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# Care Coordination for Children and Youth With Special Health Care Needs: A Descriptive, Multisite Study of Activities, Personnel Costs, and Outcomes

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## What's Known on This Subject

Although care coordination is a critical component of the medical home, it is often performed in a relatively disorganized, haphazard, reactive fashion. Very little has been reported about the cost and outcomes of care coordination.

## What This Study Adds

This study is among the first to demonstrate the outcomes of CC in pediatric primary care. It suggests that there could be significant cost savings associated with CCs. CC has a cost that needs to be supported.

## ABSTRACT

**OBJECTIVES.** Objectives included testing use of the care-coordination measurement tool in pediatric primary care practices; describing care-coordination activities for children and youth that occur in primary care practices; assessing the relationship of care-coordination activities in the medical home with outcomes related to resource use; and measuring the direct personnel costs of care-coordination activities.

**METHODS.** Six general pediatric practices were selected, representing a diverse range of sizes, locations, patient demographics, and care-coordination activity model types. The care-coordination measurement tool was used over a period of 8 months in 2003 to record all of the nonreimbursable care-coordination activity encounters performed by any office-based personnel. The tool enabled recording of activities, resources-use outcomes, and time. Cost of personnel performing care-coordination activities was derived by extrapolation from the time spent.

**RESULTS.** Care-coordination activity services were used by patients of all complexity levels. 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. Children and youth without special health care needs, without complicating family psychosocial problems, received 50% of the encounters and used 36% of the care-coordination activity minutes. The average cost per care-coordination activity encounter varied from \$4.39 to \$12.86, with an overall mean of \$7.78. A principal cost driver seemed to be the percentage of care-coordination activities performed by physicians. Office-based nurses prevented a large majority of emergency department visits and episodic office visits.

**CONCLUSIONS.** Care-coordination activity was assessed at the practice level, and the care-coordination measurement tool was used successfully during the operations of typical, pediatric, primary care settings. The presence of acute, family-based social stressors was a significant driver of need for care-coordination activities. A high proportion of dependence on care-coordination performed by physicians led to increased costs. Office-based nurses providing care coordination were responsible for a significant number of episodes of avoidance of higher cost use outcomes. *Pediatrics* 2008;122:e209–e216

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### Key Words

care coordination, children and youth with special health care needs, cost of care coordination, outcomes of care coordination, medical home

### Abbreviations

CYSHCN—children and youth with special health care needs

CC—care-coordination activity

CCMT—care-coordination measurement tool

RN—registered nurse

BLS—Bureau of Labor Statistics

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CARE COORDINATION IS defined by the American Academy of Pediatrics as “a process that links children and youth with special health care needs (CYSHCN) and their families with appropriate services and resources in a coordinated effort to achieve good health.”<sup>1</sup> It has been identified by policy makers and professional organizations<sup>1–3</sup> as an integral part of high-quality care for CYSHCN. Although objective data on the benefits of care coordination on clinical outcomes are somewhat limited,<sup>4</sup> existing data support its use to benefit children with complex illnesses.<sup>5–7</sup>

The medical home is a logical place to serve as a locus of care coordination and, in fact, has been designated by the Federal Healthy People 2010 objectives as the recommended setting for care coordination for CYSHCN.<sup>3</sup>

However, practical difficulties in achieving care coordination in the primary care medical home exist. Care coordination requires multiple skills, including identification of needs, knowledge of existing resources (both medical and nonmedical), communication with multiple professionals, close monitoring and follow-up, and especially time. Primary care pediatricians reported in 1 study that, although 71% of them provide a “medical home,” only 24% are always involved with hospital discharge planning, and only 19% always link with schools for coordinating medical and educational needs. The principal reasons cited for this limited care-coordination support were time availability, lack of staff, and inadequate reimbursement.<sup>8</sup> Families of CYSHCN perceive this difficulty, reporting in another study that, although their children’s health care professionals have the necessary skills to provide for their children, care coordination is often not provided through their primary care physician’s office.<sup>9</sup> In addition, focus group survey results obtained from families of CYSHCN in Ohio indicate that families often are the sole source of care coordination for their children, because no other source of coordination is available (D. Read, MPH and C. Bethell, PhD, written communication, 2007).

