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## Optimizing Health Services and Spending for Children with Medical Complexity in Medicaid

Jay G. Berry, M.D., M.P.H.<sup>1</sup>, Matt Hall, Ph.D.<sup>2</sup>, John M. Neff, M.D.<sup>3</sup>, Denise M. Goodman, M.D., M.S.<sup>4</sup>, Eyal Cohen, M.D., M.Sc.<sup>5</sup>, Rishi Agrawal, M.D., M.P.H.<sup>4</sup>, Dennis Z. Kuo, M.D., M.H.S.<sup>6</sup>, and Chris Feudtner, M.D., Ph.D., M.P.H.<sup>7</sup>

<sup>1</sup>Division of General Pediatrics, Boston Children's Hospital, Harvard Medical School, Boston, MA

<sup>2</sup>Children's Hospital Association, Overland Park, KS

<sup>3</sup>Seattle Children's Hospital, University of Washington

<sup>4</sup>Ann and Robert H. Lurie Children's Hospital, Northwestern University, Feinberg School of Medicine, Chicago, IL

<sup>5</sup>Hospital for Sick Children, University of Toronto, Toronto, ON, CA

<sup>6</sup>Department of Pediatrics, University of Arkansas for Medical Sciences, Arkansas Children's Hospital, Little Rock, AR

<sup>7</sup>Division of General Pediatrics, PolicyLab, and Department of Medical Ethics, The Children's Hospital of Philadelphia, Philadelphia, PA

### Abstract

A small but growing population of children with medical complexity (CMC), often covered by Medicaid, consumes a high proportion of pediatric healthcare spending. In this article, we first describe the expenditures of CMC with Medicaid across the care continuum. We report the increasingly large amount of spending on hospital care for CMC relative to the small amount of primary care and home care spending. We then present a business case that 1) estimates how cost savings might be achieved for CMC from reductions in potentially reducible hospital and emergency department use and 2) shows how the savings could underwrite investments in outpatient and community care. We conclude by discussing the importance of these findings in the context of Medicaid quality of care and healthcare reform.

### Introduction

Children with medical complexity (CMC) are a growing population of children with expensive, complex, and chronic medical conditions that often lead to 1) functional limitations, which are often severe; 2) substantial health service needs to maintain health, including numerous clinicians, medications, equipment, therapies, and surgeries; and 3) high health resource utilization.[1–4] With a prevalence of ~0.5% (n ~400,000) of all U.S. children[2], it is suspected that CMC account for as much as one-third of health care spending for all children (i.e. ~\$100 billion).[5–7]

The healthcare system struggles to serve CMC. Community pediatricians may care for only a few CMC in their practice and not develop comfort managing the heterogeneous array of rare, complex health problems endured by the children. Pediatric specialists can manage with clinical proficiency a sufficient volume of CMC. However, these specialists are in shortage, reside mostly in children's hospitals geographically distant from many CMC, and typically do not integrate care across the children's numerous providers. Payors, including state Medicaid programs, may limit the amount, scope, and duration of covered health services for CMC; certain services that would benefit CMC and their families (e.g., care management and home health care) are often insufficient. Consequently, diligent family caregivers often become the primary medical manager and health systems navigator for their child. The heavy caregiving burden endured by families can negatively affect their health and well-being.[8]

In response to these financial and quality of care concerns, innovative models of care management are emerging to help CMC and their families. In children's hospitals – the clinical site where CMC predominately receive their hospital, surgical, and outpatient specialty care - clinics have been developed specifically to manage the health of CMC, to coordinate care across numerous clinicians, and to treat their urgent health problems.[9, 10] Although helpful, these regional, hospital-based clinics may have limited capability to manage care in the children's local communities and homes. As a result, community clinics and some state Medicaid programs have increased the number of clinical personnel available to help CMC (e.g., case managers and community health workers).[11–13] CMC care integration innovations (e.g., accountable care organizations) are attempting to bridge hospital and community care for CMC as well as optimize their healthcare spending across settings.[14]

Guiding many of these initiatives is the theory that improving care management for CMC will result in tangible cost savings for the health care system by reducing future, expensive healthcare encounters. For example, a care manager could promptly help identify and respond to health problems experienced by CMC over the phone, in an outpatient clinic, or in the child's home, thereby avoiding an emergency department visit or hospitalization. Although enticing, accomplishing this challenging aim is not trivial: predicting which CMC will have substantial future expenditures is not particularly accurate, not all CMC future expenditures will be readily reducible while maintaining quality care, and the best care management methods of reducing cost are not well established. Success of any care management program is therefore contingent upon: 1) identifying CMC who have health problems, social and family circumstances, or other issues that can be improved with enhanced care management; and 2) engaging these children and families in a timely manner to reduce future healthcare expenditures before they occur.

