An innovative health-care delivery model for children with medical complexity

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Abstract
Children with medical complexity (CMC) account for a disproportionate share of pediatric health-care utilization and cost that is largely attributable to long hospitalizations, frequent hospital readmissions, and high use of emergency departments. In response, the Centers for Medicare and Medicaid Services Health Care Innovation Center supports the development and testing of innovative health-care payment and service delivery models. The purpose of this article is to describe the CMS-funded coordinated health care for complex kids (CHECK) program, an innovative system of health-care delivery that provides improved, comprehensive, and well-coordinated services to CMC. The CHECK program uses a combination of high-tech and low-tech interventions to connect patients, stakeholders, and providers. It is anticipated that the investment in additional support services to CMC will result in improved quality of care that leads to a reduction in unnecessary inpatient hospitalizations, readmissions, and emergency department visits and a total cost savings. The CHECK program has the potential to inform future cost-effective health-care models aimed at improving the quality of life and care for CMC and their families.

Keywords
Centers for Medicare and Medicaid Services (United States), child health, chronic disease, delivery of health care, medical complexity

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Introduction

Children with medical complexity (CMC) represent a growing and crucial group of children with unique medical needs that can be difficult to serve and have a tremendous impact on the health-care system around the world (Cohen et al., 2012; Graham et al., 2016; Judson, 2004). Although the definition varies in the literature, CMC have one or more chronic, severe health conditions, extensive health service needs, often have functional limitations, and have high utilization of health-care resources (Berry et al., 2013; Cohen et al., 2011). It is common for CMC to require complex medical interventions and equipment (e.g., gastrostomy tubes, wheelchairs), and they frequently have complex symptom management (e.g., complex feeding problems, respiratory issues) requiring many appointments and providers (Berry et al., 2013; Elias and Murphy, 2012; Hagvall et al., 2016; McCann et al., 2012; Ward et al., 2015). As a result, they account for a disproportionate share of pediatric health-care utilization and cost, which is approximately 15–33% of the total pediatric health-care utilization and costs in the United States (about US$50–US$110 billion annually) (Berry et al., 2013, 2014; Cohen et al., 2012; Kuo et al., 2011; Neff et al., 2004). The majority of the cost, up to 80%, is attributable to hospital care including long hospitalizations, frequent readmissions to hospitals, and high use of emergency departments (Abraham et al., 2016; Berry et al., 2013, 2014; Cohen et al., 2012; Neff et al., 2004; Neuman et al., 2014; Simon et al., 2012; Statile et al., 2016). In addition, families of CMC are challenged by exceedingly high care needs, increased underemployment and unemployment, and the substantial financial burden that impacts the emotional, social, physical, and economic well-being of their family (Chen and Newacheck, 2006; Ghandour et al., 2014; Kuhlthau et al., 2005; Kuo et al., 2011; McCann et al., 2012; Ward et al., 2015). For example, one study found families with CMC in the United States had at least 10 physician visits in the last 12 months, had a median of two hours per week coordinating their child’s care, and spent 11–20 hours per week providing direct care to their child (Kuo et al., 2011). In this same study, 46% of parents reported out-of-pocket health-care costs that exceeded US$1000 annually, 54% of parents had terminated employment to stay at home and care for their child, and more than half reported financial difficulties (Kuo et al., 2011).

In order to maintain optimal health and manage acute and chronic medical conditions, CMC and their families require comprehensive and coordinated services along the continuum of care to manage their complicated medical needs and facilitate transitions across providers and care settings (Berry, 2015; Cohen et al., 2012; McCann et al., 2012; Morin et al., 2016). However, providing this type of care to CMC is extremely challenging (Berry et al., 2014; Kingsnorth et al., 2015; Matlow et al., 2006; McCann et al., 2012), and often these children receive substandard care that is uncoordinated, fragmented, and crisis driven (Berry et al., 2013; Sobotka et al., 2016). Consequently, this leads to a risk of poor health outcomes (Gordon et al., 2007; Srivastava et al., 2005), particularly for children living in poverty (Bona et al., 2016; Klitzner et al., 2010), and increased emergency department visits, hospitalizations, and hospital readmissions (Berry et al., 2013; Cohen et al., 2012).