To improve the level of care coordination provided to families, to plan staffing and determine the cost of care-coordination activities with the goal of reimbursement, and to assess outcomes of care coordination, care-coordination activities (CCs) must be precisely described.<sup>10</sup> No well-established measures of CCs at the practice level exist. In a previous study, the development of a tool to measure care coordination for CYSHCN in a single community-based pediatric practice was described. Using this tool, time and effort expended by practice physicians and staff performing CC functions were measured. The cost of nonreimbursable CCs for this practice with 4 full-time equivalent pediatricians and 1 full-time equivalent nurse practitioner ranged from \$22 809 to \$33 048 (representing the 25th and 75th percentiles of benchmarked salary levels, respectively). The majority of CCs involved problems not considered typically medical.<sup>11</sup>

The objectives of this study were to (1) test the feasibility of implementation of the care-coordination measurement tool in a variety of pediatric primary care practices nationwide, (2) describe the types and amounts of CCs for CYSHCN that occur in the context of daily pediatric practice, (3) assess the relationship of CC activities in the medical home with outcomes reflecting service use, and (4) describe the practice-based, personnel costs of CC activities.

## METHODS

An expert work group (see “Acknowledgments”) was convened to guide all aspects of the study, including site selection, data-tool development, and data analysis.

### Sample

Practices were recruited by using an announcement through a listserv sponsored by the American Academy of Pediatrics, National Center of Medical Home Initia-

tives. Twenty-five inquiries were received, and 20 practices completed a letter of intent. The 20 practices were then interviewed by telephone to determine whether they met the selection criteria, which included previous training in medical home provision, willingness to commit to a training experience in the use of data collection tools, and willingness to collect data in a rigorously prescribed fashion. Practices were selected on the basis of these criteria and the diversity of the patient population they served, the payer mix, and practice characteristics (eg, number of providers and satellite offices). Particular attention was paid to selecting practices with a range of CC provision models. Six community-based general pediatric practices were chosen, representing a variety of practices that differed with regard to size, geographic location, diversity of patient population, and care-coordination service delivery model.

### Measurement Instrument

The care-coordination measurement tool (CCMT) (see Appendix) used in this study is an adaptation of the University of Massachusetts Medical School Care Coordination Measurement Tool described previously and used in a pilot study in 2001.<sup>11</sup> Based on recommendations of the expert workgroup, several modifications were implemented. The complexity subscale in the original version was simplified and renamed to “patient level.” Patients were stratified into 1 of 4 levels: non-CYSHCN without complicating family or social problems (level 1); non-CYSHCN with complicating family or social problems (level 2); CYSHCN without complicating family or social problems (level 3); and CYSHCN with complicating family or social problems (level 4). Designation of CYSHCN was based on the US Maternal and Child Health Bureau definition.<sup>12</sup> The attributes subscale was expanded to include social services and renamed “focus of encounter.” A care-coordination needs subscale was added, allowing documentation of the type of care coordination that was needed by the patient. The outcomes subscale was expanded by separating it into “outcomes occurred” and “outcomes prevented.” The tool was designed so that only 1 focus of encounter could be entered for each CC encounter.

### Eligible Activities

For the purposes of this study, care-coordination encounters were defined as any activity performed by any primary care office-based personnel that contributed to the development and/or implementation of a plan of care for a patient or family. Certain activities related to CC provision are billable when performed by certain credentialed and licensed providers during the course of a typical office encounter. Only those activities consuming >5 minutes of staff time that were essential to support a plan of care, but not eligible for reimbursement by third party payers at the time of the study, were included.