This article aims to improve our understanding of the opportunities and challenges for better care management and reduced health care spending for CMC with Medicaid. Using multi-state and national databases, we describe the expenditures of CMC across the care continuum. We then present a business case that 1) estimates how cost savings might be achieved for CMC from reductions in potentially reducible hospital and emergency

department use and 2) shows how the potential savings could underwrite investments in outpatient and community care management.

## Methods

### Study Population

In this retrospective study of administrative billing data, we used the open source set of pediatric Complex Chronic Conditions (CCC) to identify children with a complex and chronic health condition – the hallmark attribute of CMC - with *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnosis and procedure codes.[15] Used extensively to study CMC, the CCCs are childhood health conditions that are expected to last longer than 1 year and that are associated with severe limitations in function, high morbidity and mortality, and high resource utilization.[16, 17]

### Data Sources

We assessed healthcare use and spending for CMC with Medicaid from two administrative databases: 1) the Truven Marketscan Medicaid Database; and 2) the Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project’s Kids’ Inpatient Database (KID). The Truven database contains medical claims across the care continuum (i.e., community, hospital, pharmacy, outpatient, etc.) for 3,686,635 Medicaid enrollees age 0–18 years, including children enrolled through the Children’s Health Insurance Program (CHIP), in 2011 from 12 states representing all U.S. geographical regions. KID is the largest multi-state database of U.S. hospitalizations for children.[18] With data from 2000, 2003, 2006, and 2009, each year of the KID contains up to 3.4 million hospitalizations for children ages 0–18 years, from up to 4,121 hospitals in 44 states. The dataset includes weights to produce national estimates of hospital use for CMC.

### Patient Clinical Attributes

Using the Truven database, we describe the clinical characteristics of the study cohort, including the type of CCCs, the number of chronic conditions (i.e., complex and non-complex), and eligibility for Medicaid because of a disability. We used AHRQ’s Chronic Condition Indicator (CCI) classification system to count the number of chronic conditions. [19] Disability was identified in the dataset as “blind/disabled individual” eligibility for Medicaid.

### Business Case of Cost Savings and Care Management Investment from Reducing Potentially Avoidable Healthcare Encounters

For the business case, we integrated key concepts and evidence of care management for CMC with the healthcare cost and utilization experienced by CMC in the Truven and KID databases. Provided in the appendix is a description of the components of the business case, including examples of care management activities and approaches for CMC, amounts of reduced healthcare cost and utilization experienced by CMC when exposed to improved care management, definitions of potentially avoidable healthcare encounters, and supporting citations.[20]

Based on the prior studies, we estimated a base case reduction of 10% with a range of 0–20% of the following examples of potentially avoidable healthcare encounters: 30-day unplanned hospital readmissions, admissions for ambulatory care sensitive conditions, total days spent in the hospital across admissions, and emergency department visits not associated with hospital admission. (appendix [20]) We used the KID and Truven databases to assess the trends in and current expenditures of these encounters, respectively.

We proceeded with the Truven database to assess the percentage of CMC whose outpatient and community care management approaches could be underwritten by potential cost savings from reducing the potentially avoidable healthcare encounters described above. We assessed this percentage because care management needs vary across CMC and not all CMC need improved care management. Informed by prior studies, we included 4 care management approaches in this assessment: 1) intense care management in an outpatient, consultative, complex care clinic; 2) care management from a community nurse; 3) home nursing care; and 4) post-acute care. (appendix [20]) We also assessed the degree to which the frequency of the potentially avoidable healthcare encounters varied between and within different groups of CMC (e.g. children with a neuromuscular vs. cardiovascular condition), reasoning that some CMC conditions with higher levels of variation may be more likely reducible.

