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Medicaid and Case Management to Promote Healthy Child Development

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EXECUTIVE SUMMARY

This policy brief presents options for financing and delivering case management services to low-income and special-needs children in Medicaid. The analysis builds on a literature review of case management, a review of the legal underpinnings of Medicaid case management, and consultation with experts in the fields of health care finance and program operations. It aims to inform the policy community about the importance of case management for assuring the health and development of our youngest and most vulnerable children.

The term case management has taken on a variety of meanings across professional fields, practice settings, and populations. This brief proposes a new framework for understanding the dimensions and characteristics of case management, the continuum of services which are financed under this label. This framework can be used to distinguish, for example, the care coordination services provided by a medical home or PCCM from the utilization management activities of a managed care organization from the work of a public health nurse who helps to coordinate services through home visits with families. Medicaid finances each of these services and each can play a role in improving the health and development of children.

Child health care coordination and case management are terms used interchangeably to describe an array of activities that are designed to: link families to clinical, social, community, and other services that affect overall health and well-being; strengthen communication between families and providers; avoid duplication of effort; and improve health outcomes. This review of the literature concludes that case management represents a valuable and effective service, both for children with special health care needs and children in families that face other barriers to receiving appropriate, high quality care. Case management plays a pivotal role in reducing the barriers that result from fragmentation of the health care delivery system and the gaps among programs to promote child development. By improving children's access to and appropriate utilization of services, case management services can help to promote optimal development.

In federal Medicaid law, case management is a reimbursable set of activities is reflected in numerous provisions, which can be categorized as follows: (1) the provisions that govern program administration activities associated with case management practice; (2) provisions related to case management as a distinct class of medical assistance; and (3) and provisions relevant to case management as an incidental component of a class of covered professional, clinical, or institutional services or as a dimension of managed care.

We propose review, clarification, and improvement of federal and state policies, as well as adoption of promising practices at the community level, in order for case management to be effectively and efficiently used to promote child health and development. One key recommendation calls for the federal government to review the regulatory provisions guiding Medicaid case management for children (including administrative, medical assistance, and other activities) and propose an improved, comprehensive set of rules that clarify the various types of case management, potential case management tiers, the federal financial participation arrangements appropriate to each tier, and the payment methods that are available under federal law. Similar policy review and revision of policies at the state level are also called for.

AUTHOR BIOGRAPHIES

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Introduction

This policy brief presents options for financing and delivering case management services to low-income and special-needs children, particularly in the case of Medicaid. The analysis builds on a literature review of case management, a review of the legal underpinnings of Medicaid case management, and consultation with experts in the fields of health care finance and program operations. It aims to inform the policy community about the importance of case management for assuring the health and development of our youngest and most vulnerable children.

This paper examines:

- The various applications of the broad concept of case management, as characterized by the patient type, care setting, provider type, and financing arrangements.
- The evidence regarding the use of case management as part of a comprehensive health and social intervention for children.
- The legal framework for Medicaid coverage of various types of case management activities.

Child health care coordination and case management are terms used interchangeably to describe an array of activities that are designed to: link families to clinical, social, community, and other services that affect overall health and well-being; strengthen communication between families and providers; avoid duplication of effort; and improve health outcomes. Some entities distinguish between these two terms, and some have advocated replacing the term case management with care coordination.[1] Thus, depending on the program or source of funding, the terms may vary, even though the functions remain the same. For example, while most Title V programs emphasize care coordination, Medicaid generally uses the term "case management." At the same time, CMS has noted that the terms are not consistently applied even within Medicaid.[2] For purposes of this analysis focused on Medicaid and child health, we use the term case management to reflect a broad array of activities.

While private health insurance covers case management in certain circumstances, Medicaid has long covered a range of supportive and case management-related services not generally covered by private insurance. Medicaid plays a particularly crucial role in financing case management, not only because of its relationship to the most at-risk young children, but also because of its unique pediatric coverage and payment rules. In contrast to traditional health insurance, Medicaid covers and pays for a far more comprehensive range of developmental health care services. This broad coverage and payment policy is embodied in its early and

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[1] American Academy of Pediatrics (AAP), Committee on Children with Disabilities. Care Coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics*. 1999; 104(4):978-981. Accessed online August 8, 2007 at www.aap.org/policy/re9902.html.

[2] 72 Fed. Reg. 68077, 68078, Dec.4, 2007, recognizing the sweep of the term "case management." (Case management is commonly understood to be an activity that assists individuals in gaining access to necessary care and services appropriate to their needs. . . .In the context of this regulation, it is the individual's access to care and services that is the subject of this management. . . . Because case management has been subject to so many different interpretations of the years, many Medicaid agencies now refer to case management as "care management" or "service coordination," "care coordination" or some other term related to planning and coordinating access to health care and other services on behalf of an individual.")

periodic screening diagnostic and treatment benefit (EPSDT), as well as the related administrative services recognized as essential to assuring that children receive the EPSDT care to which they are entitled.

An important body of research suggests that case management represents a valuable and effective service, both for children with special health care needs and children in families that face other barriers to receiving appropriate, high quality care.[3] As described below, many low-income families and most families of children with chronic conditions and disabilities need, and can benefit from, case management. By improving children's access to and appropriate utilization of services, case management services can promote optimal development.[4] [5]

Case management can and should play a pivotal role in reducing the barriers resulting from a fragmented health care delivery system and the gaps among programs to promote child development (e.g., gaps between health and early intervention programs, between medical care and public health promotion services). The Institute of Medicine cites the lack of care coordination as a major factor underlying the "chasm…that exists between the health care that we have now and the health care that we could have." The fragmentation and complexity of the health care system has increased as a result of policy changes, especially in the last 50 years. The accompanying gaps between service systems and "voltage drops" (e.g., maldistribution of providers, benefit limits, and nonstandard care) that impede access to quality health services for children.[6]

This policy brief is divided into three parts: Part 1 describes the design and impact of case management services; Part 2 the legal basis for Medicaid case management services for child health and development; and Part 3 provides recommendations for improving the delivery and financing of case management services for young children under Medicaid. We conclude that:

- While the term case management has taken on a variety of meanings across professional fields, practice settings, and populations, more can be done to rationally define the continuum of services which are financed under this label. To that end, this paper proposes a new framework for understanding the dimensions and characteristics of case management.
- Case management represents a valuable and effective service, both for children with special health care needs and children in families that face other barriers to receiving appropriate, high quality care. Case management plays a pivotal role in reducing the barriers that result from fragmentation of the health care delivery system and the gaps among programs to promote child development. This is particularly true for children covered by Medicaid, who are more likely than their

[3] Antonelli RC, McAllister JW, and Popp J. 2009. Developing Care Coordination as a Critical Component of a High Performance Pediatric Health Care System: Forging a Multidisciplinary Framework for Pediatric Care Coordination. New York, NY: The Commonwealth Fund.

[4] Fine A and Hicks M. 2008 *Health Matters: The Role of Health and the Health Sector in Place-Based Initiatives for Young Children*, Battle Creek, MI: W.K. Kellogg Foundation; Fine A and Mayer R. 2006. *Beyond Referral: Pediatric care linkages to improve developmental health*, New York, NY: The Commonwealth Fund.

[5] Johnson K and Rosenthal J. 2009. Improving Care Coordination, Case Management, and Linkages to Service for Young Children: Opportunities for States. New York, NY: The Commonwealth Fund/National Academy of State Health Policy.

[6] Chung, PH and Schuster MA. 2004. Access and Quality in Child Health Services: Voltage Drops. *Health Affairs* 23(5):77-87.

more affluent peers to face access barriers and to have developmental risks and special health care needs.

- Federal law provides for financing various forms of case management, particularly for children who are entitled to services under EPSDT provisions. At the same time, DHHS has never developed a unified approach to interpreting Medicaid case management. The rules and regulations related to case management tend to be focused on one topic or another and lack an overarching policy framework.
- Federal and state agencies with responsibility for Medicaid should undertake review and revision of policies in order to improve the efficiency and effectiveness of case management activities.

PART I. THE DESIGN AND IMPACT OF CASE MANAGEMENT SERVICES

A. The Structure and Functions of Case Management

The goals and purpose of case management activities for each individual should depend on patient need, but is also driven by financing arrangements, the venue of care, capacity, and the job definition of the case manager. This section will discuss the general purposes for case management in the context of child health, as well as staffing, financing, and other structural issues.

Case management is a broad term that encompasses diverse functions designed to help patients gain access to and use appropriate and quality health care, mainly through matching services to patients' needs, avoiding duplication of effort, improving provider-family communication, and monitoring the care process (or completion of a care plan). The interdisciplinary concept describes both medical and non-medical interventions that improve the patient's access to appropriate care, such as patient education, social supports, and assistance navigating the health care system. Typical functions can be broadly classified under four main functions: assessment, care plan development, referral, and monitoring and follow-up.

1. The Continuum of Case Management Services

Case management services are provided in a variety of care settings, including primary care clinics and practices, hospitals, and home and community-based venues. Some patients only need a few specific services, while others require a broader range of case management support. As highlighted above, case management is critical both for children with special health care needs and for others facing health care access barriers.

Since case management is a complex idea that encompasses several meanings, it is useful to conceptualize three tiers in a pyramid structure. (See Figure 1.) At the base of the pyramid is what might be thought of as "basic" (i.e., first tier) case management that helps to overcome access barriers through social support and help with navigating the health system. In these situations, a case manager needs to have skills in health care navigation, as well as communication and people skills. In this instance, personnel may or may not possess any specialized medical knowledge. However, workers are typically expected to have some knowledge and understanding of the intricacies of health insurance and other public health systems and programs. The venue of service would typically be a primary care medical home (e.g., physician's office, clinic), a home visit, or another community setting.