### Practice Training

Training was conducted on-site for practices A, D, E, and F and by teleconference for practices B and C. The study

**TABLE 1 Staff Wages Used for Care-Coordination Cost Calculations**

Staff Type	BLS Code	BLS Description of Staff Position	Mean Hourly Wage, \$
MD	29-1065	Pediatricians, general: physician office	71.47
NP	29-1071	Physician assistants: physician office	30.50
RN	29-1111	RNs: physician office	23.66
LPN	29-2061	Licensed practical nurses: physician office	14.44
Clerical	43-6013	Medical secretaries: physician office	12.73
MA	31-9092	Medical assistants: physician office	12.02
SW	21-1022	Medical social workers	18.71
PA ("medical home plus resource director" or "parent advocate")			27.50

Approval was received from the University of Massachusetts Medical School Committee for the Protection of Human Subjects in Research. Each site also met institutional review board approval requirements. A site liaison was identified to facilitate communication with the central project coordinator and data coordinator in order to schedule weekly phone calls with office staff and to review CCMT forms for completeness. MD indicates physician; NP, nurse practitioner; LPN, licensed practical nurse; MA, medical assistant; SW, social worker; PA, parent advocate.

was conducted at each site consecutively, with only minimal overlap in time. This allowed the study staff to devote time for technical assistance support to each site exclusively and allowed for modification of training procedures to ensure optimal data collection quality. Training consisted of a 2-hour orientation session with all of the data collectors, in which typical case studies were analyzed and scored. A detailed manual for scoring the CCMT, along with printed instructions for data collectors, was provided. A frequently asked questions document was updated and circulated whenever coding questions arose. The central study office held weekly telephone conversations with each site liaison to review the CCMT forms from the previous week, assess compliance with the coding process, and address any questions.

#### Data Collection

All of the staff who performed nonbillable and nonreimbursable CC encounters recorded their data in real time on the CCMT forms. For several practices, it proved more practical (especially for busy triage nurses) to record a minimum of information on the CCMT at the time of the interaction and fill it out in greater detail using their triage logs when they were away from the telephone. Patient level was always determined by the patient's primary care physician or a registered nurse (RN). If the nursing staff had any doubt as to coding patient level, the primary care physician was always consulted.

#### Analysis

Because this study was primarily descriptive, aggregate data and ranges across practices are presented for CC encounter characteristics and outcomes of encounters. Statistical comparisons of proportions across practices were not undertaken, because the diversity of practice types and designs in the sample, along with methodologic variations peculiar to each site, would not support the validity of such analyses. To obtain the direct personnel-based cost of the measured CC encounter, this study used the Occupational Employment and Wages data for 2002 gathered by the US Department of Labor Bureau of Labor Statistics (BLS).<sup>13</sup> It was the most re-

cent, large, national sample and contained all of the staff types measured in this study. These national data are reflective of hourly wages across practice types (eg, private versus staff model). Table 1 lists the occupational code and hourly wage used for cost calculation in this study. For the parent advocate, actual wage data were used, because there was not a comparable BLS position. BLS data for employer costs for employee compensation determined the total benefits percentage for 2003 to be 28%.<sup>14</sup> We did not assess indirect costs (ie, nonpersonnel) costs to the practices.

## RESULTS

### Practice Demographics

Table 2 displays the characteristics of each pediatric practice in the study, as well as the proportion of patients and encounters recorded at each site. Practices were chosen from multiple regions of the United States, and represented diversity of family socioeconomic status, practice sizes, and a number of different models of CC. For example, a practice with no specifically identified staff position called a care coordinator, which shared CC across staff types, was identified as an ad hoc CC model. Other models included designated and compensated CC staff ranging from nurses devoted to serving the CC needs of patients of only certain payers (ie, Medicaid) or certain diagnostic categories (eg, patients with Down syndrome or autism). CC staff was sometimes grant supported and at other times was performed by staff whose salary was carried as overhead for the practice. One practice had a grant to hire a parent advocate, who was specifically trained to support families. In all of the cases, physicians provided much of the CCs necessary to support the patients and families. Although several of the practices in the study supported a teaching mission, none of the sites was principally a teaching site.

### Use of the CCMT

The data collection phase ran from March 5 through October 3, 2003. A total of 3855 encounters were described, representing 3172 patients. Data were collected for a total of 220 days, ranging from 31 to 45 days per

