Medical Home Finds Real Estate in a Children’s Hospital: A 7-Year Experience Coordinating Care for Children and Youth With Special Health Care Needs

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Abstract
The Center for children and youth with special health care needs (CYSHCN) at St. Christopher’s Hospital for Children in Philadelphia is one such model and has grown steadily over the last 10 years. The medical home model embraced by the Center for CYSHCN focuses on care coordination, patient- and family-centered care, and integrated communication tools (such as care plans and medical summaries). The vast majority of CYSHCN treated at the Center during this study ranged in age from 6 to 12 years. Of those children, 82% had public insurance, 17% required home-nursing services, 24% required mobility aids, and 16% required enteral nutritional/feeding tubes. The most common diagnoses included developmental delay, intellectual disability, and cerebral palsy. When compared with CYSHCN enrolled in a statewide medical home program, the severity of the medical conditions of CYSHCN cared for at the Center was statistically significantly higher/more complex.

Keywords
children and youth with special health care needs, care coordination, children’s hospitals, medical home

Introduction
The Medical Home

In the United States, approximately 15% of all children and youth have special health care needs according to the 2009-2010 National Survey of Children With Special Health Care Needs (n.d.). As elucidated by Newacheck et al. (1998), the Maternal and Child Health Bureau (MCHB) identifies children and youth with special health care needs (CYSHCN) as those with a “chronic physical, developmental, behavioral or emotional condition” who require “health and related services of a type or amount beyond that required by children generally.” According to Liptak et al. (2006) and Damiano, Moman, Tyler, Penziner, and Lobas (2006), Medical care for CYSHCN represents a portion of the top 10% of health care costs among children, which in turn accounts for 54% of all pediatric health care costs. Yet, in many ways, the social and emotional challenges associated with the care of CYSHCN are of paramount concern; the issues CYSHCN and their families face are at times complex and overwhelming. As a result, patients with chronic conditions can foster time-intensive primary care visits.

Strickland et al. (2004) define the medical home as a framework of health care delivery designed to improve the quality of care received by this vulnerable subset of children. In many ways, this model is the highest standard of care for CYSHCN, incorporating elements of care coordination, family-centered care, and comprehensive health assessments (Sia et al., 2004). First introduced by the American Academy of Pediatrics (AAP) in 1967 as a central repository for children’s medical records, the medical home has evolved over time, and its core tenets are contained in the Affordable Care Act (American Academy of Pediatrics, Council on Pediatric Practice, 1967; Patient Protection and Affordable Care Act of 2010).

In a 2007 joint statement by both pediatric and adult physicians, seven core principles of a patient-centered medical home (PC-MH) were identified (American Academy of Family Physicians, American Academy of Pediatrics, 2007):

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conditions may have encounters with up to 14 physicians in (Turchi, Gatto, & Antonelli, 2007). For example, according to time with primary care providers to maintain optimal health higher rate than other children/youth, often requiring more tals, and urban and rural regions. What is understood and private and public sectors, community and children's hospita- costs of health care.

(b) improve the health of populations, and (c) reduce per cap-

should strive to (a) improve the experience of care for patients, Mulgates Berwick, Nolan, and Whittington's (2008) "Triple

Starfield, Shi, & Macinko, 2005). Furthermore, improving 

pediatric medical home has a long history, and recent literature sug-

gests that this model of care delivery has a favorable impact on patient outcomes, health care utilization, and family-cen-

tered care (Advisory Committee, American Academy of Pediatrics' Medical Home Initiative for Children With Special Health Care Needs, 2002; American Academy of Pediatrics, Council on Pediatric Practice, 1967; Cooley, McAllister, Sherrieb, & Kuhlthau, 2009; Homer et al., 2008; McAllister, Presler, Turchi, & Antonelli, 2009; McAllister, Sherrieb, & Cooley, 2009). The goal of this article is to elabo-

rate on the merits and achievements of a pediatric medical home in clinical practice.

