Establishing the Child Health Accountable Care Collaborative: An Analysis of the Implementation of a Statewide Pediatric Public Health Program

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A Master’s Paper submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Public Health in the Public Health Leadership Program

Chapel Hill

2013

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Abstract

Introduction: The Child Health Accountable Care Collaborative (CHACC), funded by a CMS Innovations grant, aims to improve care for children with complex medical conditions. This paper explores CHACC’s implementation.

Background & Significance: Fragmentation of the U.S. health care system diminishes efficiency, resulting in potential reductions in quality and affecting cost of health care. This directly influences the value (quality/cost = value) of health care. Families and home caregivers for children with complex medical conditions often report disjointed health care, financial difficulties in part associated with missed work and lost wages, and substantial time spent coordinating medical care themselves. Lapses in care coordination for these children may contribute to higher health care expenditures. CHACC provides specialty care coordination services intending to improve comprehensive care through enhanced communication among those participating in the care of children with complex medical conditions.

Methods: I conducted 10 in-depth interviews with key elite stakeholders and CHACC staff members to explore critical components of implementing CHACC. I transcribed each interview verbatim and coded the transcripts to identify emerging themes.

Findings: The Community Care of North Carolina program, within which CHACC is embedded, provides an indispensable infrastructure, though also presents challenges for CHACC’s implementation. Staff members have defined an innovative role as specialty care coordinators and patient navigators who intend to improve communication between health care professionals involved with the child’s care. Staff members must assess and integrate into current care management structures. CHACC staff members must pay considerable attention to improving communication among care providers. Identifying patients to enroll in CHACC is an ongoing
challenge because the program must determine which children with complex medical conditions would benefit most from enrollment in the program. CHACC leaders, therefore, hope to develop a predictive model to facilitate enrollment decisions; in that model’s absence, however, CHACC staff members must dedicate substantial time to locating patients to enroll.

Discussion: CHACC is an innovative strategy to improve health care coordination through embedding care managers and patient coordinators, who work to improve communication among health care teams, within specialty clinics and hospitals. Dissemination of CHACC’s strategy and methods may lead to higher value medical care for children with complex illnesses. A reproducible method to identify patients who will benefit from enrollment in the CHACC program is needed.
Acknowledgements

First, I would like to thank both of my Master’s Paper readers, Dr. Sue Tolleson-Rinehart and Dr. Alan Stiles, for their support and guidance with both my research project and my paper. Dr. Tolleson-Rinehart provided invaluable mentorship throughout the many months preceding the completion of this research project and Master’s Paper, generously offering her time and resources. She also encouraged me to persevere when challenges arose. I also genuinely appreciate the time, insight, and advice that Dr. Stiles kindly provided during the conceptualization of my research project and subsequently during my writing of this paper.

Thank you also to everyone working with the Child Health Accountable Care Collaborative, for allowing me the privilege of working with you all and the opportunity to witness the ongoing development of this important program.

Thank you to all of the interview respondents who generously contributed your time and insight, making this research project’s completion possible. I sincerely appreciate your help.
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Introduction

The passage of the Patient Protection and Affordable Care Act (ACA) marked a defining moment in recent United States history. After many appeals to revamp the health care system, and numerous attempts to accomplish health care reform, the nation at last seized an opportunity to enact reform (Berwick, 2002; Gawande, 2009; Oberlander, 2012). Implementing large-scale health care reform, however, poses challenges on many fronts. Implementation requires cooperation among policymakers – both state and federal – and important stakeholders, in addition to contending with reform opponents (Kersh, 2011).

One particular example of implementing this vast policy is a program in the state of North Carolina, the Child Health Accountable Care Collaborative (CHACC). CHACC intends to improve care for a vulnerable pediatric population, children with complex medical conditions ("Child Health Accountable Care Collaborative," 2013). Although only five percent of North Carolina’s pediatric Medicaid population (0-21 years of age) meet criteria for children with special health care needs (CSHCN), these children account for 53 percent of the state’s pediatric Medicaid expenses ("Child Health Accountable Care Collaborative," 2013). Children with complex medical conditions, an important subgroup of CSHCN, have medical fragility and substantial care needs that existing health care systems struggle to meet (Cohen et al., 2011).