**TABLE 2 Practice Characteristics**

Characteristic	A	B	C	D	E	F
Size	Small group, 2 MDs	Large Group, 9 MDs	Mid-size, 4 MDs	Mid-size, 5MDs	Large group, 11 MDs	Large group, 11 MDs
Reporting MDs	2.0	1.0	1.0	4.0	3.5	1.0
Region of United States	New England	North East	Midwest	West	Southeast	South
Ethnicity, %						
White	Primarily	90	40	58	65	45
Black	NA	5	40	1	25	35
Hispanic	NA	4	10	40	5	20
Asian	NA	1	10	1	5	NA
SES	Middle	Low to middle	Low to middle	Mixed	Low to middle	Mixed
Payer mix, %						
Medicaid	18	5	21	33	12	30
Uninsured	NA	1	NA	3	5	15
SSI	NA	NA	6	1	5	
Commercial	82	94	73	63	78	55
CC model	Ad hoc	RN: specific diagnosis	Ad hoc	FT SW and MAs	Parent advocate and MDs	RN/Medicaid and MDs
No. of data collectors	8	28	4	22	17	13
No. of patients (% total)	421 (13.3)	773 (24.4)	155 (4.9)	737 (23.2)	724 (22.8)	362 (11.4)
No. of encounters (%)	602 (15.6)	872 (22.6)	197 (5.1)	955 (24.8)	827 (21.5)	402 (10.4)

NA indicates not applicable; SES, socioeconomic status; FT, full-time; SW, social worker; MA, medical assistant; MD, physician; SSI, social security income.

site. Ninety-two data collectors participated, representing pediatric physicians, RNs, licensed practical nurses, nurse practitioners, medical assistants, social workers, clerical staff, and a salaried parent advocate. Because a key goal of the study was to assess the feasibility of using the CCMT, we did not aim to capture CC data from all of the staff in each site. Table 2 includes the number of physicians and nonphysician staff using the CCMT at each site. The study was originally planned to capture physician on-call (ie, evening and weekend) CCs, as well as those performed during the “usual” office hours; however, this proved to be inconsistently reported and was eliminated from analysis. Virtually all of the 220 days during which data were recorded were regular office days (ie, Monday through Friday). A “ramping up” period was noted as practice staff became more comfortable using the CCMT. In general, practice personnel were able to integrate accurate and efficient use of the CCMT into the workflow of their office duties after 1 week of using the instrument.

### Characteristics of Care-Coordination Encounters

Table 3 summarizes the number of encounters and patients served as a function of patient level. The range is from 9.4 minutes per encounter for level 1 patients (non-CYSHCN without complicating family or social problems) to 19.3 minutes for level 4 patients (CYSHCN with complicating family or social problems). Thirty per-

cent of the patients in the study were CYSHCN. They received 35% of all of the CC encounters, representing 44% of the total time spent coordinating care in these practices. Note that 50% of CC encounters involved non-CYSHCN with no family or social problems (ie, level 1 patients).

The focus of each encounter is presented in the aggregate for all of the practices and all of the patient levels in Table 4. The majority of encounters were for clinical and medical management. Level 1 patient CC encounters were principally driven by clinical and referral management, growth, education, and social service concerns. Mental health, legal, and social service concerns were prominent for levels 2 and 4 (patients with complicating family or social problems). An education focus was prominent for all 4 of the levels but especially for level 1 patients.

There were 4942 total needs identified for 3855 CC encounters. The substantial majority of needs were for coordination of services among different providers, community-based organizations, and agencies (44%). A significant number of CC encounters (21%) was necessary to reconcile discrepancies between a family’s expectations or understanding and the care plan documented in the medical chart at the primary care office. At times,

**TABLE 3 Patient Level and Time Spent per Encounter**

Patient Level	No. of Encounters (%)	Range Across Practices, %	No. of Patients (%)	No. of CC Minutes (%)	Minutes per Encounter
Level 1	1932 (50)	23–68	1792 (56)	18 161 (36)	9.4
Level 2	559 (15)	3–33	461 (14)	9862 (20)	17.6
Level 3	813 (21)	13–28	617 (20)	11 446 (23)	14.1
Level 4	551 (14)	4–24	302 (10)	10 639 (21)	19.3

**TABLE 4 Focus of Encounter: Aggregate Data**

Primary Focus	Encounters, %	Range Across Practices, %
Clinical and medical management	67	41–85
Referral management	13	4–23
Social services (ie, housing, food, clothing...)	7	1–23
Educational and school	4	1–16
Developmental and behavioral	3	1–7
Mental health	3	1–6
Growth and nutrition	2	1–7
Legal and judicial	1	0–2