Studies suggest that care delivered in the context of a pedi-

atric medical home has resulted in fewer emergency depart-

ment (ED) visits and hospitalizations while bolstering quality of care and provider satisfaction (Advisory Committee, American Academy of Pediatrics’ Medical Home Initiative for Children With Special Health Care Needs, 2002; Leff et al., 2009; Reid et al., 2009; Steiner et al., 2008). Additional studies have found that health systems constructed around primary care yield more favorable outcomes while maintaining lower expenditures (Grumbach & Bodenheimer, 2002; Starfield, Shi, & Macinko, 2005). Furthermore, improving the experience of care for CYSHCN and their families pro-

mulgates Berwick, Nolan, and Whittington’s (2008) “Triple Aim” for health care delivery. Berwick posits that providers should strive to (a) improve the experience of care for patients, (b) improve the health of populations, and (c) reduce per cap-

ita costs of health care.

Provision of care in a medical home varies between the private and public sectors, community and children’s hospi-

tals, and urban and rural regions. What is understood and accepted is that CYSHCN utilize resources and services at a higher rate than other children/youth, often requiring more time with primary care providers to maintain optimal health (Turchi, Gatto, & Antonelli, 2007). For example, according to Vogeli et al. (2007), patients with five or more chronic conditions may have encounters with up to 14 physicians in one calendar year, thus warranting optimal care coordination and communication among providers.

The Medical Home in One Urban Children’s Hospital

Primary care for CYSHCN may be delivered in a variety of settings, including private practices, hospital-based clinics, community health centers, and practices based in children’s hospitals. According to the Children’s Hospital Association (CHA; 2012), there are currently 47 freestanding children’s hospitals, 152 children’s hospitals within a general hospital, and 19 specialty children’s hospitals in the United States offering comprehensive care for children. There is a paucity of literature describing the experiences of CYSHCN and families receiving care in children's hospital-based clinics. Often, parents/caregivers of CYSHCN seek primary and specialty care for their children at children’s hospitals if geographically convenient. Some families with CYSHCN (particularly in rural sectors) are located far from tertiary care centers and rely on hospital-based medical homes to receive coordinated and comprehensive care. As such, it is critical to explore models of primary care delivery for this fragile pediatric population in a children's hospital setting. This article seeks to describe the experience of a primary care practice for CYSHCN located within an urban children’s hospital.

The Center for CYSHCN at St. Christopher’s Hospital for Children in Philadelphia (an urban health care center) was conceived by primary care physicians and staff who participated in a statewide medical home initiative (www.pamedic-alhome.org). The Center for CYSHCN was founded in 2003 with a stated mission to provide ongoing, comprehensive, and family-centered medical care to CYSHCN and their families and to improve access to services, community resources, and advocacy. It is the Center’s objective to foster opportunities for children to obtain optimal support through life stages and achieve independence. Our study evaluated the Center's medical home implementation over the course of several years.

Background

Center Practices

The Center for CYSHCN branched off from a larger primary care pediatric practice to focus on the provision of comprehensive and coordinated primary care services for CYSHCN and their families. With an initial staff of two pediatricians, a nurse care coordinator, and a population of 140 CYSHCN, the Center now serves more than 1,800 CYSHCN and their siblings with a team of five pediatrics, one nurse practitioner, three nurse care coordinators, two social workers, a health navigator, and four administra-

ive personnel.
The Center for CYSHCN embraces the medical home model of care delivery, in which practice-based care coordination plays a central role. In a 2007 *Pediatrics* article on the benefits of practice-wide care coordination, McAllister et al. identify a method for implementing a model in which team members outline a “vision for care, a framework of structures and processes, and a position description with specific competencies.” The goal of this first step is to test the practice’s service capacity while integrating and evaluating care coordination services. Wagner’s Chronic Care Medical Home Model (CCM) is used as a framework at the Center. This model emphasizes the importance of community resources that serve CYSHCN and their families (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). In addition, the CCM advocates family-centered care in which proactive care teams are omnipresent during all aspects of care delivery.