The second tier is case management for patients with complex conditions and special health care needs. Case managers working at this second tier ideally would possess added and relevant medical knowledge in order to bolster value of the assistance being provided. For example, a nurse trained in high-risk pregnancy care might be deemed necessary when furnishing pregnancy case management, in order to be certain that the manager could recognize signs and symptoms that warrant different or greater levels of certain types of care. Similarly, for children with special health care needs, care coordination and case management might be

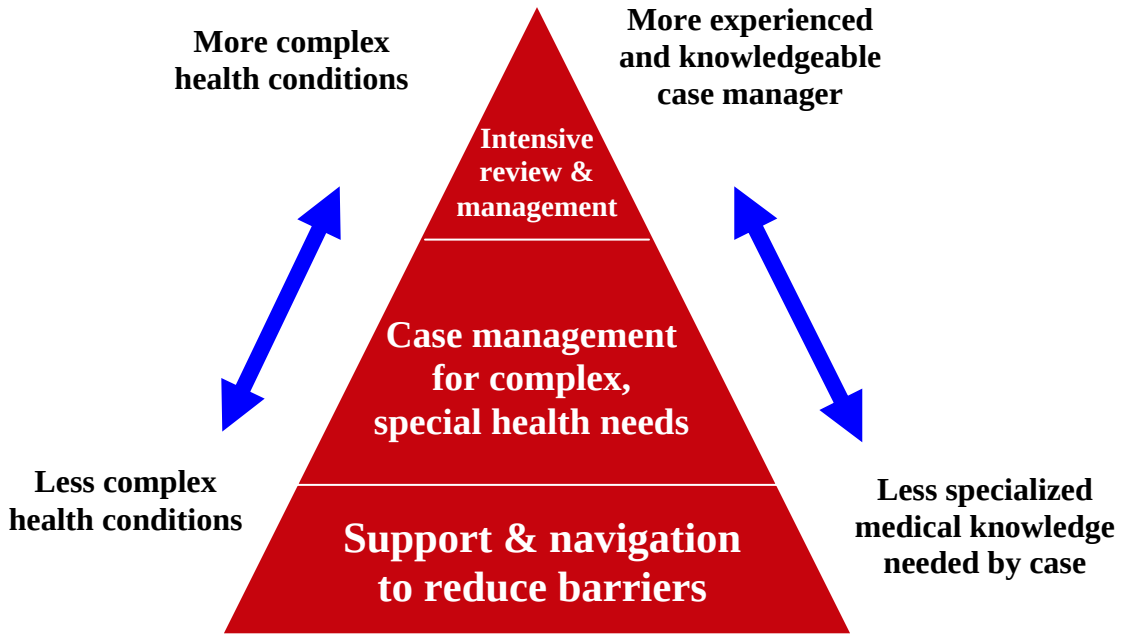
provided by an individual who has knowledge of evidence-based practice in management of asthma, cerebral palsy, developmental delays, or another condition. Equally important, the personnel in this second tier would have knowledge of the array of specialty providers who care for children with special needs, chronic conditions, or disabilities.

To deliver support in the third tier, a case manager not only needs medical knowledge to aid in access to care but is also expected to make determinations as to what care is or *is not* necessary. For management of complex needs in a care plan, more skill is required. In this situation the manager needs sufficient relevant clinical knowledge to make at least a threshold determination of medical necessity. The manager also needs to be trained in the medical necessity determination process, including the gathering and weighing of evidence, interaction with patients and treating health professionals to collect evidence, and oral and/or written communication of results in a manner that comports with notice and appeal rights.

It is conceivable that one individual might fulfill all three tiers. It also may be that three different persons could be involved as part of a case management team: a "tier one" person for basic case management; referral of a more complex patient to a "tier two" manager (imagine a developmental problem that grows in complexity); and finally, a "tier-three" case manager for specific treatment determinations involving the need for utilization management and medical judgment (e.g., what level and duration of intensive therapeutic services are medically necessary for a child?)

In sum, the concept of case management is broad, and operationalizing case management depends on the needs of the child and family and the overall purpose and function of case management in any particular context, the patients to be served, and the range and complexity of functional activities (and thus the skills of the case manager) that the case management activity will encompass.

Figure 1. Tiers of Case Management



2. Personnel to Provide Case Management

The pyramid provides an illustration of the levels of need and classes of case management services. It falls short, however, in showing the array of professionals who provide case management services.

Case management is provided by a variety of professionals in a variety of settings, depending on the patient's needs and the reimbursement limitations. Many children have family members that perform some case management functions (e.g., coordinating care plans, managing referrals). Due to factors, such as the complexity of the child's health conditions, language and cultural barriers, and lack of health literacy, however, many families are unable to effectively manage their child's care and require professional assistance.

Figure 2 arrays a variety of professionals who provide case management along a continuum from those having more or less medical/health professions training. As modeled in Figure 2, in current practice and on average, physicians spend a large majority of time providing direct, and often highly specialized, clinical services and a relatively small percentage of their time on case management. Social workers and public health nurses might spend closer to half of there time on case management activities. In contrast, a community health worker typically spends the great majority of time providing case management services and not direct care. Within the case management function of each professional, there will be gradients in the types of case management provided (i.e., tier 1, tier 2, tier 3 depicted in the pyramid in Figure 1), from less specialized to very clinically specialized case management services, as described above.

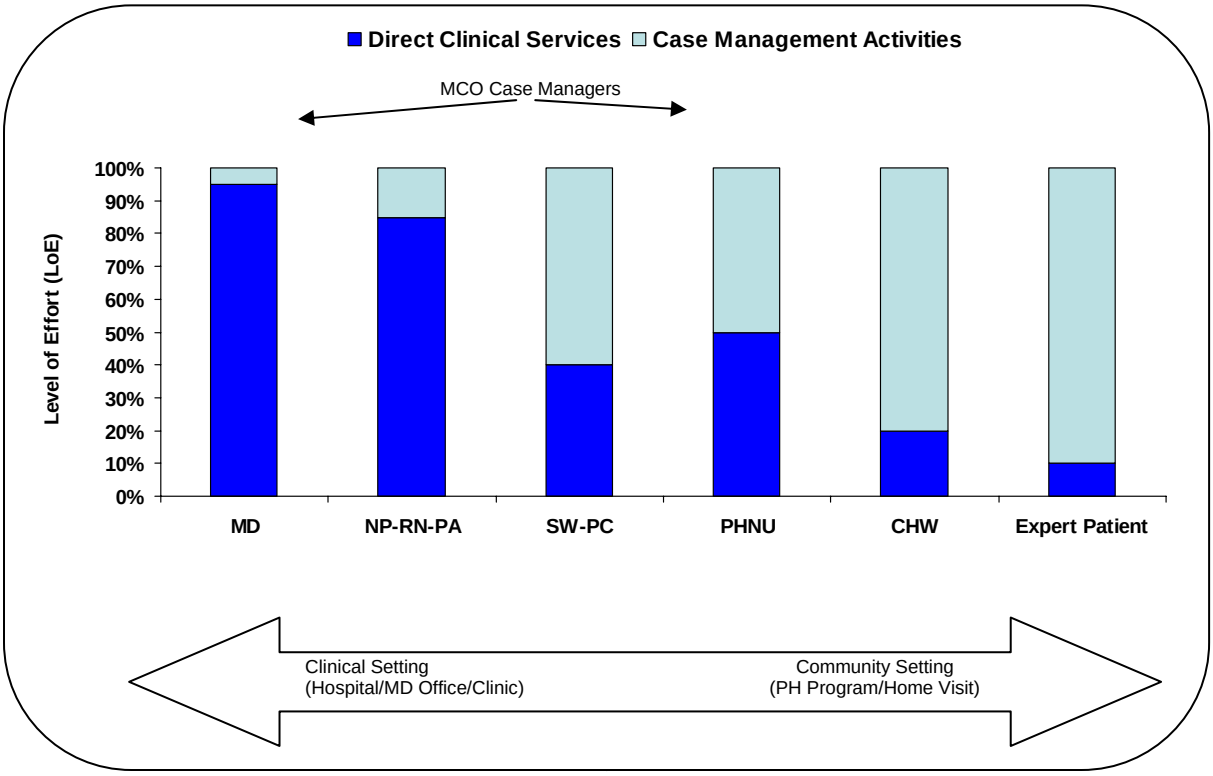
Generally, as shown in this illustration, the personnel with more health professions training are more likely to provide case management from within their clinical settings (e.g., physician's office, clinic, or hospital), whereas the community health work is more likely to work with families and clients community settings (e.g., home visits). With models for co-location of medical and social services being developed across the country, it has become more

likely that non-physician case management personnel work in clinical settings. In addition, nurse case managers working for managed care organizations may provide services via telephone or even the Internet.

The literature usually delineates between case management provided by a physician and services provided by non-physicians.[7] Case management by a physician often falls under the rubric of either the medical home or primary care case management models. The dual role of primary care physicians in many insurance plans as gatekeepers and case managers can lead to conflict as they both try to manage scarce resources and enable to patient to access all of the necessary resources.[8] Nurses in advance practice (e.g., pediatric nurse practitioners, family nurse practitioners, and certified nurse midwives) may serve as primary care providers and primary care case managers.[9] Other case managers, including registered nurses, social workers and others, more typically support patients in following a care plan and/or in securing other services. Again, as shown in Figure 2, the time, tasks, and venue of services tend to vary by type of case management provider.

[7] Silow-Carroll, S and T Alteras. 2004. "Stretching State Health Care Dollars: Care Management to Enhance Cost-Effectiveness." The Commonwealth Fund report #783.
[8] Azevedo, D. 1994. "Are We Asking too Much of Gatekeepers?" *Medical Economics* 71(7): 126-128.
[9] The Balanced Budget Act of 1997 (BBA, P.L. 105-33) encourages states to use primary care case managers and gave states an option to recognize these advanced practice nurses as primary care case managers.

Figure 2. Rethinking CM/CC as a Continuum of Care Coordination



Types of providers who perform CM activities from higher to lesser health professional training.
All must be "trained and competent to perform services, activities, and tasks within their scope of practice or job description and licensed/certified accordingly.

Key - MD: physician; NP-RN-PA: nurse midwife, nurse practitioner, physician assistant, registered nurse; SW-PC: social worker, psychological counselor; PHNU: public health/community health nurse; CHW: community health worker.