**TABLE 5 Activity to Fulfill Needs: Aggregate Data**

Activity	No. Recorded	Total Activities, %	Range Across Practices, %
Telephone	4639	58.3	45–80
Confer with PCP	1266	15.9	5–27
Chart review	609	7.6	3–21
Forms processing	609	7.6	2–14
E-mail	260	3.3	1–10
Meetings or case conference	224	2.8	0–10
Letters or reports	215	2.7	1–8
Patient research or care plans	146	1.8	1–4
Telephone activities according to contact type			
Parent/family	—	39.4	21–65
Patient	—	19.6	5–35
Pharmacy	—	18.4	1–39
Hospital or clinic	—	7.0	2–20
Consultant	—	5.0	2–9
Agency	—	4.0	1–10
School	—	2.8	0–19
Payer	—	2.5	0–7
Home care or vocational training	—	1.3	1–3

these discrepancies reflected miscommunications or lack of clarity in communication among primary care providers, subspecialists, and families. Making appointments and referrals each composed 16% of the encounters, and 30% were used to transmit medical orders. In addition, whereas 76.5% of encounters had a single identified need, ~25% had multiple needs.

Nearly 9% of CC encounters lasted 5 minutes, 48% lasted from 5 to 9 minutes, and 26% took from 10 to 19 minutes. Ten percent of the encounters used between 20 and 29 minutes. Significantly, 75% of all of the encounters fell within the 5- to 19-minute range. A total of 1.8% of encounters required >50 minutes to perform, ranging from 50 to 120 minutes in this study.

There were 7968 recorded activities for the 3855 CC encounters. Table 5 demonstrates that the single most common activity performed in CC encounters was telephone-based encounters. Fifty-nine percent of those calls were between the primary care office staff and the families themselves. Of note is that 1266 activities required consultation with the primary care provider. That represents 33% of the total 3855 encounters. This use of physician time was not reflected under the reported physician time spent and was recorded as time spent by a nonphysician staff person.

### Relationship of CCs to Outcomes

There were 6507 outcomes recorded across all of the study sites. The outcome of a CC encounter was defined as the result of CC activity for the family. Table 6 demonstrates the distribution of all of the outcomes. Note that the result “met family needs” was recorded when the primary care staff addressed a family’s questions or concerns by providing information that did not fall into any of the CCMT outcomes categories. Thirty-three percent of the encounters reflected this outcome. Interest-

**TABLE 6 Outcomes Occurred**

Outcome Occurred	Outcomes Coded, <i>n</i>	Outcomes, %	Total Encounters, %	Range Across Practices, %
Referral	1428	22.0	37	11–43
Met family needs	1290	19.8	33	10–29
Orders	1101	16.9	29	6–54
Advise home management	876	13.5	23	5–24
Reconcile discrepancies	618	9.5	16	4–20
Advocacy for family	525	8.1	14	2–19
Outcome pending	382	5.8	10	1–13
Reviewed labs, etc	274	4.2	7	2–12
Unmet needs	13	0.2	<1	0 to <1

ingly, 16% of encounters were dedicated to resolving “discrepancies,” which resulted either from misunderstanding or miscommunication of information between families and health care providers. “Outcome pending” is the category that captured when care coordinators were unable to complete specific CC activities during the sampling time frame of the study at a given site. Referral management composed 22% of the outcomes. It is important to note that this was not measuring the straightforward administrative task of referrals to subspecialists that is typically expected of primary care providers in managed care models. Generally, these CC tasks involved activities that needed additional work to accomplish referrals, such as referrals to out-of-network providers or to community-based agencies.

Table 7 depicts the number of CC encounters that prevented unnecessary service use. Although the notion of assessing prevention resulting from a CC encounter is quite subjective, the study participants were asked to use the following framework in which to make a judgment: “If you had not taken the time to perform that specific CC activity, what would have been the result?” The CCMT only allows coding for a single prevented outcome. Based on these criteria, 32% of CC encounters prevented a level of resource use that would have gone beyond the primary care setting (eg, emergency department).