The Centers for Medicare and Medicaid Services (CMS) Health Care Innovation Center supports the development and testing of innovative health-care payment and service delivery models that aim to deliver better health outcomes, improved care, and lower costs for people enrolled in Medicare, Medicaid, and Children’s Health Insurance Program (Centers for Medicare & Medicaid Services, 2016). The coordinated health care for complex kids (CHECK) program is funded by the CMS Health Care Innovation Awards Round Two. Detailed below is the design of the CHECK program model. The implementation, operational details, and evaluation of outcomes for specific
program components, economics, and sustainability plan will be described in future manuscripts. The purpose of this manuscript is to describe the design of the CHECK program, a comprehensive model of health-care delivery that expands previous models and is designed to address the unique needs of CMC and their families.

**Methods**

**CHECK program aims**

The aims of the CHECK program are to (a) reduce health-care costs, (b) reduce school absenteeism, and (c) foster greater patient and family engagement in care management for children and young adults with chronic disease.

**CHECK ethical considerations**

The University of Illinois at Chicago Institutional Review Board (IRB) initially determined that the design and formation of CHECK did not meet the definition of human subject research. Specific protocols and analyses that involve CHECK data and/or patients are reviewed, and when appropriate are monitored, by the IRB.

**CHECK program setting**

The CHECK program is located at the University of Illinois at Chicago Hospital and Health Sciences System (UI Health). UI Health is an urban safety net hospital and health-care system that encompasses a large, diverse collection of providers from seven health sciences colleges. UI Health has 22 outpatient care clinics, 13 federally qualified health centers, primary and specialty care for patients of all ages, and pediatric dental clinics. The UI Health primary service area covers approximately 2 million people, which includes many of the poorest communities in Cook County that are struggling with multiple social and economic challenges.

**CHECK theoretical model**

The CHECK theoretical model is an amalgamation of multiple models and approaches designed to create a comprehensive quality health-care delivery system for CMC (Figure 1). While the details of CHECK are described below and in future manuscripts, the CHECK theoretical model parallels the key elements of the chronic care model (CCM), a well-established and commonly adopted framework for improving care for individuals with chronic conditions (Coleman et al., 2009; Stellefson, 2013; Wagner, 1997; Wagner et al., 2001). The premise of CCM is that health systems are embedded in the greater community; and accordingly, partnerships and collaboration between health systems and the community are fundamental to quality care and effective management of chronic conditions. The CCM delineates crucial components of a health-care delivery system including, the health system, community, delivery system design, decision support, self-management support, and clinical information systems (Wagner, 1997; Wagner et al., 2001). The CHECK theoretical model expands these elements by designing a comprehensive health system that addresses specific needs of CMC.
CHECK program components

**Health systems domain.** CHECK has developed a ‘medical neighborhood’ to address the organization of health care and its relationship to the families and communities in an effort to systematically preempt disease complications and potential high-cost medical encounters (Fisher, 2008; Taylor et al., 2011). The medical neighborhood approach expands the ‘patient-centered medical home’ practice model, an integral part of CCM (Berenson et al., 2008), which is focused on the primary care setting to include a neighborhood of other providers including specialists, health plans, hospitals, and other stakeholders (Taylor et al., 2011). Specifically, the CHECK program uses an innovative combination of ‘high-tech’ (care coordination software, disease-specific online health education, short message service (SMS) two-way interaction, online repository of social service referrals,
telehealth-mental health education) and ‘low-tech’ (care coordination and support, mental health services, legal services, and community engagement) interventions to connect children, stakeholders, and providers. The CHECK program establishes a system of family-centered care (Shelton, 1987) to promote engaged, informed children and families as well as a proactive, prepared practice team to reduce health costs, reduce school absenteeism, and increase children and parent engagement. To improve and integrate care transitions, CHECK utilizes community health workers (CHWs) and care managers as well as technology-based smart tools to foster information flow, communication, and coordination of care via partnership with a network of community health providers. To increase access to care, CHECK also brings care to children by utilizing a mobile van, school-based clinics, in-house mental health services, and an online repository of social and clinical service resources based on children’s zip codes. Transportation is coordinated by CHWs for children and their families, and a network of community clinics provides local access to care linked by technology to the tertiary care center at UI Health. To enhance family and community engagement, children and families are involved in the care planning process and parents serve on CHECK advisory boards. Finally, disease-specific interventions were developed for diabetes, sickle cell disease, asthma, prematurity, and mental health conditions that can be delivered via an integrated platform of web-based education, two-way SMS interactions, phone coaching, paper handouts, and direct interventions. The CHECK delivery system is designed to offer effective, efficient clinical care and self-management support for children and families (Wagner, 1997; Wagner et al., 2001).