Studies have long shown the importance of having a routine source of care for children.[10] Recently, leading professional associations concerned with primary care have emphasized the importance of a "medical home." Case management or care coordination is a part of the function of a medical home. The American Academy of Pediatrics — in partnership with the Maternal and Child Health Bureau, Health Resources and Services Administration, DHHS — has defined a medical home for children as an approach to providing comprehensive primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[11] The National Committee for Quality Assurance (NCQA) has released an updated program designed to assess how medical practices are functioning, the Physician

[10] Starfield B and Shi L. The medical home, access to care, and insurance: a review of evidence. *Pediatrics*. 2004 May;1135 (Suppl):1493-8.
[11] American Academy of Pediatrics. http://www.aap.org/healthtopics/medicalhome.cfm (Accessed March 19, 2009.) Also see, Center for Medical Home Improvement. http://www.medicalhomeimprovement.org/ (Accessed March 19, 2009.)

Practice Connections® – Patient-Centered Medical Home™ (PPC®-PCMHTM). [12] These new medical home standards are aligned with the joint principles of the AAP, American Academy of Family Physicians (AAFP), American College of Physicians (ACP), and American Osteopathic Association (AOA), which define the key characteristics of the patient-centered medical home. Notably, while the AAP has accepted the joint principles for the patient-centered medical home, the emerging definitions vary somewhat from the traditional definition of a medical home for children. The joint principles focus more on the care process than the values that underly the traditional medical home concept for children.

The NCQA program includes nine standards for medical practices to meet, including use care coordination. The care coordination/care management/case management standard focuses on activities such as: a) disease management for important conditions, b) reminders about preventive services for clinicians, c) use of non-physician staff to manage patient care, d) care management, including care plans, assessing progress, addressing barriers to care, and e) care coordination and follow-up for patients. This standard suggests use of a full staff team in a health care practice, with roles for physicians, nurses, administrative, and others.

3. Case Management Coverage and Payment: In General and Under Medicaid

Depending in part on whether it is considered medical or administrative in nature, case management services might be reimbursable in one of three basic ways. This assumes the case management activities fit within an insurer's terms of coverage and payment.

- *As a stand alone class of coverage.* Because case management is a "hybrid" activity that arguably encompasses both health care and coverage administration, an insurer might recognize the cost as either clinical or administrative in nature. Federal Medicaid law recognizes case management activities in both categories.

- *As part of a broader case-driven or practice-driven health care activity.* Case management might be recognized and paid as incidental to a case-driven or practice-driven activity, such as a medical home case management function, support for a care plan, or built into a disease management treatment plan. Federal Medicaid law recognizes case management as a component of treatment, particularly in managed care or organized care arrangements.

- *As a component of administration costs.* Insurers may recognize utilization management as case management, and general case management, from a member management perspective, also may be a recognized cost of operation. Medicaid managed care organizations are paid to do both, and in the fee for service component of Medicaid, both activities are recognized for children, as part of general state plan administration and as a component of EPSDT administration.

[12] National Committee for Quality Assurance (NCQA). http://www.ncqa.org/tabid/631/Default.aspx (Accessed March 19, 2009.)

Depending on how the activity is covered or paid, the payment principles and methods can vary as well. The case management payment might be structured as:

- a component of a broader "bundled" set of procedures (e.g., a hospital stay, a global encounter in a federally qualified health center or rural health clinic, or part of a disease management case payment rate for an episode of care);

- a separate procedure that is paid separately in accordance with an administered or negotiated rate; or

- part of a monthly capitation fee (an amount paid to an insurer on a per enrollee basis, representing all covered services and payable costs).

- a salary paid to an employee of an insurer or a managed care entity

Many combinations of these classes of coverage and payment structures are in use today for children, and all approaches to recognizing and paying for case management are in use in Medicaid today. Such variations often are driven by the nature of the service, the service component, and the manner in which the activity will be carried out.

B. The Role of Case Management in Promoting Child Development

1. The Purpose of Case Management to Promote Child Development

Assuring optimal health and development for U.S. children depends upon a complex interaction of family support, health financing, access to health providers, and other determinants of health. From a public policy standpoint, low-income families need the support of public policies and programs that can help them carry out their role as their children's first caregiver and teacher. These needs are particularly great among lower income families who face higher health risks, and as a result, much of the case management experience in terms of coverage, payment, performance, and outcome, is found in the Medicaid program.

As summarized in the next section of this paper, the child health literature supports the proposition that case management (or equivalent services referred to as care coordination) can play a useful role in promoting access to appropriate health care for two groups of children:

- children whose health care needs fall within what an insurer might consider to be a "normal" range (i.e., do not have special health care needs) but who may experience access barriers related to geographical distance, language, culture, health literacy of a caregiver, or some other factor unrelated to medical care need.

- children whose health conditions place them above health norms, that is, who experience serious and chronic health conditions that elevate the challenges inherent in health management and are generally called children with special health care needs).

Medicaid provides health financing to children in low-income families, with eligibility extending to an estimate four out of ten infants and about one in three children between the ages of 1 and 5.[13] Given an economic downturn and financing to states for increased outreach to enroll eligible children, this proportion is likely to increase. The population of children enrolled in Medicaid is more likely than other children to need case management services, because of both social and medical needs.

Nearly 40 percent of children enrolled in Medicaid are at risk for developmental or behavioral problems.[14] These risks have a broad array of underlying causes. For example, developmental problems might be the result of: physical problems both inborn and acquired (e.g. hearing impairment, cognitive disabilities, and chronic illness) or psychosocial risk factors (e.g., maternal depression, abuse and neglect). A substantial proportion of children in Medicaid also have socio-demographic risks such as living in a family with low literacy. Multiple risk factors

[13] Rowland, D; A Salganicoff and PS Keenan. 1999. "The Key to the Door: Medicaid's Role in Improving Health Care for Women and Children." *Annual Review of Public* Health 20: 403-426; National Center for Children in Poverty, Columbia University Mailman School of Public Health. 2006. "Short Take No. 2: Maximizing the Use of EPSDT to Improve the Health and Development of Young Children."
[14] Schor et al, 2007.

have a compound effect on health status. Moreover, children with multiple risks and poorer health status are more likely to face barriers in access to health care.[15]

Young children growing in poor families often experience disadvantages that can compromise their health and development. Studies of poor U.S. families point to less adequate parenting, more limited access to quality health care,[16] lower quality early child care, and more exposure to violence and environmental hazards as particular risks to optimal development.[17] Low-income families, whose children face higher developmental risks, may need more services, and often face greater access barriers to care. National survey data indicate that low-income families seeking care for their children are more likely than middle/high income families to: have a "big problem" getting necessary care (2.4 vs. 1.0 percent) and have trouble getting a referral to a specialist (11.5 vs. 5.3 percent).[18] National survey data also show that poor and uninsured children are less likely to have a well-functioning medical home.[19] Thus the poor children eligible for Medicaid have an increased need for both developmental services and assistance in securing those services.

Because effective developmental interventions generally involve more than one provider or system of care (e.g., education, health, social services), linkages among health providers and other providers are critical to assuring that young children and their families receive needed services. Recent experience in more than half of the states indicates that families and pediatric primary care providers face challenges in assuring appropriate follow up for problems identified through well child examinations and developmental screening.[20] For families facing access barriers or in need of assistance in navigating the health care system, case management is an essential service.

Children with Special Health Care Needs

Children with special health care needs (CSHCN) "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and

[15] Stevens GD, Seid M, Mistry R, Halfon N. 2006. Disparities in primary care for vulnerable children: the influence of multiple risk factors. *Health Services Research*. 41(2):507-31.
[16] Stevens GD, Seid M, Mistry R, Halfon N. 2006. Disparities in primary care for vulnerable children: the influence of multiple risk factors. *Health Services Research*. 41(2):507-31.
[17] National Institute of Child Health and Human Development (NICHD) Early Child Care Research Network. 2004). Type of child care and children's development at 54 months. Early Childhood Research Quarterly, 19 (2), 203-230; NICHD Early Child Care Research Network. (2005). Early Child Care and Children's Development in the Primary Grades: Follow-Up Results from the NICHD Study of Early Child Care.. American Educational Research Journal, 42 (3), 537-570.
[18] Simpson L, Owens PL, Zodet MW, et al. 2005. "Health Care for Children and Youth in the United States: Annual report on patterns of coverage, utilization, quality, and expenditures by income," *Ambulatory Pediatrics.* 5(1):45-46.
[19] Stevens GD, Seid M, Pickering TA, Tsai KY. 2009. "National Disparities in the Quality of a Medical Home for Children." *Matern Child Health J*. Feb 12 [Epub ahead of print].
[20] Kaye N, May J, and Abrams M. 2006. S*tate Policy Options to Improve Delivery of Child Development Services: Strategies from the Eight ABCD States*. New York: The Commonwealth Fund.

related services of a type or an amount beyond that required by children generally."[21] Estimates of the prevalence of special needs ranges from 2 percent of children to over 30 percent, depending on the measurement tools, age of children, and criteria used.[22] The prevalence of chronic illness, disability and other special health needs among children has been increasing, and the distribution of the disease burden contributes to disparities in child health status by race/ethnicity and income.[23]

CSHCN use more health care services than other children, leading to higher costs for this group.[24] Given their need for enhanced medical care, these children, on average, have twice as many physician visits, five times the number of prescriptions, seven times the number of hospital days, and more emergency department and home health days annually than other children.[25] Newacheck et al., using MEPS data, found that compared with other children, CSCHN have, on average, health care expenditures three times as high.[26]

These high rates of utilization and expenditures underscore the need and potential benefits of care coordination[27] and case management for this population. According to the American Academy of Pediatrics, care coordination for CSHCN is defined as "a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care."[28]

There is also evidence of unmet need for case management (see Figure 4). In a national survey of the families of children with special health care needs, about half had a case manager (49 percent).[29] In addition, significant unmet need for case management services was reported,

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[21] This definition was developed by the Maternal and Child Health Bureau and endorsed by the American Academy of Pediatrics. McPherson, M; Arrango, P; Fox, H et. al. 1998. "A New Definition of Children with Special Health Care Needs." *Pediatrics* 102: 137-140.