Of note, 62% of CC encounters by nurses (RNs) and 33% of CC encounters by physicians resulted in the prevention of more costly levels of service use. Eighty-one percent of prevented emergency department visits and 63% of prevented office visits were accomplished by RN CC encounters.

**TABLE 7 Outcomes Prevented: Aggregate Data**

Outcome Prevented	CC Encounters, <i>n</i>	Aggregate Percentage, %	Range Across Practices, %
Visit to pediatric office or clinic	714	58	47–70
Emergency department visit	323	26	11–41
Subspecialist visit	124	10	9–14
Hospitalization	47	4	0–8
Laboratory or radiograph	16	1	1–5
Specialized therapies	8	1	0–5

**TABLE 8 Direct Cost of Care Coordination According to Staff Type: Aggregate Data**

Staff Type	Encounters, %	Total Time, %	Total Cost, \$	Total Cost, %	Average Cost per Encounter, \$
Physician	16	18	13 713	46	21.63
Nurse practitioner	2	2	472	2	6.74
Registered nurse	32	33	8419	28	6.77
Licensed practical nurse	6	4	619	2	2.80
Clerical	32	25	3423	11	2.79
Medical assistant	7	8	1030	3	3.69
Social worker	4	7	1436	5	10.18
Parent advocate	1	3	865	3	22.76

**Care-Coordination Direct Personnel Costs**

Table 8 presents the aggregate data of CC direct (ie, personnel) costs by staff type as derived from the percentage of time spent performing CCs, and Table 9 displays the proportion of CC encounters undertaken by physicians and RNs from each practice, as well as the costs of providing nonreimbursable CC services in the 6 practices. The cost per CC encounter ranged from \$4.39 to \$12.86.

**DISCUSSION**

Multiple models exist for delivering care coordination within the framework of the pediatric primary care setting. The design of these models is significantly influenced by factors including staff training, family expectations, funding sources, reimbursement mechanisms, and practice-driven “traditions.” This study demonstrates that the staff within a busy, pediatric primary care medical home can use this CC assessment tool. Its design allows it to be integrated into the typically hectic workflow of the office. Practices reported that engaging in this project caused them to be more mindful of the reality that CC is a critical function of a medical home. Giving attention to CC as a measurable function allowed practices to begin to design performance improvement strategies, including improvement of office systems supporting internal care coordination. Furthermore, the data about cost and outcomes have already been used by several of the practices to negotiate with payers to obtain funding to support CC activities.

This study found that CC services are used across patient complexity levels, with level 1 patients (non-CYSHCN, without complicating family or social problems) receiving 50% of the encounters and using 36% of the CC minutes and level 4 patients receiving 14% of the CC encounters and using 21% of the CC minutes. The presentation of an acute, family-based social stressor demands the provision of significant CC services. The patients in levels 2 and 4 represented 24% of the patients served but required 41% of the CC minutes. In fact, level 2 and 4 patients had the highest mean minutes per CC encounter, suggesting 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 CC services.

The amount of CCs can be measured by the time spent performing the activity. In this study, 75% of all of

**TABLE 9 Cost per Care-Coordination Encounter**

Practice Site	Physician CC Time, %	RN CC Time, %	Cost per CC Encounter, \$	Mean Time per CC Encounter, min
A	20	57	7.52	11
B	6	31	4.39	10
C	13	87	12.00	19
D	7	2	5.76	14
E	41	34	12.86	14
F	16	46	7.76	13
Aggregate	18	33	7.78	13

the CC encounters used between 5 and 19 minutes. The measurement paradigm used here has great potential to support providers in documenting their CC activities. Current procedural terminology codes for CC have been developed to enable physicians to bill for CC activities, with a code of 99339 representing 15 to 29 minutes per month and 99340 representing >30 minutes per month overseeing care plan development and implementation.<sup>15</sup> With the ability to bill for these activities, it is even more critical to document the cost and outcomes of CC so that appropriate reimbursement and auditing strategies can be linked to the use of these codes.