At the Center for CYSHCN, the entire practice team is involved in coordinating care for patients with special health care needs. The unique aspects of each role (from front desk attendant to physician) cannot be underestimated, and all team members are vital in interfacing with the patient and family (Grumbach & Bodenheimer, 2004). A crucial member of the Center’s medical home team is the practice care coordinator, whose role includes developing medical summaries and care plans, promoting patient counseling about medical and educational services, and increasing access to community resources (Gupta, O’Connor, & Quezada-Gomez, 2004; McAllister, Presler, et al., 2009). The care coordinator works with families during hospitalization, transition from hospital to home, outpatient specialist appointments, and home visits. The coordinator participates in interdisciplinary meetings with home-nursing agencies and equipment companies, and also connects families to resources (such as Early Intervention) and attends Individualized Education Plan meetings. These diverse responsibilities emulate the AAP’s vision for care coordination as crossing multiple systems and services (Council on Children With Disabilities, 2005).

**Method**

**Data Collection and Statistical Analysis**

Data collection and analysis is integral to the growth and quality improvement at the Center. The care coordinator conducts rigorous data collection on resources and health care utilization from the first day that a patient is seen at the Center. In examining data distribution, frequency and percentages of the variables were displayed, and the mean of the Medical Home Index scores for varying services was plotted over the course of 3 years (Cooley, McAllister, Sherrieb, & Clark, 2003). The distribution of the overall burden due to referrals, communication tools, admission, and emergency visits were assessed over a 6-year period from 2004 to 2010. Furthermore, Poisson regression using year as a risk factor was fitted to assess the significant difference in rates and to test the linear trend(s) over the designated years. Ordinal logistic regression was used to assess the difference in diagnostic severity levels between the Center’s CYSHCN population and patients in other medical home practices across Pennsylvania. The above analyses were conducted using SAS 9.2 (SAS, 2008). Data collection efforts for this work were reviewed and approved by the Drexel University College of Medicine’s Institutional Review Board.

**Results**

**Patient Population**

Table 1 shows that the Center’s patient population has increased steadily since its inception. The majority of the Center’s patients are publicly insured. In addition, the Center serves a disproportionate number of children who are

### Table 1. Center for CYSHCN Patient Demographics.

| Age group distribution | Frequency (%) |
|------------------------|---------------|
| 0-1                    | 50 (4)        |
| >1-5                   | 314 (25)      |
| 6-12                   | 489 (39)      |
| 13-18                  | 301 (24)      |
| >18                    | 100 (8)       |

| Insurance              | Frequency (%) |
|------------------------|---------------|
| Public                 | 991 (79)      |
| Private                | 201 (16)      |
| Public + Private       | 63 (5)        |

| Race                   | Frequency (%) |
|------------------------|---------------|
| Caucasian              | 176 (14)      |
| African American       | 426 (34)      |
| Asian/Pacific Islander | 13 (1)        |
| Hispanic               | 514 (41)      |
| Other                  | 125 (10)      |

| Percentage CYSHCN requiring home-nursing services | Frequency (%) |
|--------------------------------------------------|---------------|
| Home nursing                                     | 213 (17)      |

| Percentage dependent on Technology for breathing | Frequency (%) |
|-------------------------------------------------|---------------|
| Enteral nutrition/feeding tube                   | 201 (16)      |

| Percentage requiring mobility aids or medical equipment | Frequency (%) |
|--------------------------------------------------------|---------------|
| Require aids                                           | 301 (24)      |

| Diagnoses                                             | Frequency (%) |
|-------------------------------------------------------|---------------|
| Developmental delay                                   | 288 (23)      |
| Mental retardation                                    | 276 (22)      |
| Cerebral palsy                                        | 251 (20)      |
| Seizure disorder                                      | 176 (14)      |
| Autism                                                | 138 (11)      |
| Genetic syndrome                                      | 125 (10)      |

Note. CYSHCN = children and youth with special health care needs.
dependent on technology when compared with previous estimates (Palfrey et al., 1994).