[22] Mulvihill et al. 2007; Chernoff, Ireys, DeVet and Kim 2002; Wise, PH; Huffman, LC and G Brat. June 2007. "A Critical Analysis of Care Coordination Strategies for Children with Special Health Care Needs." AHRQ Publication No. 07-0054; Halfon, N; Olson, L and M Inkelas, et al. 2002. "Summary Statistics from the National Survey of Early Childhood Health." *National Center for Health Statistics, Vital Health Statistics* 15(3).

[23] Wise, Huffman and Brat 2007; Newacheck, P et al. 1998. "An Epidemiologic Profile of Children with Special Health Care Needs." *Pediatrics* 102: 117-123.

[24] Newacheck et al. 1998; Stein, RE and EJ Silver. 2002. "Comparing different Definitions of Chronic Conditions in a National Data Set." *Ambulatory Pediatrics* 2: 63-70.

[25] Newacheck, PW and SE Kim. 2005. "A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs." *Archives of Pediatric and Adolescent Medicine* 159: 10-17 (correction published in Vol. 159, April 2005, page 318).

[26] Newacheck, PW and SE Kim. 2005. "A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs." *Archives of Pediatric and Adolescent Medicine* 159: 10-17 (correction published in Vol. 159, April 2005, page 318).

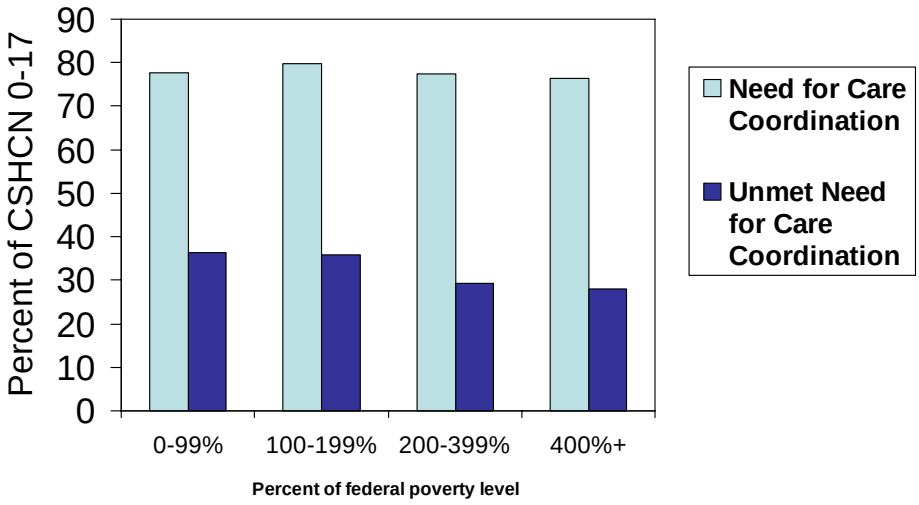
[27] Stille CJ, Antonelli RC. 2004. Coordination of care for children with special health care needs. *Curr Opin Pediatr.* 16(6):700-5.

[28] See, AAP, Committee on Children with Disabilities: Care Coordination: integrating health and related systems of care for children with special health care needs, *Pediatrics* , 1999 104(4) 978-981; AAP, Medical Home Initiatives for Children with Special Needs project Advisory Committee, The Medical Home. *Pediatrics* 2002 110:184-186; AAP, Care Coordination in the Medical Home: Integrating health and related systems of care for children with special health care needs, *Pediatrics.* 2005; 116(5) 1238-1244.

[29] Family Voices. February 2000. "The Health Care Experiences of Families of Children with Special Health Care Needs: Summary Report of Findings from a National Survey." http://www.familyvoices.org/pub/projects/Sum-rep-find.pdf

even among the families who indicated that they have access to a case manager.[30] An estimated 31.8 percent of all CSHCN reported unmet need for assistance coordinating their child's care, a figure which was higher for low-income families (36.3 percent) than for high-income families (28.1 percent).[31] Case management service needs for CSHCN increase with the complexity of the patient's health condition. One study of CSHCN in Alabama found that as the severity and complexity of the patient's condition increases, the strain on family resources and relationships with providers is worsened, indicating need for case management.[32] Another study reinforced these findings: the severity of the child's condition, inadequate provider communication, and lack of insurance are associated with higher need for case management among CSHCN in Illinois.[33]

Figure 4. Unmet Need for Care Coordination among Children with Special Health Care Needs, By Income, United States, 2005



Source: National Survey of Children with Special Health Care Needs

[30] Ibid.
[31] The Health Resources and Services Administration. 2001. National Survey of Children with Special Health Care Needs, Chartbook. Available at <http://mchb.hrsa.gov/chscn/pages/coordination.htm>
[32] Mulvihill, BA; Wingate, MS; Altarac, M; Mulvihill, FX; Redden, DT; Telfair, J; Pass, MA and DE Ellis. 2005. "The Association of Child Condition Severity with Family Functioning and Relationship with Health Care Providers Among Children and Youth with Special Health Care Needs in Alabama." *Maternal and Child Health Journal* 9(2 suppl): S87-97.
[33] Rosenberg, G; Onufer, C; Clark, G; Wilkin, T; Rankin, K and K Gupta. 2005. "The Need for Care Coordination Among Children with Special Health Care Needs in Illinois." *Maternal and Child Health Journal* 9(2 suppl): S41-47.

A survey of physicians found that the main barriers cited to providing adequate case management are lack of time, lack of staff, lack of community of government agencies with services in their area, lack of training, and lack of administrative support. More than half of the physicians surveyed acknowledged unmet need for case management services for their patients.[34]

Healthy People 2010 set a goal for all CSHCN to be cared for in a medical home that provides coordinated, ongoing, and comprehensive care.[35] [36] The American Academy of Pediatrics affirms that medical homes are critically important for CSHCN, and has called for increased family involvement in decision making about medical options and long-term planning.[37] There is a model of medical home improvement, especially useful for practices that serve CSHCN, developed by the Center for Medical Home Improvement at Dartmouth Medical Center.[38]

Children Who Experience Other Barriers in Access to Care

Some children without special health care needs experience barriers to receiving appropriate and adequate care, and thus can benefit from case management. Simply being insured does not guarantee access to care, especially in medically underserved communities. One set of barriers relates to provide supply, where communities may have an insufficient supply of primary and/or specialty care providers, an insufficient supply of health providers who accept Medicaid, or both. Another set of obstacles are faced by families who seek care for their children but do not speak English, have low literacy, or have low health literacy. Case managers can help to overcome these and other physical, social, or cultural barriers to health care.

A study by Riportella-Muller et al., which interviewed parents about barriers to their child's access to EPSDT services, found that in addition to financial barriers, nonfinancial issues prevent families and children from accessing care. Some reasons were general, such as limited time and resources and other urgent priorities, and some were related to interaction with the health care system. Inadequate outreach efforts, scheduling difficulties, problems with transportation, and a lack of a perceived need for well-child checkups loomed large for the families interviewed, underscoring that even when families are aware of available services and there are no financial barriers, they may need the services of a case manager to enable access to care.[39]

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[34] Gupta, V; O'Connor, K and C Quezada-Gomez. 2004. "Care Coordination Services in Pediatric Practices." *Pediatrics* 113(5): 1517-1521.

[35] United States Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health* 2nd ed. Washington DC: Department of Health and Human Services, 2000.

[36] Perrin JM, Romm D, Bloom SR, Homer CJ, Kuhlthau KA, Cooley C, Duncan P, Roberts R, Sloyer P, Wells N, Newacheck P. 2007. A family-centered, community-based system of services for children and youth with special health care needs. Arch Pediatr Adolesc Med. 161(10):933-6.

[37] American Academy of Pediatrics Medical Homes Initiatives for Children with Special Needs Project Advisory Committee. 1992. "The Medical Home" *Pediatrics* 90:774.

[38] Cooley, WC and JW McAllister. 2004. "Building Medical Homes: Improvement Strategies in Primary Care for Children with Special Health Care Needs." *Pediatrics* 113(5): 1499-1506.

[39] Riportella-Muller, R; Selby-Harrington, ML; Richardson, LA; Donat, PL; Luchok, KJ and D Quade. 1996. "Barriers to the Use of Preventive Health Care Services for Children." *Public Health Reports* 111: 71-77.

Children in low-income families are more likely to be affected by all of these barriers, having a bigger problem than middle and high income families accessing necessary care, getting referred to a specialist, and communicating effectively with the provider.[40] Children who are uninsured, low income, African American, and disabled are less likely to have a medical home that includes an element of care coordination.[41]

An in-depth study of twenty general pediatric practices using care coordination activities for patients of all complexity levels using a care coordination measurement tool found that the presence of acute, family-based social stressors was a significant driver of need for care-coordination activities. Children and youth with special health care needs with acute-onset, family-based psychosocial problems experienced 14% of the care-coordination activity encounters and used 21% of the care coordination activities minutes. Regardless of special health needs, those with family social stressors were 24 percent of patients served but required 41% of the care coordination minutes. These findings suggest that the presence of family social stressors is at least as important as the presence of a special health care need in assessing the need for care coordination services. Notably, a substantial share (44%) of care coordination was to arrange for referrals and services among different providers, community-based organizations, and agencies.[42]

Prenatal and infant care case management is another critical service that is more likely to be needed, and less likely to be received, by vulnerable and disadvantaged populations. States have utilized Medicaid case management funds to provide prenatal care since 1986. Both home-based and clinic-based prenatal and postpartum care programs have been developed by states, and Medicaid funds are available when the programs are considered medical, not social, interventions.

C. The Benefits of Case Management

There are many studies demonstrating the benefits of linking children with needed health and developmental services.[43] Childhood is a critical period in an individual's lifetime, and access to adequate appropriate care is crucial to start every individual on the path to a healthy and productive life. Prompt and early identification of physical and mental problems and delays, followed by intervention, can make a significant difference in the individual's future stock of

[40] Simpson, L; Owens, PL; Zodet, MW; Chervrley, FM; Dougherty, D; Elixhauser, A and MC McCormick. 2005. "Health Care for Children and Youth in the United States: Annual Report on Patterns of Coverage, Utilization, Quality, and Expenditures by Income." *Ambulatory Pediatrics* 5(1): 45-46.