It is interesting that the average cost per CC encounter across the individual practices varied from \$4.39 to \$12.86, with an overall mean of \$7.78. The cost was influenced by CC model type, with the principal cost driver being the percentage of CCs performed by physicians. These findings corroborate those in our earlier, single-site study, where the average cost per CC encounter was \$12.27 in a highly physician-driven CC model.<sup>11</sup> The high cost of physician-driven CCs stands in contrast to the apparent high cost-effectiveness of nurse CCs, which prevented a large majority of emergency department visits and sick office visits. This relationship is new, deserves further investigation, and has important implications for how cost-effective CCs should be reimbursed, because no payment mechanisms currently exist for CC services of office nurses.

This study raises the possibility that properly performed CCs may prevent the higher cost of resources. Specifically, 32% of all of the CC encounters prevented unnecessary service use. Of these, 84% led to prevention of either an emergency department visit or an episodic, acute visit to the office for the family. Measuring the specific cost savings of these prevented outcomes is beyond the scope of the current study, although it is highly likely that, given the costs of services prevented, such as ED visits, CCs resulted in a large net savings for the health care system. These savings are substantial for both health care payers and health care systems. They are also appreciable in terms of costs prevented for families as measured by avoidance of time missed from work or school. By extension, employers might experience a benefit if their employees miss less time at work because of CC needs of their CYSHCN being met without requiring face-to-face office visits.

This practice-based, observational study has several limitations. Although the inclusion of a variety of practice designs permitted us to assess a diverse sample of CC mod-

els and collect aggregate, descriptive data, it made meaningful statistical analysis virtually impossible. Data collection methodologies across sites were tailored to the needs of the staffing mix of each site, and, thus, comparability of outcomes is statistically meaningless. Indeed, that was never a goal of our study. In addition, office-based CCs were measured in real time by staff providing the actual CC service. We were unable to independently audit data collection in real time, but we did provide weekly assessments of the data for completeness and internal consistency. In a busy primary care setting, it is not likely that all of the CCs composing CCs on an hour-to-hour basis could be captured. Therefore, it is likely that we underestimated time and effort spent doing CCs. By extension, our measured personnel costs for nonreimbursable CCs are likely to be underestimates. In addition, outcome measures were based on the subjective judgment of the staff person providing the CC service and may not represent the result of the encounter if another observer was asked to render an opinion. However, this is one of the first studies to examine CC outcomes in the practice setting and may serve as a foundation for the development of more robust, validated measures.

We advise caution in generalizing our findings to practice models not represented in this study. Specifically, none of the sites were located exclusively within a university hospital setting, and none of them served a predominantly Medicaid-insured population. Finally, although the aggregation of data across the various practice models is useful to demonstrate the diversity of CC models and outcomes, the descriptive study design and the methodology preclude our ability to perform statistical analyses comparing cost and outcome efficacy of CCs across model types.

## CONCLUSIONS

To provide support to CYSHCN and families within a fully functional medical home model, care coordination must be regarded as an integral and organic pediatric office-based capability. CC must be measurable, auditable, and amenable to continuous quality improvement. This study demonstrates that CC can be assessed at the practice level, as well as across multiple practices, and that the CCMT can be successfully used during the day-to-day operations in a variety of pediatric, primary care settings. Its use can raise awareness among clinical and administrative office personnel of the value of providing CC and its resulting resource use, potentially leading to improvements in the system of CC provision. In addition to the presence of preexisting conditions that qualify a child or youth as a CYSHCN as defined by the US Maternal and Child Health Bureau, the occurrence of an acute, family-based social stressor was a significant driver of need for CC.

The direct personnel cost of providing care coordination within a medical home is influenced by the model of CC for a given practice. A high degree of dependence on physician care coordination may lead to increased costs, whereas the highest-cost prevention may come as a result of the efforts of office-based nurses. Quality improvement techniques must be developed to optimize CC delivery, and appropriate reimbursement strategies

must be informed by these efforts. Additional research efforts to assess the activities that compose CC in other clinical settings, including subspecialty clinics, inpatient settings, Medicaid predominant, and teaching settings, should be made. Measuring the efficacy and time and resource use by families coordinating the care of their own CYSHCN should be done. Furthermore, as additional information is gleaned about the role that CC needs to play to support a robust system of pediatric health care, curricula should be developed to support the evolution of CC as a critical component of a high-performance pediatric health care system.