Pediatric health practitioners recognize the need to coordinate care for CSHCN, who require a complex network of medical and community services to ensure comprehensive care (Stille & Antonelli, 2004). Primary care pediatricians report substantial barriers to care coordination for CSHCN, however, including insufficient time, office staff, and training in this area (Gupta, O'Connor, & Quezada-Gomez, 2004). Parents of CSHCN indicate receiving inadequate care coordination support; families of more medically complex CSHCN report
financial difficulties and employment barriers relating to their child’s health, in addition to unmet medical needs (Kuo, Cohen, Agrawal, Berry, & Casey, 2011; Strickland et al., 2004). The intensive medical needs, community-based service needs, and technology dependence of children with complex medical conditions yield a greater need for coordinating care for this population (Cohen et al., 2011).

As North Carolina’s novel effort to address these problems and make progress toward the triple goals of more effective treatment, reduced costs, and better patient and family experiences of care, CHACC provides care coordination services as a tool to foster collaboration among the providers involved in caring for children with complex medical conditions. CHACC utilizes care coordination to improve the quality of care children with complex medical conditions receive. By reducing service duplication, improving adherence to plans of care, and improving communication among providers, CHACC also targets cost reduction for this population’s care. In addition, CHACC intends to improve patients’ and families’ experiences by embedding patient and family advocates in the health care system. This paper explores the process of implementing CHACC, seeking to elucidate critical components of the program’s implementation and offer insights for others undertaking similar programs.

**Background and Significance**

The ACA aspires to reform the current health care system in an effort to reduce health care expenses while improving quality of care. In one of many resolutions with this goal, the ACA established the Center for Medicare and Medicaid Innovation within the Centers for Medicare and Medicaid Services (CMS) (Patient Protection and Affordable Care Act, 2010). Congress tasked the Innovation Center with testing “innovative payment and service delivery
models” (Patient Protection and Affordable Care Act, 2010). The Innovation Center provides rapid and ongoing evaluation of models being tested; using the resulting data, the Secretary of Health and Human Services may choose to expand promising models (Shrank, 2013). The Innovation Center must prioritize programs improving service coordination, quality, and efficiency (Shrank, 2013).

The United States health care system’s insufficient coordination of care has drawn substantial attention for many reasons. The health care system consists of multiple layers of care, including outpatient primary care facilities, outpatient specialty care, and various levels of inpatient care (see Figure 1). Thorough communication between these independent entities is difficult to ensure, often resulting in incomplete information exchange and disconnected plans of care. Fragmentation reduces the quality of care that patients receive, creates difficulty for patients navigating the complex medical system, and leads to costly errors, waste, and service duplication (Shih et al., 2008). In an analysis of wasteful spending in the U.S. health care system, Berwick and Hackbarth estimate that in the year 2011, failed coordination of care resulted in $25 to $45 billion of unnecessary, wasteful health care spending (Berwick & Hackbarth, 2012).

The necessity for coordinated medical care is particularly significant for CSHCN. The Maternal and Child Health Bureau defines CSHCN as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998). Children with medical complexity are a subset of CSHCN with medical fragility and substantial health care needs (Cohen et al., 2011). In addition to these

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1 Children with medical complexity have been referred to by many other terms, including “children with complex chronic conditions” or “children with complex medical conditions.”
medical needs, children with complex medical conditions often have functional limitations that require technological support, such as feeding tubes or wheelchairs; experience multiple or prolonged hospitalizations; and may require hospital readmissions because of medical fragility ("Child Health Accountable Care Collaborative," 2013; Berry et al., 2011; Cohen et al., 2011). This population’s medical complexity and fragility, along with their need for multiple health care providers and other services, lead to a heightened need for care coordination (Cohen et al., 2011).