[41] Mulvihill 2007; Strickland, B; McPherson, M; Weissman, G; van Dyck, P; Juang, ZJ and P Newacheck. 2004. "Acccess to the Medical Home: Results of the National Survey of Children with Special Health Care Needs." *Pediatrics* 113(5 suppl): 1485-1492; Nageswaran, S; Roth, MS; Kluttz-Hile, CE and A Farel. 2006. "Medical Homes for Children with Special Healthcare Needs in North Carolina." *North Carolina Medical Journal* 67(2): 103-109.

[42] Antonelli RC, Stille CJ, Antonelli DM. 2008. Care coordination for children and youth with special health care needs: a descriptive, multisite study of activities, personnel costs, and outcomes. *Pediatrics*. 122(1):e209-16.

[43] Starfield B and Shi L. The medical home, access to care, and insurance: a review of evidence. *Pediatrics*. 2004 May;113(5 Suppl):1493-8; Wise PH. 2007. The Transformation of Child Health in the United States. *Health Affairs* 23(5):9-25.

health as well as health care expenditures for the duration of their lifespan. Effective interventions exist for nearly every identifiable condition.[44]

Case management may be particularly useful in assuring and promoting optimal development. When a developmental problem is suspected, young children often fall into the gaps between different health coverage plans, health care providers, and mental health, child development, and early childhood education programs.[45] For example, screening might occur in a doctor's office, child care center, WIC nutrition site, health department immunization clinic, nurse home visit, or early intervention program office. Since more than 80 percent of young children had a well-child visit within the past year,[46] most often and for most children, developmental problems can be detected at visits to a pediatric primary care provider.[47] When pediatric primary care providers identify a concern through developmental screening, they need information about where to refer a child for further diagnostic assessment and intervention; however, they may have limited knowledge of community resources.

The benefits of case management have been examined by several types of studies, although the interventions often include other elements, so it can be difficult to isolate the benefits attributable to case management alone. The versatility of the term 'case management' means that the literature explores the various meanings of the term, often in different contexts, for different outcomes, and for different populations.

An evaluation using claims data of a fee-for-service managed care program that included a primary care medical home component found that pediatric patients used more ambulatory primary care and reduced hospitalization, both avoidable and emergent.[48]

Evaluations of case management programs for maternal prenatal care, as well as infant care and screening, also find benefits as well as cost-effectiveness. Since 1986 states have been using Medicaid to provide case management to pregnant women and mothers of newborns in order to increase appropriate use of prenatal care and improve infant health. North Carolina was a pioneer in developing a maternal case management program, and utilized a clinic-based approach. An evaluation showed that the program was effectively meeting its goals and also that it was cost-effective.[49] Evaluations of efforts in South Carolina also have shown positive results.

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[44] Shonkoff, JP and Phillips DA, Eds. 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development.* Washington DC: National Academy Press.

[45] Johnson K and Knitzer J. 2005 *Spending Smarter*, New York, NY: National Center for Children in Poverty; Rosenthal J and Kaye N. 2005. *State Approaches to Promoting Young Children's Healthy Mental Development: A Survey of Medicaid, and Maternal and Child Health, and Mental Health Agencies*, Portland, ME: National Academy of State Health Policy.

[46] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. 2006. *Child Health USA 2006*, (Rockville, MD: U.S. Department of Health and Human Services.

[47] Sices L et al. 2004. "How do Primary Care Physicians Identify Young Children with Developmental Delays? A National Survey with an Experimental Design," *Pediatrics*; 113(2):274-282; Halfon N, Regalado M, Sareen H, et al. 2004. "Assessing development in the pediatric office," *Pediatrics* 113(6):1926–33.

[48] Gadomski, A; Jenkins, P and M Nichols. 1998. "Impact of a Medicaid Primary Care Provider and Preventive Care on Pediatric Hospitalization." *Pediatrics* 101(3): e1-e11.

[49] Buescher, PA; Roth, MS; Willimas, D and CM Goforth. 1991. "An Evaluation of the Impact of Maternity Care Coordination on Medicaid Birth Outcomes in North Carolina." *American Journal of Public Health* 81(12): 1625-1629; Buescher, PA and NI Ward. 1992. "A Comparison of Low Birth Weight Among Medicaid Patients of Public Health Departments and Other Providers of Prenatal Care in North Carolina and Kentucky." *Public Health Reports*

One study found a benefit to infants in terms of preventive care utilization.[50] Kentucky, on the other hand, utilizes a home-based prenatal care program, and outcomes such as birth weight are improved.[51] A review of care management programs concluded that Medicaid should be required to provide intensive, individualized prenatal and postpartum care to high risk women (e.g., medical risks, adolescents), including home visits, health education, nutrition counseling, and linkages to clinical prenatal and postpartum care.[52]

Many evaluations focus solely on CSHCN. A meta-analysis of care coordination for CSHCN prepared for the Agency for Healthcare Research and Quality noted a paucity of studies, but most of the seven studies identified indicate modest but positive effects of care coordination.[53] A review of studies examining psychosocial interventions for children with chronic illness notes modest positive effects of the interventions; children and their families were better able to cope with social and psychological aspects of their health condition.[54]

Three randomized, controlled trials of interventions that include case management components for CSHCN show benefits. One study by Chernoff et al. placed children with chronic conditions in a "family support" intervention through their pediatric clinic found that the program decreased the likelihood of mental health problems and improved the functional adjustment of children with chronic conditions, especially those with physical self-esteem problems.[55] A second study by Pless et al. focused on psychosocial functioning and found that case management in specialty clinics was likely to improve the adjustment of children with chronic disorders, although the study had mixed results.[56] Criscione et al. placed individuals with developmental disabilities in a hospital-based program with inpatient and outpatient elements, and found that length of stay and hospital charges fell for the treatment group. The program is estimated to have saved over $200,000 over the three year duration of the experiment.[57]

Evaluations of interventions (not randomized, controlled studies) that include a case management component also point to benefits. Palfrey et al. examined a medical home intervention in six private pediatric practices, based on the Pediatric Alliance for Coordinated

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107(1): 54-59; Buescher, PA; Smith, C; Holliday, JL and RH Levine. 1987. "Source of Prenatal and Infant Birth Weight: the Case of a North Carolina County." *American Journal of Obstetrics and Gynecology* 156(1): 204-210.

[50] Elizabeth A. Erkel EA, Morgan EP, Staples MA, Assey VH, Michel Y. 2007. Case Management and Preventive Services Among Infants from Low-Income Families. *Public Health Nursing*. 11(5):352-360.

[51] Buescher, PA and NI Ward. 1992. "A Comparison of Low Birth Weight Among Medicaid Patients of Public Health Departments and Other Providers of Prenatal Care in North Carolina and Kentucky." *Public Health Reports* 107(1): 54-59.

[52] Meyer J and Smith B. 2008. Chronic Disease Management: Evidence of Predictable Savings. Health Management Associates.

[53] Wise, Huffman, and Brat 2007.

[54] Bauman, LJ; Drotar, D; Leventhal, JM; Perrin, EC and IB Pless. 1997. "A Review of Psychosocial Interventions for Children with Chronic Health Conditions." *Pediatrics* 100: 244-251.

[55] Chernoff, RG; Ireys, HT; DeVet, KA and YJ Kim. 2002. "A Randomized, Controlled Trial of a Community-Based Support Program for Families of Children with Chronic Illness: Pediatric Outcomes." *Archives of Pediatric and Adolescent Medicine* 156: 533-539.

[56] Pless, IB, Feeley, N; Gottleib, L; Rowat, K; Dougherty, G and B Willard. 1994. "A Randomized Trial of a Nursing Intervention to Promote the Adjustment of Children with Chronic Physical Disorders." *Pediatrics* 94(1): 70-75.

[57] Criscione, T; Walsh, KK and TA Kastner. 1995. "An Evaluation of Care Coordination in Controlling Inpatient Hospital Utilization of People with Developmental Disabilities." *Mental Retardation* 33(6): 364-373.

Care model, and found strong evidence of increased parent satisfaction with primary care. Findings also indicated that health outcomes improved and disease burden was eased, at an estimated annual cost of only $400 per patient. Patients with the most severe needs benefit the most from being placed in a medical home with case management.[58] The same medical home model was used by Farmer et al. in university-affiliated primary care practices, and the authors found some positive results—reduced absence from school and work, decreased caregiver strain, and led to fewer ambulatory care visits. But mixed results were found for parental satisfaction, and hospitalizations did not decrease.[59]

Liptak et al. evaluated a hospital-based case management program providing ambulatory care coordination for children with chronic conditions and found that admissions, length of stay, and inpatient charges were reduced by the program. The program, financed by a local insurance carrier, saved $77.7 million in inpatient care over a ten-year period, representing a return on investment of more than ten-fold. More than half of the activities conducted during the intervention were not eligible for reimbursement under fee-for-service.[60]

Fields et al. examined a case management program administered by a community-based home care agency for technology-dependent children residing at home and found no impact on outcomes, cost, or utilization of health care services. (These findings may be expected for a group of children who have lifelong needs for technologically and medically complex care.) However, parental satisfaction was high, especially since the program was viewed as integral to enabling the children to be cared for at home.[61]

Many evaluations are of interventions that do not focus solely on pediatric patients. Care management, a closely related topic that encompasses disease management programs, has been shown to be cost-effective in evaluations of pilot programs.[62] These activities are designed to improve the quality of care and reduce the costs of care for chronic diseases. Generally, care management or disease management programs have been designed for adult-focused chronic diseases (e.g., heart failure disease). A smaller number have been used for management of chronic disease in childhood (e.g., asthma).[63]

Finally, Medicare conducted fifteen demonstration programs focusing on adults that included a variety of care coordination interventions in a variety of settings, and found some

[58] Palfrey et al. 2004.
[59] Farmer, JE; Clark, MJ; Sherman, A; Marien, WE and TJ Selva. 2005. "Comprehensive Primary Care for Children With Special Health Care Needs in Rural Areas." *Pediatrics* 116(3): 649-656.
[60] Liptak, GS; Burns, CM; Davidson, PW and McAnarney, ER. 1998. "Effects of Providing Comprehensive Ambulatory Services to Children with Chronic Conditions." *Archives of Pediatric and Adolescent Medicine* 153: 1003-1008.
[61] Fields, AI; Coble, DH; Pollack, MM and J Kaufman. 1991. "Outcome of Home Care for Technology-Dependent Children: Success of an Independent, Community-Based Case Management Model." *Pediatric Pulmonology* 11(4): 310-317.
[62] Silow-Carroll and Alteras 2004; Margolis PA, Stevens R, Bordley WC, et al. 2001. "From concept to application: the impact of a community-wide intervention to improve the delivery of preventive services to children," *Pediatrics* 108(3):E42.
[63] Meyer and Smith 2008.

positive effects, mostly in terms of health literacy and patient and provider satisfaction with the care process.[64]

There is also a body of literature examining the impact of managed care, especially Medicaid managed care's effects on CSHCN. Results are generally mixed and outside the scope of this report.[65]

[64] Brown, R; Schore, J; Archibold, N; Chen, A; Peikes, D; Sautter, K; Lavin, B; Aliotta, S and T Ensor. 2004. "Coordinating Care for Medicare Beneficiaries: Early Experiences of 15 Demonstration Programs, Their Patients, and Providers." Mathematica Policy Research Inc. Report to Congress, CMS Contract Number 500-95-0047(09).
[65] Wise, Huffman and Brat 2007.