**Technology and data team.** Emerging evidence indicates that the use of health information technology has both quality and economic benefits in the management of chronic diseases (Rao et al., 2012). The CHECK technology and data team utilizes a variety of customized health technologies to provide disease-specific self-education, initiate behavior changes, and enhance care coordination to better support children, their families, and caregivers managing chronic health conditions. These health technologies use an integrated health insurance portability and accountability (HIPAA) compliant platform collecting patient-level data that allows for self-efficient disease management and effective care coordination. The goal of such technologies is to enhance children’s health through services that focus on the social determinants of health.

**Care coordination team.** The CHECK care coordination team provides services to all engaged children and their families. CHWs, in conjunction with the other service providers, develop individualized care plans to address the child and family needs that were identified in the initial comprehensive assessment. The child-centered and family-centered care plan summarizes the medical strategy developed by the primary provider and includes a care coordination plan for delivering needed education, mental health, and support services. CHWs are the primary points of contact with children and families outside of clinical services, and they provide a wide variety of individualized supportive social services to the child and his or her entire family (Hsu et al., 2016; Johnson and Gunn, 2015). Recognizing the importance of addressing barriers to care, services include assistance scheduling medical appointments, arranging transportation to and from appointments, medication management, and providing referral resources for housing, child care, legal assistance, and other services. Children also receive timely reminders regarding appointments, medication refills, and other activities by telephone and/or text, depending on the family’s preference. Children’s missed clinic and lab appointments, hospitalizations, and emergency department visits are monitored and addressed directly with each family. CHWs contact the families to obtain additional information about barriers, provide additional support to children,
reschedule missed appointments, and address issues to prevent future unnecessary hospitalizations and emergency department visits.

**Mental health promotion team.** We developed a stepped care model of service delivery that provides a continuum of mental health services to CHECK children and families based on their level of need. The mental health promotion team administers mental health screenings and assessments to all engaged CHECK children and their parents to determine the level of mental health service needs. A variety of mental health services are provided within four major categories including preventive interventions, consultative services, direct interventions, and referral services to community-based mental health providers. At a minimum, preventive mental health services are available to all children and families through self-directed online modules, DVD mailings, and SMS messages. Brief evidence-based interventions and referrals to community and specialist providers are provided for both children and their parents with more severe mental health symptoms and/or impaired functioning.

**The legal services team.** The CHECK program developed a partnership with the Legal Council for Health Justice, Chicago Medical-Legal Partnership for Children program that aims to use the power of the law to improve the health and well-being of Cook County children with serious chronic illnesses. The legal team offers legal assessment, consultation, and assistance to all enrolled CHECK children and their families. The CHECK onsite legal team has one attorney and two advocates that focus on supporting child’s health by addressing education, income, housing, and family stability issues. For example, many of the CHECK families need legal assistance to obtain special education services and public benefits for their children with disabilities.

**Provider support services.** CHECK has a team of subspecialty medical directors representing asthma, diabetes, prematurity, sickle cell disease, oral health, mental health, development, and community pediatrics. These subspecialty medical directors contributed to the formation of best practices guidelines for the management of each of the target diseases. These guidelines are available for all CHECK clinical partners. The subspecialty medical directors also provide general advice and support for the CHWs and care coordinators as well as consultation on specific cases when needed. They are also available for consultation from clinical partners.

