needs fare? Pediatrics. 2004 Aug;114(2):489-90.
60. Hohlen MM, Manheim LM, Fleming GV, et al. Access to office-based physicians under capitation reimbursement and Medicaid case management. Findings from the Children's Medicaid Program. Medical care. 1990 Jan;28(1):59-68.
61. Reis J. Medicaid maternal and child health care: prepaid plans vs. private fee-for-service. Research in nursing & health. 1990 Jun;13(3):163-71.

62. Alessandrini EA, Shaw KN, Bilker WB, Perry KA, Baker MD, Schwarz DF. Effects of Medicaid managed care on health care use: infant emergency department and ambulatory services. Pediatrics. 2001 Jul;108(1):103-10.
63. Baker LC, Afendulis C. Medicaid managed care and health care for children. Health services research. 2005 Oct;40(5 Pt 1):1466-88.
64. Hughes DC, Newacheck PW, Stoddard JJ, Halfon N. Medicaid managed care: can it work for children? Pediatrics. 1995 Apr;95(4):591-4.
65. Wang EC, Choe MC, Meara JG, Koempel JA. Inequality of access to surgical specialty health care: why children with government-funded insurance have less access than those with private insurance in Southern California. Pediatrics. 2004 Nov;114(5):e584-90.
66. Kastner TA, Walsh KK, Criscione T. Overview and implications of Medicaid managed care for people with developmental disabilities. Mental retardation. 1997 Aug;35(4):257-69.
67. Currie J, Fahr J. Medicaid managed care: Effects on children's Medicaid coverage and utilization. Cambridge, MA: National Bureau of Economic Research; 2002.
68. LewinGroup. Medicaid managed care cost savings - A synthesis of fourteen studies. Falls Church, VA: America's Health Insurance Plans; 2004.
69. Berman S, Rannie M, Moore L, Elias E, Dryer LJ, Jones MD, Jr. Utilization and costs for children who have special health care needs and are enrolled in a hospital-based comprehensive primary care clinic. Pediatrics. 2005 Jun;115(6):e637-42.
70. Mele NC, Flowers JS. Medicaid managed care and children with special health care needs: a case study analysis of demonstration waivers in three states. Journal of pediatric nursing. 2000 Apr;15(2):63-72.
71. Berman S, Armon C, Todd J. Impact of a decline in Colorado Medicaid managed care enrollment on access and quality of preventive primary care services. Pediatrics. 2005 Dec;116(6):1474-9.
72. Kaye N, Curtis D, Booth M. Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCFA's Interim Criteria. Washington, DC: National Academy for State Health Policy; June 2000.
73. Mauldon J, Leibowitz A, Buchanan JL, Damberg C, McGuigan KA. Rationing or rationalizing children's medical care: comparison of a Medicaid HMO with fee-for-service care. American journal of public health. 1994 Jun;84(6):899-904.
74. Lieu TA, Finkelstein JA, Lozano P, et al. Cultural competence policies and other predictors of asthma care quality for Medicaid-insured children. Pediatrics. 2004 Jul;114(1):e102-10.
75. Shatin D, Levin R, Ireys HT, Haller V. Health care utilization by children with chronic illnesses: a comparison of medicaid and employer-insured managed care. Pediatrics. 1998 Oct;102(4):E44.
76. Chan B, Vanderburg N. Medicaid TEFRA option in Minnesota: implications for patient rights. Health care financing review. 1999 Fall;21(1):65-78.
77. Finkelstein JA, Barton MB, Donahue JG, Algatt-Bergstrom P, Markson LE, Platt R. Comparing asthma care for Medicaid and non-Medicaid children in a health maintenance organization. Archives of pediatrics & adolescent medicine. 2000 Jun;154(6):563-8.
78. Mitchell JB, Khatutsky G, Swigonski NL. Impact of the Oregon Health Plan on children with special health care needs. Pediatrics. 2001 Apr;107(4):736-43.
79. Mitchell JM, Gaskin DJ. Do children receiving Supplemental Security Income who are enrolled in Medicaid fare better under a fee-for-service or comprehensive capitation model? Pediatrics. 2004 Jul;114(1):196-204.
80. Valet RS, Kutny DF, Hickson GB, Cooper WO. Family reports of care denials for children enrolled in TennCare. Pediatrics. 2004 Jul;114(1):e37-42.
81. Mitchell JM, Gaskin DJ. Factors affecting plan choice and unmet need among supplemental security income eligible children with disabilities. Health services research. 2005 Oct;40(5 Pt 1):1379-99.
82. Gadomski A, Jenkins P, Nichols M. Impact of a Medicaid primary care provider and preventive care on pediatric hospitalization. Pediatrics. 1998 Mar;101(3):E1.
83. Fox HB, McManus MA, Almeida RA. Managed care's impact on Medicaid financing for early intervention services. Health care financing review. 1998 Fall;20(1):59-72.
84. Cooper WO, Hickson GB, Gray CL, Ray WA. Changes in continuity of enrollment among high-risk children following implementation of TennCare. Archives of pediatrics & adolescent medicine. 1999 Nov;153(11):1145-9.
85. Grossman LK, Rich LN, Michelson S, Hagerty G. Managed care of children with special health care needs: the ABC Program. Clin Pediatr (Phila). 1999 Mar;38(3):153-60.
86. Roberto PN, Mitchell JM, Gaskin DJ. Plan choice and changes in access to care over time for SSI-eligible children with disabilities. Inquiry. 2005 Summer;42(2):145-59.
87. Millar JS, McCauley D, Hays C, Winston T, Mitchell L. Consumer Assessment of Health Plans Survey (CAHPS) results for Oklahoma managed care Medicaid, 1997, 1998, and 1999. J Okla State Med Assoc. 2000 Mar;93(3):109-17.
88. American Board of Pediatrics. Residency Review and Redesign in Pediatrics. [Accessed: December 16, 2006]; Available from: http://innovationlabs.com/r3p_public/
89. Shenkman E, Wu SS, Nackashi J, Sherman J. Managed care organizational characteristics and health care use among children with special health care needs. Health services research. 2003 Dec;38(6 Pt 1):1599-624.