As a participant in the Pennsylvania Medical Home Initiative (PA MHI) program at the Pennsylvania Chapter of the AAP, the Center used many aspects of evidence-based medical home and quality improvement models (www.pamedicalhome.org). Initially, a comprehensive patient database was developed including the patient’s name, date of birth, diagnoses, insurance, race, home nursing and equipment needs, and a medically determined severity score. This severity score calculation is based on the Phoenix Severity Scoring system developed by Dr. David Hirsch (2001). This system allows practitioners to score the severity of a patient’s medical condition(s) (1 being the least severe and 4 being the most severe) on organ system involvement and psychosocial issues (designated by an “S” after the numeric score).

As shown in Figure 1, the percentage of CYSHCN with severity scores greater than 2 was statistically significantly higher in the Center when compared with other primary care pediatric practices involved in the PA MHI across the Commonwealth of Pennsylvania who do not exclusively treat CYSHCN.

| Severity Score | PA        | Center for CYSHCN |
|----------------|-----------|-------------------|
| 1              | 9025 (58%)| 154 (21%)         |
| 2              | 3184 (21%)| 232 (31%)         |
| 3              | 2470 (16%)| 293 (39%)         |
| 4              | 772 (5%)  | 64 (9%)           |

Figure 1. Percentage of CYSHCN and severity score for Pennsylvania Medical Home Initiative versus the Center for CYSHCN.

Note. The odds of being in the upper end of the severity score for patients in the Center for CYSHCN is 3.6 times higher than those in Pennsylvania. CYSHCN = children and youth with special health care needs. p < .001.

Discussion

Figure 1 demonstrates that patients at the Center are over three times more likely to have severity scores of 2 or higher than CYSHCN in other PA MHI practices. It can be assumed that the Center’s patient population shows a higher rate of medical complexity due to the practice’s focus on primary care provision for CYSHCN through referrals. Regardless of the etiology of this disparity in scores, it highlights the complexity of patients in this practice. Linking severity of diagnosis to time spent on care coordination may help primary care practices determine the appropriate allocation of resources, as well as allotment of staff hours, roles, and responsibilities. It would be worthwhile to corroborate this trend with other care maps and scoring systems in an attempt to predict the levels of services that CYSHCN with particular diagnoses/severity scores might require.

In a study conducted at the Special Primary Care Clinic (SPCC) at the Children’s Hospital of Denver, researchers...
found a distinct correlation between decreased length of stay and increased surgical procedures for CYSHCN cared for in a hospital-based primary care clinic (Berman et al., 2005). Although our study did not examine this variable specifically, it is interesting to examine health care utilization for fragile populations based on distance to tertiary care centers, as few studies focus solely on hospital-based clinics.

Our evaluation of the impact of the Center’s practices for health care utilization demonstrates several interesting trends. As mentioned previously, the overall number of patients enrolled at the Center increased steadily over time. The study identified an intriguing trend among ED visits and hospitalizations over time. There was a statistically significant increase in ED visits over a 6-year period. For hospitalizations, there was a peak in 2009 followed by a decrease in 2010. One explanation for this finding is that by the final year of the observation, care coordination at the Center was institutionalized to such a degree that its multidisciplinary benefits helped prevent unnecessary expenditures with respect to unplanned hospitalizations. For example, some of the CYSHCN with acute needs may have been appropriately treated in the Center or at their specialist’s office due to increased access to care coordination services. This finding is limited in that patient diagnosis may be a confounder. Moreover, the data collected were not able to discern the level of ED visits (acute vs. routine) and planned versus unplanned hospitalizations. It is a finding that warrants future studies that follow the same patient(s) longitudinally to confirm our hypothesis in explaining this trend.