### Statistical Analysis

With SAS version 9.1.3 (SAS Institute Inc, Cary, NC), we used the Mantel-Haenszel Chi-Square test to assess whether hospital resource use in the KID from 2000 to 2009 for CMC stayed constant. Significance threshold was defined as p value <.05.

### Limitations

Clinical data obtained from health record review or patient and family interview may be more specific to ascertain a cohort of CMC when compared with ICD-9-CM codes. The data presented in this article are cross-sectional, and thus cannot assess the probability of CMC experiencing future healthcare expenditures. The administrative data are not equipped to distinguish completely which CMC need improved care management. Continuous years of KID data may be preferable to study hospital trends for CMC when compared with the four discrete time points in a 10-year period.

The Truven database contains a variety of outpatient health care encounters aggregated into an “other” category; most of the encounters in this category appear to be for specialty visits. Absent a nationally representative, validated database of children with Medicaid and Truven’s inability to disclose the states in their database, the generalizability of the Truven database remains unknown. We compared the demographic and clinical characteristics of hospitalized CMC with Medicaid in the Truven and nationally-representative KID databases. The characteristics are very similar.

## Results

### Prevalence, Impact, and Health Care Spending for Children with Medical Complexity Using Medicaid

In 2011, CMC accounted for 5.8% (n = 214,765) of all children with Medicaid in the Truven database. The most prevalent chronic conditions endured by CMC were neurologic/neuromuscular (24.5%), congenital/genetic (22.1%), and cardiovascular (18.9%); and 45.8% of CMC had three or more chronic conditions. One-fourth of CMC were eligible for Medicaid because of a disability. CMC accounted for 34.0% (\$1.6 billion) of all health care spending for children with Medicaid. Spending was highly concentrated within a subset of CMC: 5% of CMC accounted for 50% of total CMC spending.

### Out-of-Hospital Health Care Use and Spending for Children with Medical Complexity Using Medicaid

Out-of-hospital care accounted for 48.8% of total healthcare spending for all CMC with Medicaid. (Exhibit 1) Outpatient specialty and other care (e.g., dentistry) accounted for 25.1% of total healthcare spending. Prescription drugs accounted for 13.4% of spending. The remaining out-of-hospital spending for CMC with Medicaid was attributable to therapies (e.g., physical therapy) (6%), primary care (3%), laboratory and radiographic testing (2%), home health care (1%), and medical equipment/supplies (1%).

**Primary, Specialty, and Home Care Use**—Of CMC with Medicaid, 59.6% of children had one or more primary care visits. (Exhibit 1) Of CMC who visited primary care, the median (IQR) number of annual primary care visits per child was 5 (3–9). Sixty-seven percent of children had one or more other professional outpatient visits that included specialty care. The median [interquartile range (IQR)] number of such annual visits per child among users was 2 (1–4). Three percent of CMC with Medicaid used home health care.

**Medications and Medical Equipment**—Of CMC with Medicaid, 89.9% of children had one or more medication prescriptions filled. (Exhibit 1) The median (IQR) number of prescription fills was 13 (5–29). The median (IQR) number of distinct medications filled was 5 (3–9). Common therapeutic groups of medications used by CMC included central nervous system agents (51.6%), gastrointestinal agents (22.7%), and respiratory tract agents (17.0%). Seventeen percent of CMC used medical equipment, including wheelchairs (12.8%) and respiratory supplies (e.g., oxygen and nebulizers) (9.7%).

### Hospital Use and Spending for Children with Medical Complexity Using Medicaid

Nationally, KID data revealed that from 2000 to 2009, the use of Medicaid by hospitalized CMC increased from 40.5% to 48.4% and, among children with Medicaid, there was an increase in the percentages of hospitalizations (20.9%), hospital days (19.2%), and hospital charges (16.1%) attributable to CMC. (appendix[20]) In 2009, 2.3% of hospitalized CMC with Medicaid were discharged to a post-acute care facility and 7.3% were discharged with home health care. In the 2011 Truven database, hospital care accounted for 47.2% of total healthcare spending for all CMC. (Exhibit 1) Annual spending on hospital care per CMC

(\$5903) was 21.5 and 28.9 times the spending of primary care (\$275) and home care (\$204), respectively. Of hospitalized CMC (13.0%), most (75%) were hospitalized once.