Studies examining fragmentation of care for children with complex medical conditions confirm deficiencies in care coordination that present multiple challenges to caregivers. In one study, parents of children with complex chronic conditions reported inadequate continuity in their children’s care and related services (e.g., school resources). Parents perceived service providers in separate institutions as disconnected, and often filled this communication void themselves; although some parents believed that coordinating care is a necessary responsibility with which parents should feel comfortable, others found this a difficult and frustrating duty (Miller et al., 2009). An analysis of the 2005-2006 National Survey of CSHCN examined hardships among caregivers for more complex CSHCN, a population comparable to children with medical complexity.² Coordinating and providing medical care consumed substantial time for these families; caregivers reported a median of 11 to 20 hours per week providing direct home care, and a median of two hours per week coordinating care. Families also reported unmet needs and financial burdens; 48.8% of children experienced unmet medical needs, and in greater than half of families, a family member ceased work because of the child’s health (Kuo et al., 2011).

² Authors defined more complex CSHCN as having at least one chronic condition leading to elevated service needs, functional impairments necessitating medical equipment, multiple subspecialty providers, and elevated health service use.
One parent’s account of seeking care for her son’s undiagnosed complex condition illustrates the confusion, stress, and demands on time and energy that a caregiver experiences when navigating a disconnected medical system. This mother discusses the necessity to learn as many details about her son’s condition as possible, allowing her to communicate effectively and knowledgeably with her son’s health care providers. Additionally, she describes the struggle to assimilate vast, sometimes inconsistent information about her son’s health care, and to evaluate treatment recommendations based on this information. She must also coordinate medical records and procedures, and she attends so many medical appointments that staying abreast of her own work responsibilities is challenging (Ghose, 2003).

In addition to presenting formidable demands for parents, many studies suggest that insufficient care coordination results in elevated health care utilization and expense. In one study, although children with medical complexity comprised less than one percent of all children in Ontario, their health care expenses constituted nearly one-third of total pediatric health expenses. Hospitalizations constituted a sizable portion of their medical expenses, and re-hospitalizations accounted for over one-quarter of the total cost of their care. In this population, emergency department visits contributed a relatively low proportion of total health care expenses (0.4%) (Cohen et al., 2012). In a study of U.S. children’s hospital admissions, less than three percent of children experienced at least four hospital re-admissions within any one-year interval during the study’s five-year span. This small fraction of the population accounted for nearly one-quarter of inpatient expenses. More than one-quarter of re-admissions resulted from problems in the same organ system, leading authors to propose careful re-admission prevention services to reduce re-hospitalizations for these children (Berry et al., 2011).
Problems relating to this population’s health care – including lapses in communication, stress for families, and expense – have driven many interventions to improve care coordination for children with medical complexity. In one example, Arkansas Children’s Hospital launched a hospital-based multidisciplinary clinic to coordinate care for Medicaid-enrolled children with medical complexity. Following program enrollment, inpatient care costs declined dramatically, emergency department costs fell, and overall cost of care for each Medicaid patient decreased (Casey et al., 2011). Another study evaluated the effects of a hospital-based complex care clinic on parent and provider perceptions, parental quality of life, and health care utilization. This initiative demonstrated a reduction in hospital admission days and a rise in outpatient visits. Satisfaction and quality of life measures indicated improved parental quality of life, increased parent satisfaction with many aspects of care, and provider approval of the program (Cohen et al., 2010). To enhance communication among various providers involved in caring for medically complex children, another program coordinated care among tertiary and primary care providers. Similarly, following program enrollment, outpatient service use increased while hospital days and overall health care expense declined. Although the study did not formally evaluate parent and provider satisfaction, authors observed that both parents and providers indicated program approval (Gordon et al., 2007).