Examples of Current Uses of Medicaid Financing for Case Management

Primary care case management to support the medical home

The American Academy of Pediatrics and other medical societies stress the importance of having a routine source of primary care and, particularly for children, having a primary care provider who accepts responsibility for coordination and overall management of health services. The primary care case management (PCCM) model is a type of managed care in which a provider assumes such responsibility and is paid a small fee for administrative time/services. PCCM is intensively used by many State Medicaid agencies for pediatric care (e.g., Connecticut, Illinois, and Texas). In some states, these activities are fulfilled under Medicaid contracts with managed care organizations, while in others the relationship is defined by an agreement between the state and the provider practice or clinic. In most instances, the "case management" activities are of an administrative nature and are not financed using medical case management dollars.

EPSDT Informing, Outreach, and Case Management

Since the enactment of EPSDT, State Medicaid agencies have faced challenges in their attempts to effectively carry out their statutory obligations to provide outreach and informing, as well as assistance with scheduling and transportation. Over the years, many State Medicaid agencies have used Title V Maternal and Child Health Programs to assist in carrying out these obligations. One approach is to reimburse for time spent in assisting families in appropriate use of the EPSDT benefit. Activities might include reminder and recall activities to help reduce missed appointments or contacts to reconnect with families whose children are overdue for an EPSDT (well-child) screening visit. Such local EPSDT coordinators also have the time, capacity, and capability to assist providers making referrals to community services. Typically the staff are public health nurses or social workers, employed by a local health department. In some states, these activities are fulfilled under Medicaid contracts with managed care organizations, with case management administration built into the premium along with other administration factors.

Case management for children with special health care needs

Virtually every State has care coordination/case management for CSHCN supported by Title V dollars. In most states, some care coordination/case management for CSHCN is funded by Medicaid, sometimes under Title V-Title XIX agreements and other times just as services billed by providers outside of a formal interagency structure. In addition, some States' Medicaid agencies have structured contracts with managed care organizations (MCOs) specifically to assure that the services and care coordination/case management needed for CSHCN and their families will be provided. In a smaller number of states, Title V agencies have contracts with private entities such as "Parent-to-Parent" family support organizations or university centers. While they are sometimes strictly administrative in nature, care coordination/case management for CSHCN is more likely to fall under the medical assistance case management.

Maternity and Infant Care Coordination/Case Management

Since the mid-1980s states have been using their option to design Medicaid targeted (medical assistance) case management benefits for pregnant women and mothers of newborns in order to increase appropriate use of prenatal care and improve infant health. North Carolina was among the first States to develop such a benefit and that approach was found to be effective and cost effective. These services are often delivered through home visits. Many other States developed similar programs, typically using a combination of Medicaid and Title V funding. Providers tend to be nurses and social workers, who may be working for a local public health department, a private visiting nurses association, or a private, non-profit home visiting program.

PART 2. THE LEGAL BASIS FOR MEDICAID CASE MANAGEMENT SERVICES FOR CHILD HEALTH AND DEVELOPMENT

A. Case Management Practice and Federal Medicaid Law

The preceding section of this policy brief considers the range of activities and interventions that together can be thought of as "case management practice." This section explores the legal basis for case management practice in Medicaid. Because Medicaid is a complex statute, several provisions of law come into play.

Many of the specific interventions and activities that fall within case management practice historically have been encompassed within the various provisions of the federal Medicaid statute. In recent years, much attention has been given to how states have implemented and claimed federal financing for one specific type of case management practice (i.e., "case management" as a defined class of medical assistance). But case management practice within Medicaid is far older than this particular benefit class, which was added to the law in 1986[66] and a discussion of what the law permits where case management practice is concerned necessarily extends well beyond this particular provision.

How federal Medicaid law recognizes and permits payments for case management practice is an important one in child health and development because, as the preceding section documents, case management is associated with both higher quality health care and better child health and developmental outcomes. Evidence regarding the value of case management suggests that effective case management practices extend beyond the incidental patient management activities that are part of any routine clinical care (e.g., medical charting and notes; patient communication incidental to the clinical procedures that are the subject of the visit). Indeed, the literature on case management suggests that case management is now recognized as a set of skills and competencies in their own right, with interventions of various length and intensity depending on the level of consumer or patient need (e.g., social; social and clinical; social and complex clinical).

In approaching the issue of what federal Medicaid law permits in terms of case management practice in a child health and development context, it is important to bear in mind that case management is not a single procedure but instead a range of interventions and activities that take on different purposes and tasks depending on the health and social conditions of the child and family to be assisted (see Figures 1 and 2 above). Viewed in this manner, the legal issue thus becomes the permissibility of federal funding for case management practices, not simply the much narrower question of whether a specific service class known as "case management" exists and if so, what can be billed to that service class.

For example, assuring appropriate utilization of care is commonly associated with case management practice; in federal Medicaid statutory parlance however, the term is known as "utilization management."[67] Similarly, arranging for transportation and assuring that an

[66] §sec 1980(a)(19) as added by Pub. L. 99-509 (The Omnibus Budget Reconciliation Act of 1986)
[67] 42 U.S.C. §1396a(a)(30)(A)

appointment is kept is a basic aspect of case management practice; at the same time, these activities are required of all states in the case of children under 21.[68]

Where case management and children are concerned, the basis for a broad interpretation of the law can be found in Medicaid's special purposes in relation to child health. All children are entitled under Medicaid to Early and Periodic Screening, Diagnosis and Treatment (EPSDT), an unusually comprehensive range of health care services whose purpose is the provision of "early" assessments, diagnosis and treatment in order to "ameliorate" (i.e., lessen the effects of) physical and mental health conditions that otherwise would delay growth and development.[69] The purpose of EPSDT is preventive; as a result, states' administrative obligations transcend coverage alone, and actually encompass administrative practices that produce access. These administrative obligations, which have been part of the federal Medicaid statute since 1981 and part of federal law since 1972,[70] necessarily encompass a range of case management practices tailored to the needs of eligible children.

Thus, in examining the statute in relation to case management, it is important to identify both those provisions that bear on *case management-related activities* (as understood from modern case management practice), as well as those provisions that explicitly refer to case management as a distinct class of activity.

Even a cursory review of U.S. Department of Health and Human Services (DHHS) policies on the subject underscores that much of the confusion over what the federal Medicaid statute might permit regarding federal financial participation in activities that fall within case management practice lies in the absence of comprehensive policies. DHHS has never developed a unified approach to interpreting Medicaid in a case management context. DHHS policies (both within CMS, which oversees Medicaid and in other parts of the Department) tend to be reactive and piecemeal and lack a clear overarching policy framework. DHHS pronouncements have been in response to specific events such as Congressional legislation or matters involving state program administration. Collectively the various DHHS policy statements on case management practice are not presented as an integrated whole; instead they address one aspect of the topic or another, and they are scattered across various publications: limited regulations;[71] isolated state

[68] 42 U.S.C. §1396a(a)(43); 42 C.F.R. §441.62.

[69] Rosenbaum S, Maurey DR, Shin P, and Hidalgo. 2005 *National Security and U.S. Child Health Policy: The origins and continuing role of Medicaid and EPSDT*. Washington, DC: George Washington University.; Rosenbaum S and Wise P.2007. Crossing the Medicaid-Private Insurance Divide: The case of EPSDT. *Health Affairs*. 26(2):382-392; Rosenbaum S and Johnson K. 1986. "Providing Health Care for Low-income Children: Reconciling Child Health Goals with Child Health Financing Realities." *Milbank Quarterly*. 64:422-478.

[70] The EPSDT benefit itself dates to 1967. In 1981 Congress amended the Medicaid statute to add the service obligations that previously had been part of the Aid to Families with Dependent Children program, thereby broadening the reach of the obligation to all Medicaid eligible children and making the duty to provide access to services a direct state plan administration requirement. See P.L. 97-35, Medicare and Medicaid Amendments of 1981, §2181(a)(2)(C).

[71] See, e.g., 72 Fed. Reg. 68077-68093 (Optional State Plan Case Management Services). The American Recovery and Reinvestment Act of 2009 (P.L. 111-5) subjects these regulations to a Congressional moratorium, in effect until June 30, 2009. Separate regulations define primary care case management (42 C.F.R. §441.168) case management as part of home and community based services (42 C.F.R. §440.180(b)). Additional regulations specify covered services relevant to case management practice as part of EPSDT (42 C.F.R. §441.56 and 441.60).