### **Business Case of Cost Savings and Care Management Investment from Reducing Potentially Avoidable Healthcare Encounters**

As shown in Exhibit 2, cost savings varied by the type of potentially avoidable healthcare encounter proposed for reduction. The cost savings achieved from reductions in emergency department (ED) visits not associated with admission, 30-day unplanned readmissions, and admissions for ambulatory care sensitive conditions were substantially smaller than the cost savings achieved from an equal reduction in overall days spent in the hospital.

**Emergency Department Visits Not Associated with Admission**—CMC accounted for 12.0% of all ED visits that did not result in admission in children with Medicaid. Thirty-two percent of CMC had one or more of these ED visits. For children that used the ED, the median number of such annual ED visits was 2 (IQR 1–3). ED care accounted for 4.0% of total healthcare spending for CMC. (Exhibit 1) Five distinct types of CMC (out of 1,218), including children with a neurologic/neuromuscular condition, accounted for 58.9% of all such ED expenditures, and higher-than-average variation in ED spending was observed in each of these CMC. (appendix [20]) Cost savings from a 10% reduction in expenditures for ED visits not associated with admission would underwrite a budget neutral 14% increase in spending on primary care, equaling \$38 available for investment of care management for each CMC over one year. (Exhibit 2)

**Hospitalizations for Ambulatory Care Sensitive Conditions**—CMC accounted for 40.1% of all hospitalizations for ambulatory care sensitive conditions (ACSC) in children with Medicaid. Twelve percent of CMC hospitalizations were for an ACSC and these hospitalizations accounted for 7.5% of total Medicaid spending for CMC. Five distinct types of CMC, including children with a neurologic/neuromuscular condition, with higher-than-average variation in ACSC spending accounted for 23.6% of all hospital spending on ACSC for CMC. (appendix [20]) Cost savings from a 10% reduction in expenditures for ACSC admissions would underwrite a budget neutral 26% increase in spending on primary care, equaling \$70 available for investment of care management for each CMC over one year. (Exhibit 2)

**Hospital Readmissions**—CMC accounted for 71.4% of 30-day unplanned hospital readmissions for all children with Medicaid. Ten percent of CMC hospitalizations were for 30-day readmissions and these readmissions accounted for 5.1% of total Medicaid spending for CMC. Five distinct types of CMC, including children with a neurologic/neuromuscular condition, with higher-than-average variation in readmission spending accounted for 19.1% of spending on 30-day readmissions for CMC.(appendix [20]) Cost savings from a 10% reduction in expenditures for 30-day unplanned readmission would underwrite a budget neutral 23% increase in spending on primary care, equaling \$63 available for investment of care management for each CMC over one year. (Exhibit 2)



**Hospital Days**—The average length of stay for hospitalizations of CMC with Medicaid was 7.2 days with an average spend of \$3,928 per hospital day. Cost savings from a 10% reduction in hospital days would underwrite a budget neutral 215% increase in spending on primary care, equaling \$587 available for investment of care management for each CMC over one year. (Exhibit 2) Nationally, \$2.9 billion would be potentially available from a 10% reduction in hospital days for CMC with Medicaid.

Five distinct types of CMC, including children with a neurologic/neuromuscular condition, accounted for 40.5% of all hospital days and higher-than-average variation in hospital days was observed in each of these CMC. (Exhibit 3) If appropriated to the CMC who were the most in need of improved outpatient and community care management, a 10% reduction in hospital days could underwrite 10 hours of home nursing care for 3% of CMC; 7 days of admission to a post-acute care facility for 11% of CMC; continuous access to intense care management in an outpatient, consultative, complex care clinic for 17% of CMC; or two hours per month of care management from a nurse for 49% of CMC. (Exhibit 4)