It is clear that there is a natural increase in the number of referrals to specialists over time that mirrors the increase in the absolute number of patients cared for at the Center. When a child with special health care needs is first seen in any practice, there is often an initial increase in service utilization and referrals to community resources as the patient is connected with support services to maintain and improve their functioning. This finding may also explain the plateau in community and mental health referrals as CYSHCN were routinely linked to appropriate resources. Moreover, staff turnover and training may account for some decreases.

The Medical Home Index proved to be an important self-assessment tool. The Center demonstrated statistically significant increases in reported scores over time, which helped define measures of success and best practices for continued medical home utilization. In addition, since community outreach and quality improvement were two of the team’s
lowest initial scores, the index fostered robust efforts to focus on these areas. Assessment of the medical home practice’s increased efficacy over time is a useful exercise in monitoring quality improvement, staff training, and practice expansion (Homer & Baron, 2010).

The practice team is a vital component of any medical home. Defining the roles and responsibilities of all team members is paramount in fostering efficiency and optimal communication (Chen et al., 2010; Grumbach & Bodenheimer, 2004). Among the Center’s medical home team members, the care coordinator spent the most time on care coordination activities by an overwhelming margin. Having a designated care coordinator certainly contributes to this finding. One survey of pediatricians found that the two biggest barriers to providing care coordination services were the physician’s lack of available time and an inadequate number of office staff or allocated hours (Gupta et al., 2004). “Relational coordination”—an emerging health care topic—may prove helpful in overcoming these obstacles (McDonald et al., 2010). This level of care coordination is defined as “a mutually reinforcing process of interaction between communication and relationships carried out for the purpose of task integration.” Relational coordination is particularly relevant to care coordination at the Center; the care coordination “activities” were as important as the team (i.e., families, community partners, physicians, nurses, mental health providers, social works) and the care coordinator performing those activities.

Care planning is one of the most important aspects of the medical home framework at the Center. As outlined by McAllister, Presler, and Cooley (2007), care planning includes the use of an “actionable” care plan with assigned tasks/roles, a care plan document, emergency information form, and/or a medical summary including past medical history and salient specialist information. Practices can use tools such as the Care Coordination Measures Atlas, developed by the Agency for Health Care Research and Quality (McDonald et al., 2010). The Atlas provides a list of activities proposed as a means of achieving coordinated care that is organized by domains and perspectives (i.e., patient/family, health care professional, system representative).

### Figure 3.
Admission and ED visits among the total CYSHCN over the years of 2004-2010.

| Calendar Year (n) | Admissions* | Admission /Patient | ED Visits* | ED Visit/ Patient | Total CYSHCN |
|------------------|-------------|--------------------|-----------|------------------|-------------|
| 2004             | 91          | 0.224              | 113       | 0.278            | 407         |
| 2005             | 179         | 0.396              | 238       | 0.527            | 452         |
| 2006             | 187         | 0.376              | 273       | 0.548            | 498         |
| 2007             | 266         | 0.516              | 336       | 0.651            | 516         |
| 2008             | 325         | 0.505              | 432       | 0.671            | 644         |
| 2009             | 535         | 0.688              | 631       | 0.811            | 778         |
| 2010             | 503         | 0.571              | 761       | 0.864            | 881         |

*Significant increase in rate over the years (p < .001).

**Conclusion**

All children deserve a medical home. The subset of children who have unique medical needs require care coordination and, at times, services in the setting of a children’s hospital. As stated by Palfrey et al. (1994), there are limited data on the prevalence of CYSHCN who are extremely medically fragile (i.e., technology dependent). This small subset of children is the focus of the primary care service delivery in this study. Data collection strategies in a hospital-based clinic may lend themselves to infrastructure and resource planning.