Appendix A: Summary of Quality Assessment Criteria*

Domains	Critical Elements
Study question	Clearly focused and appropriate question
Study population	Description of study populations
Comparability of subjects	-Specific inclusion/exclusion criteria applied to all groups -Comparability of groups at baseline -Study groups comparable to non-participants with regard to confounding factors† -Use of concurrent controls -Comparability of follow-up among groups at each assessment
Exposure or intervention	Clear definition and measurement of exposure or intervention††
Outcomes	Clear definition and measurement of outcomes
Statistical procedures	Assessment of confounding factors†
Results	Measurement of magnitude of effect for outcomes (e.g., odds ratio (OR) or relative risk (RR))
Discussion	Conclusions supported by results, with biases and limitations taken into consideration
Project funding or sponsorship	Type and source of support for study

* SOURCE: West S, King V, Carey TS, et al. Systems to Rate the Strength of Scientific Evidence. Evidence Report/Technology Assessment No. 47 (Prepared by the Research Triangle Institute-University of North Carolina Evidence-based Practice Center under Contract No. 290-97-0011). AHRQ Publication No. 02-E016. Rockville, MD: Agency for Healthcare Research and Quality. April 2002.

† Confounding is the alteration of the effect of one risk factor by the presence of another. Age, gender and socioeconomic status often are confounding factors because children with different values of these may be at differential risk of problem or disease. Confounding can be controlled by restricting inclusion criteria, by matching groups on the confounding factor, or by including the confounding variable in statistical analyses.

†† Specific exposure and outcomes definitions help to address measurement bias, the systematic error that occurs when measurement methods are consistently different between groups in the study.