## Discussion

In an era when healthcare costs are of increasing concern, the care received by children with medical complexity has come under scrutiny. Indeed, as the findings presented in this article suggest, CMC have a major impact on Medicaid spending for child enrollees. This is chiefly due to hospital care: nationally, CMC account for a half of Medicaid spending on hospital care for all children, and this proportion is increasing over time. Compared with hospital care spending, CMC spending for primary care and home care is small, and CMC barely use post-acute care facilities after hospitalization. Focusing on potential cost savings from reducing different forms of care, a given percentage reduction in overall total days spent in the hospital would yield much larger cost savings than from either reductions in ED visits or reductions in admissions for ACSCs or hospital readmissions. The absolute dollar amount of the cost savings from a reduction of overall hospital days, however, may not be sufficient to completely underwrite the necessary investment in care management that would provide benefit the entire population of CMC.

Our business case analysis is based on a combination of empirical health care cost data (drawn from very large or even nationally representative data sources) and assumptions regarding potential reductions in different kinds of healthcare utilization. The published data on these reductions for CMC show much larger reductions in hospital use (e.g., up to 80%[9]) than the ones that we used (i.e., up to 20%). Absent the use of control groups in these studies, we assumed that modest reductions are more likely occurring. The Medicare-sponsored complex care initiatives associated with up to 20% reduction in hospital use are intense; they included a care management team that participated in medical decision-making with the patients' physicians, recurrently accessed their patients' medical records across settings, and interacted frequently with their patients by phone and in person during physician visits and hospitalizations.[21, 22] These care management activities, which are directly analogous to CMC complex care clinics[9], prevented or quickly addressed health problems that, if not contained, would have required hospitalization, and facilitated more timely discharge from the hospital.

One of our key findings is that potential cost savings from a modest reduction of hospital days would underwrite the more intense (and potentially effective) approaches to care management for only a small proportion of CMC, whereas less intensive (and expensive) care management could be delivered to a larger portion of CMC. For the overall system of care management of CMC to be optimally effective, we need to know the relative effectiveness of these different approaches in terms of reducing particular types of healthcare utilization, and to identify which CMC have the greatest need for each approach. Although our analysis only accounted for broad diagnostic categories, CMC with neurologic or neuromuscular conditions (as shown in Exhibit 3 and the appendix[20]) contribute substantially to the total number of and variation in hospital days across CMC. This finding, combined with the knowledge that this population has unmet care management needs[2], suggests that this population might benefit from targeted care management.

Our analysis does not account for the fact that many families of CMC are currently providing in-kind care management activities in their homes that are equivalent, in some aspects, to the level of home health care or post-acute care. The effort, out-of-pocket expenses, and missed days of work endured by families to conduct these activities are substantial. There is insufficient payment by some state Medicaid programs as well as a shortage of clinical personnel and facilities to provide home and post-acute care for children. [23] This may explain, in part, why only 2% of hospitalized CMC with Medicaid used post-acute care (as we noted), compared with nearly 40% of high-cost, hospitalized Medicare beneficiaries.[24] From 2001 to 2011, Medicare beneficiaries experienced a remarkable reduction in spending on hospital care (38% to 24%) as spending increased for home health care and post-acute care.[25] Further assessment is needed of the child and family benefits that could result from increased access and use of home health care and post-acute care.

Optimization of care management for the population of CMC with Medicaid may be more likely to occur with standardization of health services across states.[26] Currently, states determine the coverage amount, duration, and scope of many of the health services that are essential to the health and wellbeing of CMC (such as home health care). As a result, substantial variation exists across states in the access to, quality of, and spending on health services for child Medicaid enrollees, especially children with disabilities.[27, 28] Medicaid spending affects beneficiaries' use of health services. Enrollees in states with lower Medicaid payments for outpatient care experience higher rates of hospitalization.[29]

This article underscores important challenges and potential opportunities to improve care for CMC while addressing costs. The results suggest several directions of subsequent research on behalf of CMC. First, we need a better understanding of how healthcare encounters occur over time for CMC. At the patient level, past or current CMC expenditures appear to poorly predict future CMC expenditures[30], but are there ways to identify particular children or groups of children more likely to benefit from enhanced care management? Second, we need to compare the effectiveness of different approaches of care management of CMC, to identify potential best practices and then learn how to disseminate such practices. Third, we urgently need to develop a national publicly available database of healthcare cost and utilization, combining data from Medicaid and private payors, in order to assess longitudinal trends in spending and health outcomes for CMC, especially in the context of predicting



future expenditures and examining innovations aiming to both improve the quality and efficiency of healthcare for these children.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