Care coordination has been shown to not be cost prohibitive in practice and essential in practice growth and the establishment of a sustainable medical home model (Antonelli & Antonelli, 2004). Future studies of cost benefit analyses of services rendered (i.e., care coordination) and health care utilization are warranted. Employing these data in reimbursement strategies for care coordination activities is an important next step.

Studies suggest that care coordination favorably impacts family satisfaction while reducing barriers to care (Turchi et al., 2009; Wood et al., 2009). Family satisfaction with care coordination services was not evaluated in this study, but it represents an area for future research. With the future of health care reform and accountable care organizations, data from hospital-based clinics and affiliates may become plethoric (Joint Principles for Accountable Care Organizations, 2010).

Finally, as members of the medical community, we must prioritize care coordination as a “critical and reimbursable element of a medical home” while “creating rigorous, auditable, and broadly applicable training programs” (Turchi et al., 2007). In this quest, we can address Berwick’s “Triple Aim” by partnering with patients and families to redesign primary care, address population health management, achieve solvent financial management, and integrate the systems of care for our patients (Berwick et al., 2008).
Limitations

The data from this study represent one children’s hospital, and thus are not generalizable to all children’s hospitals. However, this study does contribute much-needed knowledge to a limited area of research. In addition, health care utilization analyses were not controlled for diagnoses, severity of condition(s), or unplanned versus planned hospitalizations. These deficits represent areas for future work and research. While the data were collected and recorded by one staff person, recall bias is possible when considering individual care coordination encounters. Finally, the Medical Home Index scores reflect self-reporting from all staff in the Center. As a result, these data may over- or underestimate the level of care coordination activity at the Center.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research and/or authorship of this article: This work was presented at the American Academy of Pediatrics, Future of Pediatrics Meeting, July, 2007, Orlando, Florida, and at the National Quality Colloquium Meeting, June 2008, Boston, Massachusetts.

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**Francis X. McNesby** attended Jefferson University Medical College and completed his residency at St. Christopher’s Hospital for Children. He is an attending physician at the Center for CYSHCN at St. Christopher’s Hospital for Children in Philadelphia, Pennsylvania. He is an assistant professor of pediatrics at Drexel University College of Medicine. He has a clinical interest in children dependent on technology.

**Monica Kondrad** is the senior care coordinator at the Center for CYSHCN at St. Christopher’s Hospital for Children. She is the liaison between families, medical providers, schools, home care providers, community resources, and insurance companies. She is responsible for clinical care of the patient, patient/family education, community outreach and education, and has assisted the program development. She has participated in the Pennsylvania Medical Home program for 10 years and is a leader in care coordination.

**Zekarias Berhane** received his BSc in mathematics from Addis Ababa University, and an MS and PhD in biostatistics from the Graduate School of Public Health at the University of Pittsburgh. He worked as a postdoctoral associate on the development of a generalized model for post-transplant survival and has done collaborative work on analyzing Medicare Database focusing on intensive care unit (ICU) deaths in the Medicare population at the University of Pittsburgh. As a graduate student researcher, he worked on developing an innovative statistical approach to modeling multiple outcome data from the National Surgical Adjuvant Breast and Bowel Project (NSABP) Breast Cancer Prevention Trial (BCPT) and also on the analysis of the Traffic Safety Data Project.

**Angelo P. Giardino** is a professor and section chief of academic general pediatrics at Baylor College of Medicine (BCM), Houston, Texas, and is senior vice president/chief quality officer at Texas Children’s Hospital, Houston. He is a fellow of the American Academy of Pediatrics (FAAP), a distinguished fellow of the American College of Medical Quality, and sub-boarded in Child Abuse Pediatrics by the American Board of Pediatrics. He is a recipient of the Fulbright & Jaworski L. L. P. Faculty Excellence Award. His academic accomplishments include publishing several textbooks on child abuse and neglect and medical education, presenting on a variety of pediatric topics at national and regional conferences, and having numerous published chapters on education, mentoring, child maltreatment, and quality improvement.