Medicaid directors letters addressing case management as a form of medical assistance,[72] manual instructions and policy transmittals (which explicitly recognize administrative case management in a child health context);[73] numerous specific state agency audits performed by the DHHS Office of the Inspector General (typically involving medical assistance case management);[74] and specific rulings by the DHHS Departmental Appeals Board.[75] The result is a legal and policy hodgepodge that creates confusion and acts as a disincentive to a well defined approach to case management practice. The same is true with other official analyses, which similarly tend to consider isolated dimensions of the question but do not assess the full legal basis of case management practice.[76]

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[72] See. e.g., State Medicaid Directors Letter 01-013 regarding medical assistance targeted case management services in the context of child welfare and Medicaid. http://www.cms.hhs.gov/smdl/downloads/smd011901c.pdf (Accessed March 2, 2009)

[73] See for example, State Medicaid Manual §5230 related to EPSDT and case management:
5230. COORDINATION WITH RELATED AGENCIES AND PROGRAMS

Interagency collaborative activities address several goals simultaneously: o Containing costs and improving services by reducing service overlaps or duplications, and closing gaps in the availability of services; o Focusing services on specific population groups or geographic areas in need of special attention; and o Defining the scope of the programs in relation to each other.

Regulations require Medicaid agencies to coordinate services with title V programs, and enter into arrangements with State agencies responsible for administering health services and vocational rehabilitation services and with title V (Maternal and Child Health) grantees. Coordination includes child health initiatives with other related programs, such as Head Start, the Special Supplemental Food Program for Women, Infants and Children (WIC), school health programs of State and local education agencies (including the Education for all Handicapped Children Act of l975), and social services programs under title XX.

Federal financial participation (FFP) is available to cover the costs to public agencies of providing direct support to the Medicaid agency in administering the EPSDT program. There is no single "list of approved roles", but cooperating agencies provide a variety of outreach, screening, diagnostic or treatment services, health education and counseling, **case management**,[emphasis given] facilities, funding, and other help in achieving an effective child health program. State and local program managers can help identify available child health resources and make appropriate cross referrals. Active child health coordinating committees, with representation from providers, private voluntary and public agencies are helpful in promoting cooperation in providing health services.

Written agreements are essential to effective working relationships between the Medicaid agency and agencies charged with planning, administering or providing health care to low-income families. Although agreements by themselves do not guarantee open communication and cooperation, they can lay the groundwork for collaboration and best use of each agency's resources. Successful relationships are based upon detailed planning, clearly identified roles and responsibilities, program monitoring, periodic evaluation and revision, and constant communication. Agreements are formal documents signed by each agency's representative or written statements of understanding between units of a single department. Whatever their form, it is essential that their content be developed by all parties involved and that they provide a clear statement of each agency's responsibilities.

[74] http://search2.google.cit.nih.gov/search?q=medicaid+case+management&site=OIG&client=OIG_frontend&proxystylesheet=OIG_frontend&output=xml_no_dtd&filter=0&getfields=*&btnG.x=8&btnG.y=10 (Accessed on March 2, 2009.)

[75] A Google search using the terms "Medicaid" and "case management" reveals more than 800 separate rulings, a number of which relate to claims for federal financing related to case management expenditures. See, e.g., DAB Decision 2177 (Nebraska Department of Health) which recognizes case management as an administrative activity under EPSDT but disallowed Nebraska's claim for FFP as untimely filed

[76] See, e.g., CRS Report for Congress, *Medicaid Targeted Case Management (TCM) Benefits (March 27, 2008);* GAO, Department of Health and Human Services, Centers for Medicare and Medicaid Services, Optional State Plan Case Management Services (B310919, 2007)

B. The Medicaid Statute and the Three Legal "Legs" of the Case Management Practice "Stool"

Case management practice as a federally reimbursable set of activities is reflected in numerous provisions of the federal Medicaid statute, which can be categorized as follows: (1) the provisions that govern **program administration** activities associated with case management practice; (2) provisions related to case management as a **distinct class of medical assistance**; and (3) and provisions relevant to case management as an **incidental component** of a class of covered professional, clinical, or institutional services or as a dimension of managed care.

A. Statutory Provisions Governing Program Administration

Case management practice to support care for specific beneficiaries can be a component of state plan administration.

1) *In general: case management practice related to efficient program administration, utilization management, and administration in the best interest of recipients.*

- The statute requires that state Medicaid programs "provide such methods of administration . . . as are found by the Secretary to be necessary to be necessary for the proper and efficient administration of the [state plan for medical assistance.]"[77]

- The statute also specifies that state plans must "provide[ ] such methods and procedures relating to the utilization of, and payment for care and services . . . as may be necessary for to safeguard against unnecessary utilization of such care and services and to assure that payments are consistent with efficiency, economy, and quality of care. . ."[78]

- In addition, state Medicaid programs must "provide such safeguards as may be necessary to assure that . . . care and services will be provided in a manner consistent with simplicity of administration and the best interests of the recipients."[79]

Taken together, these state plan administration provisions appear to support federal financial assistance for case management practices related to the efficient utilization of care including utilization review and service planning, as well as practices that are in the best interest of children by promoting access to necessary care and services. Indeed, federal regulations require that all state plans for medical assistance "include a description of the methods and standards used to assure that services are of high quality,"[80] and permit states to employ utilization management mechanisms linked to the medical necessity of care.[81]

[77] 42 U.S.C. §1396a(a)(4)(A)
[78] 42 U.S.C. §1396a(a)(30)(A)
[79] 42 U.S.C. §13296a(a)(19)
[80] 42 C.F.R. §440.260
[81] 42 C.F.R. §440.230

2) Case management practice related to state plan administration duties involving coordination of Medicaid and WIC.

- Where child nutrition is concerned, federal law specifically requires state agencies to coordinate their activities with those of the Special Supplemental Food Program for Women, Infants and Children (WIC).[82] This coordination requirement builds on Medicaid's emphasis on preventive child health services that achieve proper child health and development and that ameliorate the effects of physical or mental health conditions that could affect child health.

Thus, case management practices related to enrollment in WIC and retention of benefits, review of information regarding a child's medical and nutritional status, and modification of care plans to promote the use of nutritional services would appear to fall within this provision of the statute.

3) Case management practices related to state plan administrative obligations related to the EPSDT service obligation

- State agencies are required to provide or arrange for the provision of screening services as well as to arrange for treatment services.[83]

- Implementing regulations specify that states must "coordinate" with related programs and assist children and families secure uncovered but needed services from related programs including health, educational, and social programs.[84]

- The state Medicaid Manual specifies coordination and case management as intrinsic elements of the EPSDT administrative obligation[85]

4) Coordination with Title V Maternal and Child Health Agencies

- State Medicaid agencies must "provide to the extent prescribed by the Secretary, for entering into agreements with any agency, institution, or organization receiving payments under (or through an allotment under) Title V . . . making such provision as may be appropriate for reimbursing such agency, institution, or organization for the cost of any care and services furnished any individual for which payment would

[82] 42 U.S.C. §1396a(a)(11)(C); 42 C.F.R. §431.635
[83] 42 U.S.C. §1396a(a)(43)(B) and (C).
[84] 42 C.F.R. §441.61 (c) requires that state Medicaid agencies must "make appropriate use of state health agencies, state vocational rehabilitation agencies and Title V grantees. Further, the agency should make use of other public health, mental health, and education programs and related programs such as Head Start, Title XX, the Special Supplemental Food Program for Women, Infants and Children(WIC) to ensure an effective child health program. The regulations do not define what activities qualify for federal financial assistance in relation to "making use" but clearly the activities that fall within the "making use" category would also represent activities within the broader rubric of case management for individual patients, since EPSDT is an individual entitlement that requires coverage and care within the specific needs of individual children.
[85] State Medicaid Manual §5230, supra, note 8

> otherwise be made to the state with respect to the individual under §1903 [relating to federal financial participation for both medical assistance and administrative services][86]

This provision, which has been further implemented by regulation,[87] appears to envision a cooperative arrangement between Medicaid and the Title V maternal and child health agencies and its sub-recipients, for payment by Medicaid for the cost of services furnished to Medicaid beneficiaries if such services represent an activity for which federal financial participation is available under the statute. Because EPSDT administration is an activity for which federal payment is available as an administrative service necessary for the efficient operation of the state plan, child development related case management practice overseen by Title V agencies would appear to fall within the ambit of this provision.

5) Federal Financial Participation for State Plan Administration Related to Case Management Practice

Federal financial participation for state plan administration is governed by numerous provisions of law, including both general federal laws governing federal payments for program administration, as well as specific provisions within the Medicaid statute that specify payment at certain rates. Federal financial participation is typically available at a 50% contribution level; when administrative activities related to case management practice are carried out by skilled medical professionals and requisite standards are met,[88] federal financial participation is available at 75%.

B. Statutory Provisions Governing Case Management as a Distinct Class of Medical Assistance

Federal law recognizes case management as a specific medical assistance service class.[89] Furthermore, because case management is a specific service class falling within the definition of medical assistance, it would be considered a required service for children under 21 who are entitled to EPSDT coverage. As is the case with all classes of covered medical assistance (required or optional) case management practices, when billed as medical assistance, must be medically necessary, which in the case of children entitled to EPSDT presumably would mean that the case management practices are necessary to ameliorate a physical or mental condition

[86] 42 U.S.C. §1396a(a)(11)(B)(ii)

[87] 42 C.F.R. §441.615 (c). Specifically state Medicaid agencies are required to "provide for arrangements with Title V grantees, under which the Medicaid agency will utilize the grantee to furnish services that are included in the state plan." EPSDT administration duties are a required element of all state plans. Arrangements between Medicaid and Title V agencies must address the services to be provided, methods for early identification of individuals in need of medical and remedial services, reciprocal referrals, coordinating plans for health services provided or arranged for recipients, exchange of reports, periodic review, and other matters. 42 C.F.R. §431.615(d)

[88] 42 C.F.R. §432.50. the federal regulation sets forth a five-prong test for when FFP at a 75% rate is available in the case of skilled medical professionals employed by the Medicaid agency: (i) the expenditure is for activities directly related to state plan administration; (ii) professional education and training requirements are met; the duties of the professional are in fact professional in nature; (iv) the state documents an employer/employee relationship; (v) the directly supporting staff have duties that are necessary to complete the professional duty function.