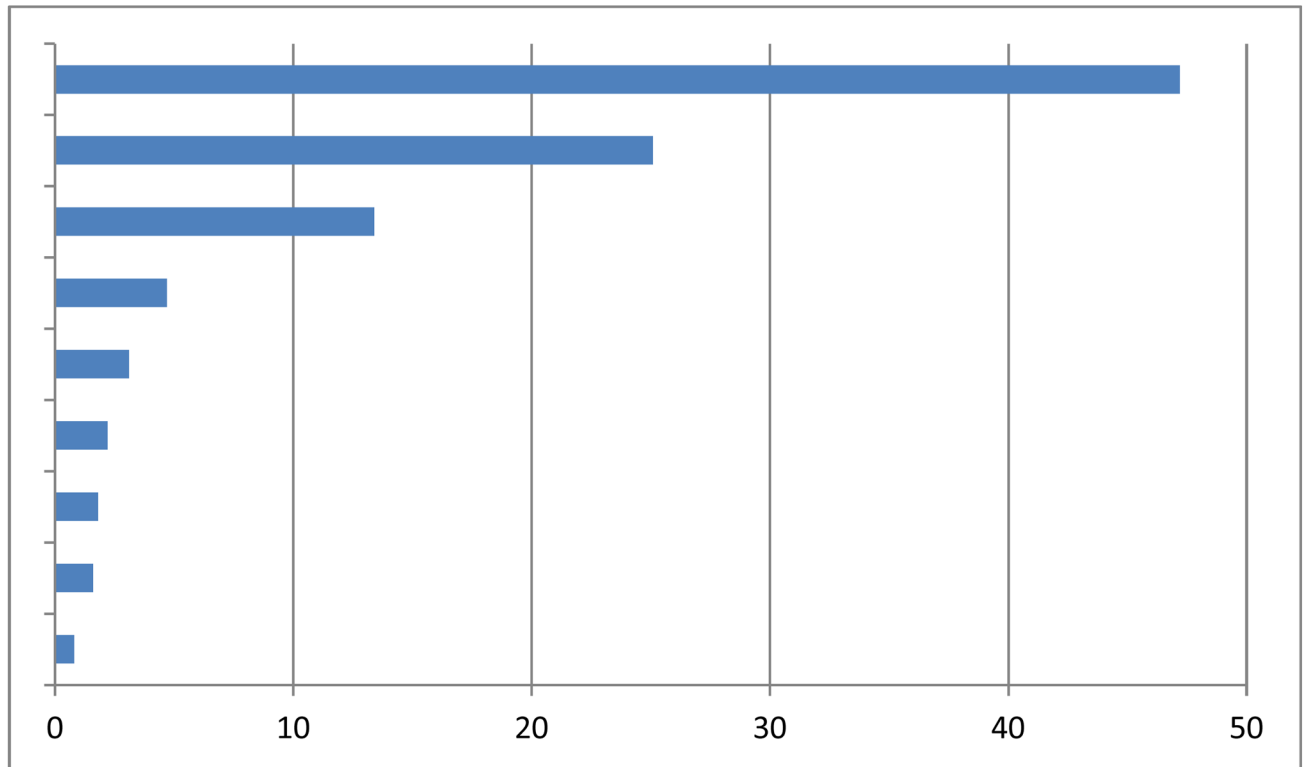
## Acknowledgments

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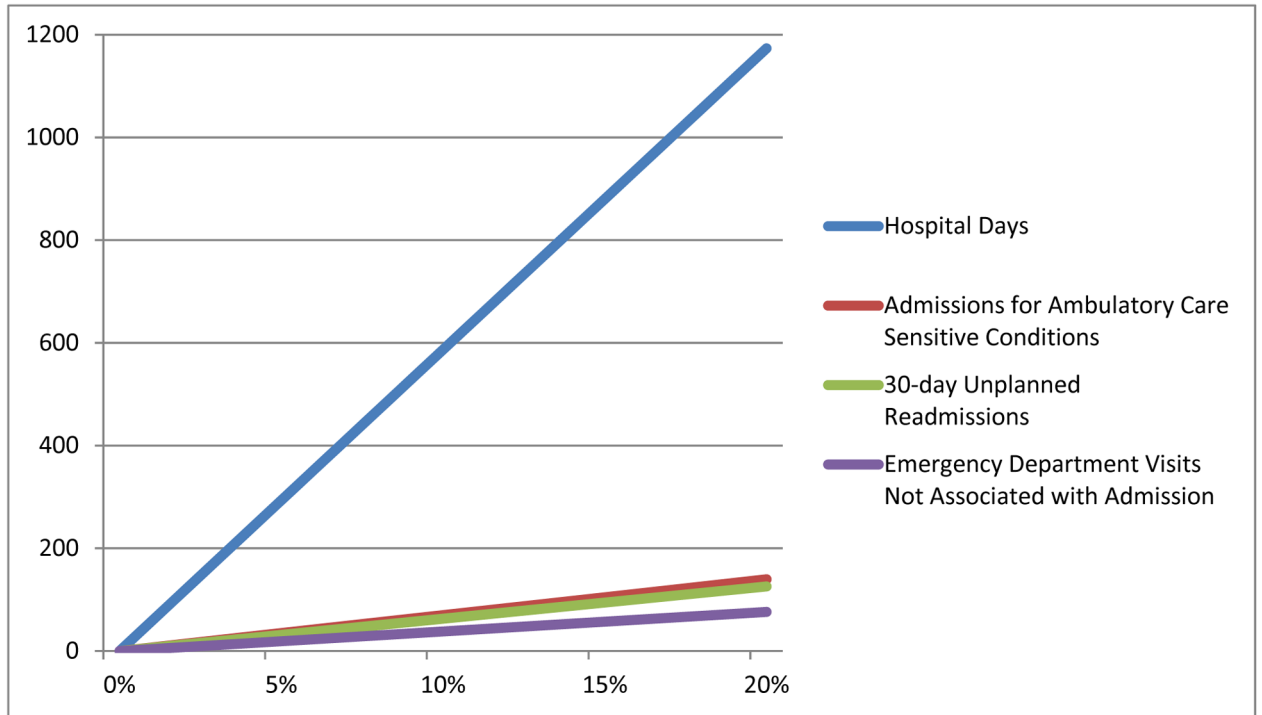
**Exhibit 1.**

Healthcare Utilization and Spending for Children with Medical Complexity Who Use Medicaid. (Figure)

**Source:** Truven Marketscan Medicaid Data 2011

**Caption:** This exhibit describes the allocation of healthcare spending across the care continuum, from hospital