**Community domain.** The CHECK health system is embedded in the larger community. The CHECK program has built a comprehensive health delivery system that is a community-based medical neighborhood network of affiliated clinics, providers, and community partners to support the effective care management for CMC. The CHECK community engagement team developed relationships with and serves as the liaison between the CHECK health system and key community partners including, community health centers, subspecialty medical services, community mental health providers, community dental providers, schools, and social service providers. For example, the CHECK program developed a partnership with a community dental mobile van to provide free, basic dental care to CHECK patients in their neighborhood.

**Eligibility**
Children were enrolled into the CHECK program beginning on December 1, 2014, and enrollment is ongoing. Eligibility criteria includes children and youth (1) aged 25 years or younger at the time
of enrollment, (2) are enrolled in traditional Medicaid (fee-for-service) or one of the managed care plans, and (3) have a diagnosis of asthma, diabetes mellitus (type 1 or 2 if on daily diabetes-related medication), sickle cell disease, or prematurity (discharged from neonatal intensive care unit less than six months from date of enrollment).

Enrollment

The CHECK program enrolls eligible children receiving care at UI Health and from multiple partnerships with other Cook County providers. Medicaid paid claims data are examined to determine the child’s eligibility for the CHECK program. After identifying the potentially eligible child, a letter of enrollment is sent to the child and their family. The letter provides information about the CHECK program, including the extra services that are available, and informs the child that he or she will continue to see their regular primary care provider. The letter also states the child and their family may opt-out of the CHECK program. After two weeks, all recipients receive a follow-up phone call from CHECK staff to verify receipt of the letter and to confirm enrollment in the CHECK program. Once verbal confirmation is obtained, the CHECK program staff conduct an initial baseline assessment to determine the child’s medical and social service needs. CHWs attempt to contact children and/or their caregivers at least four times by phone and attempt to conduct one in-person visit (home or clinic). As of September 2016, the CHECK program has enrolled 13,802 children.

Conclusion

Results from the CHECK program will provide crucial information about the development and testing of an innovative health-care model that delivers improved, comprehensive, and well-coordinated care for CMC enrolled in Medicaid. To date, we have made significant progress in building and implementing the CHECK program infrastructure, and almost 14,000 CMC have been enrolled in the CHECK program. Subsequent manuscripts will describe the methods and operational details of the CHECK services, data collection process, community engagement, sustainability, and evaluation of the multiple outcomes. Data are being collected about children’s demographic, medical, financial, and school information (i.e. electronic medical record, managed care claims, questionnaire/assessment, school attendance) and about CHECK services to children (i.e. assessments, services, contacts, referrals). With the data collected over the course of the grant, we will be able to quantify the expense needed to properly deliver care to CMC as well as gain critical insights about the most impactful of these interventions. This will facilitate further fine-tuning and focusing of resource deployment to those areas in an effort to continue to increase quality of care while driving down the costs. The CHECK program is an innovative model of health-care delivery that has the potential to inform future cost-effective health-care models aimed at improving the quality of life and care for CMC and their families, both in the United States and elsewhere. Providing adequate care for CMC is a challenge to health systems around the world (Judson, 2004). CMC require medical care from a variety of providers which strains systems that are attempting to increase care delivery while limiting costs (Freund et al., 2015; Sibbald et al., 2004). CHECK offers a model for how to merge social and health services in order to obtain improved care for these children. While children everywhere would benefit from comprehensive well-coordinated care, the CHECK model may be premature for low- and middle-income countries where access to basic health care is the first priority (Graham et al., 2016). Also, implementation of
a model such as CHECK may not be necessary in countries where strong connections already exist between health-care and social service systems. Finally, it is not yet known if the CHECK model translates into improvements in outcomes or if changes in outcomes can be captured within the constraints of this quality improvement design.

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