[89] 42 U.S.C. §1396a(a)(19)

and (consistent with EPSDT) are furnished in an "early" fashion, that is, as soon as a condition is suspected.[90]

Other statutory provisions related to furnishing medical assistance also become relevant. These include laws related to provider participation, payment of claims, and third party liability recovery. Thus, for example, unless a free-choice-of-provider waiver is in place for case management services,[91] a state agency covering medically necessary case management services for children would have to permit families free choice of participating provider. Medical assistance case management providers would be required to comply with billing and claims payment requirements; similarly, the state Medicaid agency would be required to pay claims in accordance with recognized payment methodologies such as a fee schedule, an all-inclusive rate tied to the cost of an encounter or an episode of care, or other recognized payment system such as contractual payment as part of a managed care payment arrangement. Federal financial participation would be available at the state's federal (or where applicable in the case of certain children, enhanced federal) medical assistance rate.[92]

Medicaid's third party liability coverage provisions would also apply. These provisions apply to legally liable third parties such as health insurers, self-insured plans, group health plans, or other third parties that are legally liable by contract or statute for "the payment of a claim."[93] For example, third parties payment obligations would exist in cases involving children who with coverage through private insurance or a parent's employer sponsored health plan that covers medical case management when necessary to ameliorate physical or mental conditions.

C. Statutory Provisions Governing Case Management as an Incidental Component of Professional Services or as an Element of Managed Care

Case management practices can take place as an incidental component of a professional or institutional service or as part of the duties of a managed care entity such as a primary care case manger or a managed care organization. In this case, the payments would be considered medical assistance as an incidental benefit or as a primary care case management fee. In the case of a managed care organization the payment would be part of the monthly capitation methodology, which blends medical assistance and administration costs.

D. Recent Developments in Medicaid Case Management Affecting Children

In 2006, Congress amended the Medicaid statute to clarify the circumstances under which Medicaid payments could be made for case management as a medical assistance service and to further clarify the application of third party liability recovery rules where medical assistance case management payments are made. The amendments did not alter those conditions under which case management payments are made as part of state program administration, such

[90] 42 U.S.C. §§1396d(a)(4)(B), 1396d(r)
[90] 42 U.S.C. §1396d(a)(4)(B), 1396d(r)
[91] 42 U.S.C. §1396n
[92] 42 U.S.C. §1396b(a)(1)
[93] 42 U.S.C. §1396a(a)(25)(A)

as EPSDT scheduling and transportation assistance, arrangements with Title V agencies, utilization management activities or managed care administration components. In addition, the amendments set out more specific rules for case management payments in the case of children receiving both Medicaid and child welfare services.

Federal regulations published on October 1, 2008[94] extended these reforms to reach case management more generally. The regulations restricted payment for case management in multiple outpatient and institutional settings. Equally significantly, the regulations appeared to eliminate case management as a recognized administrative activity even though no changes were made in the administrative components of Medicaid. In addition, the regulations applied third party liability recovery theory – meant for coordination of benefits between Medicaid and insurers – to reach public programs that provide health, educational and social services to children and that were designed to work with Medicaid, leaving such programs potentially subject to payment denials or recoupment.

The interim final regulations were proposed for rescission on May 6, 2009[95] and the future of case management policy for children thus remains unsettled.

[94] 42 CFR 441.18. http://edocket.access.gpo.gov/cfr_2008/octqtr/pdf/42cfr441.18.pdf
[95] Federal Register, Vol. 74, No. 86: 21232-21237. http://edocket.access.gpo.gov/2009/E9-10494.htm

PART III. WHAT ARE THE IMPLICATIONS FOR MEDICAID AND CASE MANAGEMENT TO PROMOTE CHILD DEVELOPMENT?

A. Conclusions

This review of the literature concludes that case management represents a valuable and effective service, both for children with special health care needs and children in families that face other barriers to receiving appropriate, high quality care. Case management plays a pivotal role in reducing the barriers that result from fragmentation of the health care delivery system and the gaps among programs to promote child development (e.g., gaps between health and early intervention programs, between medical care and public health promotion services). By improving children's access to and appropriate utilization of services, case management services can help to promote optimal development. This is particularly true for children covered by Medicaid, who are more likely than their more affluent peers to face access barriers and to have developmental risks and special health care needs.

The term case management has taken on a variety of meanings across professional fields, practice settings, and populations. This paper proposes a new framework for understanding the dimensions and characteristics of case management, the continuum of services which are financed under this label. This framework can be used to distinguish, for example, the care coordination services provided by a medical home or PCCM from the utilization management activities of a managed care organization from the work of a public health nurse who helps to coordinate services through home visits with families. Medicaid finances each of these services and each can play a role in improving the health and development of children.

This framework can help to move beyond the current struggles to impose a single definition on case management. For example, the Deficit Reduction Act provisions on Medicaid medical assistance (targeted) case management defined the assistance case managers may provide as: assessment, development of care plan, referral and related activities, and monitoring and follow-up activities. This definition fits only in a narrow set of case management activities. It does not, for example, fit with administrative case management for utilization review or care coordination in a medical home.

This paper also describes the legal provisions that under gird Medicaid's obligation to provide case management services for children. Various forms of case management have been covered under federal law provisions throughout the history of the program. As described above, case management is not a single procedure or benefit but a range of interventions and activities (see Figures 1 and 2 above). These various activities are reflected in numerous provisions of the federal Medicaid statute. Three broad categories of reimbursable services are defined in federal law. These are: (1) program administration (e.g., administrative case management intended for assuring access or utilization review); (2) case management as a distinct class of medical assistance (aka targeted case management); and (3) and case management as a component of covered professional, clinical, or institutional services or as a dimension of managed care (e.g., PCCM).

For children in particular, the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) provisions of federal law define administrative obligations for State Medicaid agencies which transcend coverage alone, and include administrative practices to result in access to covered services. These administrative obligations, which have been part of federal law for decades, encompass a range of case management practices intended specifically to promote children's access to services and in turn their optimal growth and development. Federal law also requires that State Medicaid agencies coordinate services with other State agencies concerned with the health and well-being of children, including those administering the Title V Maternal and Child Health Services Block Grant program, the Special Supplemental Food Program for women, Infants, and Children (WIC), school health, Individuals with Disabilities Education Act (IDEA), Head Start, mental health, and social services programs.

At the same time, DHHS has never developed a unified approach to interpreting Medicaid case management. The rules and regulations related to case management tend to be focused on one topic or another and lack an overarching policy framework. The result is confusion that acts as a disincentive to States in their efforts to define, effectively finance, coordinate, and promote the efficiency of case management. CMS efforts between 2005 and 2009 to interpret and issue rules for provisions of the Deficit Reduction Act related to targeted case management are an example of confusing federal interpretations and failure to fit distinct case management activities into an overarching framework.

In order for case management to be effectively and efficiently used to promote child health and development, changes are needed in federal law, in State agency policy implementation, and in professional approaches. None of the action proposed below would require changes in federal statutory provisions and many could be promptly implemented administratively, thereby facilitating access to much needed care.

B. Recommendations

Federal-level Action

- Review the regulatory provisions guiding Medicaid case management for children (including administrative, medical assistance, and other activities) and propose an improved, comprehensive set of rules that clarify the various types of case management, potential case management tiers, the federal financial participation arrangements appropriate to each tier, and the payment methods that are available under federal law. These payment methods would appear to range from a specific fee to payment as an incidental procedure, inclusion in a broader bundle of services, items and procedures (e.g., as part of an all-inclusive encounter payment, a case payment for an episode of care, or as payment for program administration).
- Encourage State Medicaid agencies to use case management for both children with special health care needs and those who face barriers to access related to geographical distance, language, culture, health literacy of a caregiver, or some other factor unrelated to medical care need. Notably, some children have both special health needs and other barriers.

- Use the opportunity of the case management rules rescission to re-state broadly Medicaid case management policy, clarify potential case management functions, clarify the types of case management activities recognized under law in the case of children and other beneficiaries who need case management, and the types of payment methods that can be used.

State-level Action

- Use this analysis and the proposed framework to review policies and procedures related to Medicaid case management for children (including administrative, medical assistance, and other activities) and make modifications necessary to meet the purposes defined under federal law (i.e., meet administrative obligations under EPSDT, support efficient utilization of care, and promote access to high quality child health services). Once policies are revised provider guidance and training are an essential step toward assuring their implementation.
- Review payment policies related to Medicaid case management for children, considering the framework proposed above. For example, payment policies should support and encourage a continuum of case management from the clinical practice setting to the home and community setting. States should consider tiered or graduated fee schedules. Adequate financing for case management services in the context of the medical home and those provided by public health nurses, community health workers, and others all play a role in assuring access to child services that promote health and development.
- Update and improve case management provisions within interagency agreements between Medicaid and other child service agencies. Medicaid and Title V agencies have reciprocal responsibilities to create interagency agreements. Such agreements can support structures for delivery and financing of case management. Similar agreements with other agencies such as IDEA, child welfare, school health, and WIC.
- Review and modify as necessary the process of making referrals from EPSDT comprehensive well-child visits (aka EPSDT screening visits) to other providers. States have an opportunity to assure increased numbers of completed referrals through improved case management when a problem is detected in an EPSDT visit. For example, states could develop mechanisms (e.g., referral forms, codes) for reporting and tracking referrals made subsequent to an EPSDT well-child comprehensive screening exam. With such mechanisms in place, states might pay bonuses to providers with high rates of completed referrals.

Community-level Action

- Adopt and adapt promising approaches underway across the country.[96] Many such projects and initiatives aim to help families benefit from screening and surveillance in

[96] Fine A and Hicks M. 2008 Health Matters: The Role of Health and the Health Sector in Place-Based Initiatives for Young Children, Battle Creek, MI: W.K. Kellogg Foundation; Fine A and Mayer R. 2006. Beyond Referral: Pediatric care linkages to improve developmental health, New York, NY: The Commonwealth Fund. Johnson K and Rosenthal J. 2009. Improving Care Coordination, Case Management, and Linkages to Service for Young Children: Opportunities for States. New York, NY: The Commonwealth Fund/National Academy of State Health Policy.

pediatric primary care by using case management and care coordination to connect children to the services and supports they need.

- Review and coordinate existing case management programs. For example, use a triage approach to maximize available staff capacity in community settings (e.g., from community health workers to advanced practice nurses).
- Develop structures that streamline and coordinate multiple care plans for families served by multiple public agencies. Such efforts might involve, for example, pediatric primary care providers, specialty care providers, child welfare programs, and special education.