to outpatient to home care, for children with medical complexity. Physician fees are included in emergency, hospital, primary, and specialty care.

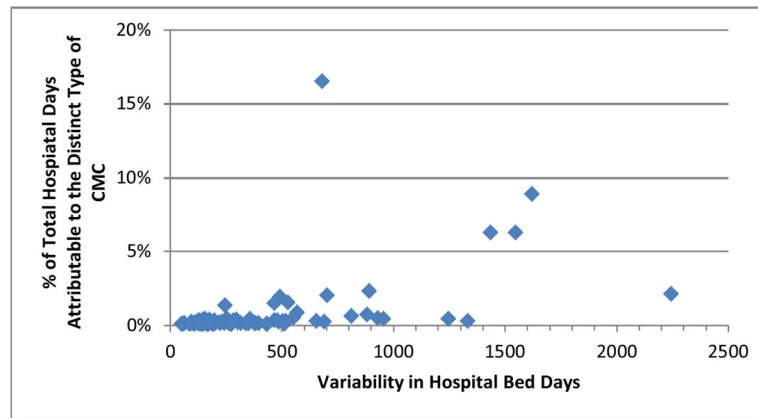
Health Service	% Utilizing	% of total spend
Medical equipment	17	0.8
Home health care	3	1.6
Testing	55	1.8
Primary care	60	2.2
Emergency care	32	3.1
Outpatient therapy	22	4.7
Medications	90	13.4
Specialty care	66	25.1
Hospital care	13	47.2