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### APPENDIX: Medical Home Care Coordination Measurement Tool<sup>®</sup>

Site Code: \_\_\_ Form # \_\_\_ of \_\_\_

Patient Name	Date	Patient Study Code And Age	Patient Level	Focus	Care Coordination Needs	Activity Code(s)	Outcome(s)		Time Spent*							Staff	Clinical Comp.	Initials
							Prevented	Occurred	1	2	3	4	5	6	7			
<b>Patient Level</b> Level Description <b>I</b> Non-CSHCN, Without Complicating Family or Social Issues <b>II</b> Non-CSHCN, With Complicating Family or Social Issues <b>III</b> CSHCN, Without Complicating Family or Social Issues <b>IV</b> CSHCN, With Complicating Family or Social Issues Focus of Encounter (choose ONLY ONE) 1. Mental Health 2. Developmental / Behavioral 3. Educational / School 4. Legal / Judicial 5. Growth / Nutrition 6. Referral Management 7. Clinical / Medical Management 8. Social Services (i.e. housing, food, clothing, ins., trans.) Rev-03/20/03		<b>Care Coordination Needs</b> (choose all that apply) 1. Make Appointments 2. Follow-Up Referrals 3. Order Prescriptions, Supplies, Services, etc. 4. Reconcile Discrepancies 5. Coordination Services (schools, agencies, payers etc.) <b>Time Spent</b> 1 – less than 5 minutes 2 – 5 to 9 minutes 3 – 10 to 19 minutes 4 – 20 to 29 minutes 5 – 30 to 39 minutes 6 – 40 to 49 minutes 7 – 50 minutes and greater* (*Please NOTE actual minutes if greater than 50) <b>Staff</b> RN, LPN, MD, NP, PA, MA, SW, Cler <b>Clinical Competence</b> C= Clinical Competence required NC= Clinical Competence not Required		<b>Activity to Fulfill Needs</b> (choose all that apply) <b>1. Telephone discussion with:</b> a. Patient e. Hospital/Clinic b. Parent/family f. Payer c. School g. Voc./training d. Agency h. Pharmacy <b>2. Electronic (E-Mail) Contact with:</b> a. Patient e. Hospital/Clinic b. Parent f. Payer c. School g. Voc./training d. Agency h. Pharmacy <b>3. Contact with Consultant</b> a. Telephone c. Letter b. Meeting d. E-Mail <b>4. Form Processing</b> (eg. school, camp, or complex record release) <b>5. Confer with Primary Care Physician</b> <b>6. Written Report to Agency</b> (eg. SSI) <b>7. Written Communication</b> a. E-Mail b. Letter <b>8. Chart Review</b> <b>9. Patient-focused Research</b> <b>10. Contact with Home Care Personnel</b> a. Telephone c. Letter b. Meeting d. E-Mail <b>11. Develop / Modify Written Care Plan</b> <b>12. Meeting/Case Conference</b>			<b>Outcome(s)</b> 1. As a result of this care coordination activity, the following was <b>PREVENTED</b> (choose ONLY ONE, if applicable): 1a. ER visit 1b. Subspecialist visit 1c. Hospitalization 1d. Visit to Pediatric Office/Clinic 1e. Lab / X-ray 1f. Specialized Therapies (PT, OT, etc) 2. As a result of this care coordination activity, the following <b>OCCURRED</b> (choose all that apply): 2a. Advised family/patient on home management 2b. Referral to ER 2c. Referral to subspecialist 2d. Referral for hospitalization 2e. Referral for pediatric sick office visit 2f. Referral to lab / X-ray 2g. Referral to community agency 2h. Referral to Specialized Therapies 2i. Ordered prescription, equipment, diapers, taxi, etc. 2j. Reconciled discrepancies (including missing data, miscommunications, compliance issues) 2k. Reviewed labs, specialist reports, IEP's, etc. 2l. Advocacy for family/patient 2m. Met family's immediate needs, questions, concerns 2n. Unmet needs (PLEASE SPECIFY) 2o. Not Applicable / Don't Know 2p. Outcome Pending R. Antonelli, MD, FAAP Supported by grant HRSA-02-MCHB-25A-AB											

**Care Coordination for Children and Youth With Special Health Care Needs: A Descriptive, Multisite Study of Activities, Personnel Costs, and Outcomes**

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