**Exhibit 2.**  
 Funds Available for Investment from Spending Reductions in Hospital and Emergency Department Expenditures for Children with Medical Complexity. (Figure)

**Source:** Truven Marketscan Medicaid Database, 2011.

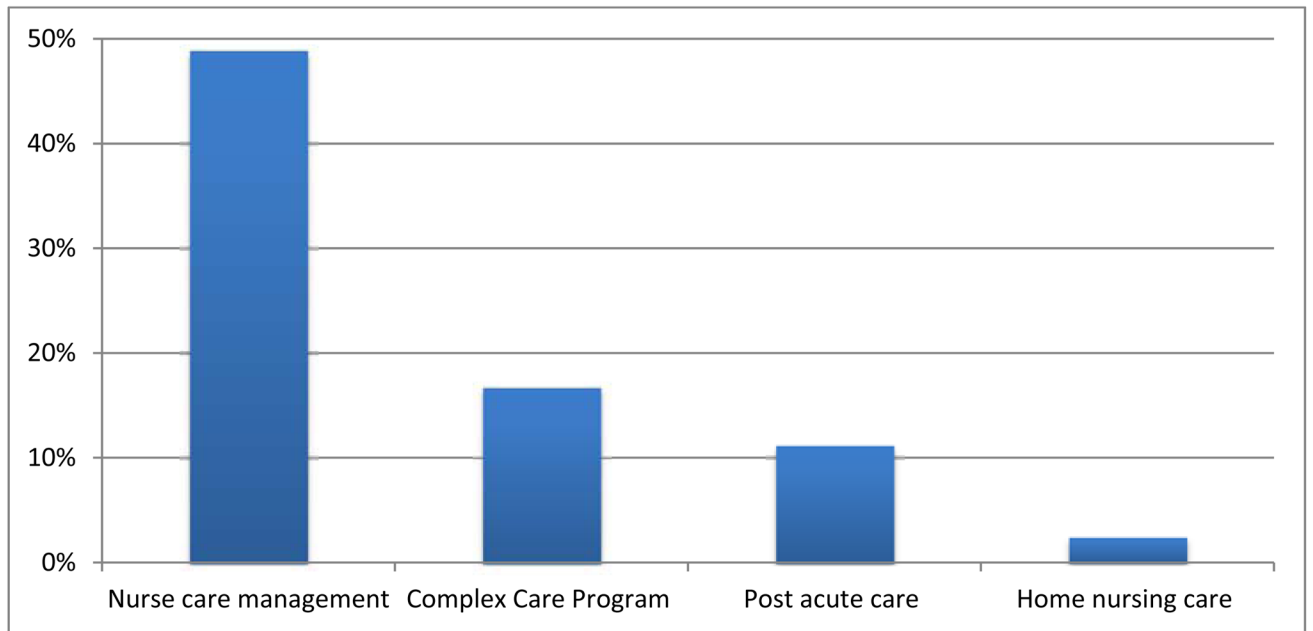
**Caption:** Annual investments per each child with medical complexity are shown relative to spending reductions in hospital and emergency department care.

**Exhibit 3.**

Variation in Number of Days Spent in the Hospital Across Distinct Types of Children with Medical Complexity. (Figure)

**Source:** Truven Marketscan Medicaid Database, 2011.

**Caption:** Shapes indicate a distinct type of CMC based on their complex chronic conditions. The list of complex chronic conditions is cardiovascular, gastrointestinal, hematologic or immunologic, malignancy, metabolic, neurologic and neuromuscular, other congenital or genetic defect, premature and neonatal, renal and urologic, respiratory, technology dependence, and transplantation. Shown on the x axis is the covariance (i.e., variability) of days spent in the hospital for each distinct type of CMC. Shown on the y axis is the percent of total hospital bed days attributable to each distinct type of CMC.

**Exhibit 4.**

Budget Neutral Investments in Care Management Underwritten by a 10% Reduction in Hospital Days for Children with Medical Complexity. (Figure)

**Source:** Truven Marketscan Medicaid Database, 2011.

**Caption:** Shown are the percentages of children with medical complexity who could receive the care management approach with funds available from the spending reduction in hospital days.