The state of North Carolina has a long, robust history of fostering communication between providers, initiating quality improvement strategies, and reducing health care expenses for its Medicaid population, through the Community Care of North Carolina (CCNC) program (Steiner et al., 2008). CCNC provides statewide support and infrastructure through 14 locally-operated networks, allowing local implementation tailored to each network’s environment. Local physicians, hospitals, health departments, and departments of social services organize and
manage each independent community network, and representatives from each of these entities serve as network leaders. These individuals make decisions about implementation of quality improvement initiatives or other programs in the network based on community needs. CCNC encourages collaboration among community practices and within each network, therefore allowing local ownership, fostering valuable partnerships, and encouraging active participation of community organizations. Additionally, CCNC connects each patient to a medical home that provides care coordination services and improved access to care. Care managers within the medical home use CCNC’s care management software system to view Medicaid claims data, monitor clients’ health care utilization, and communicate with other care managers (Steiner et al., 2008).

At a broader, statewide level, CCNC provides support to the local networks in multiple ways. The CCNC organization offers financial assistance to each network, in addition to arranging meetings and developing clinical protocols. CCNC generates practice-specific data to provide feedback to individual practices about clinical performance (e.g., aggregate blood pressure measurements or lipid levels for all patients of one practice) ("Special Programs and Initiatives," 2013; Steiner et al., 2008). CCNC also administers a web-based Informatics Center that allows exchange of health information, including laboratory results, pharmacy and claims data, and information from patient medical records. Participating health care providers and other health care team members can visit the Informatics Center for assistance with communication, care coordination, and monitoring quality of care ("Provider Portal," 2013; "Truth in Numbers," 2013). In addition to various forms of support, CCNC conducts pilot programs seeking to improve care or to test new models of care; CCNC may choose to expand successful pilot programs statewide (Steiner et al., 2008). Thus, separate networks benefit from the resources
CCNC offers, the initiatives that CCNC tests and disseminates, and the ability to utilize CCNC resources and programs in a manner that suits the local environment.

The CMS Innovation Center awarded CCNC a three-year grant to implement CHACC, a novel service delivery model fitting the Innovation Center’s goals of enhancing quality and efficiency of care and reducing cost of care. CHACC seeks to promote cooperation among the health care providers caring for children with complex medical conditions ("Child Health Accountable Care Collaborative," 2013). These children account for a substantial proportion of North Carolina’s pediatric Medicaid expenses; therefore, CHACC employs several methods to curb inefficiency in care, improve coordination and quality of care, reduce costs, and enhance patient and family satisfaction.

Building on CCNC’s infrastructure of primary care medical homes with embedded care managers, CHACC places care managers within academic medical centers, tertiary hospitals, and specialty clinics to improve specialty care coordination and shared responsibility among subspecialists and primary care physicians. The CHACC care manager’s primary role is to coordinate patients’ medical care. As a significant component of this role, CHACC care managers work with the health care team to develop comprehensive treatment plans for each patient. The patient’s treatment plan lists active and inactive diagnoses; outlines medications, including dosage and frequency; describes a management plan for specific diagnoses, as well as alarm signs for the related organ system; and lists contact information for different providers who participate in the child’s care. Additionally, CHACC care managers update the treatment plan when the patient’s plan of care changes – for instance, during specialist visits or hospitalizations. CHACC staff members disseminate each patient’s comprehensive treatment plan to care managers and providers who contribute to the child’s health care (L. Guerrant,
personal communication, April 17, 2013), thus improving communication among health care team members about patients’ individual medical needs.

CHACC care managers also work closely with primary care managers to coordinate patient care and foster communication between members of the patient’s care team. For example, CHACC care managers collaborate with community-based care managers to ensure that the comprehensive treatment plan thoroughly addresses patient and family needs. CHACC care managers also work with community care managers to assure that patients’ medical needs are met effectively; for instance, CHACC staff members may arrange conferences in which various care managers discuss a particular patient’s plan of care and treatment needs. Similarly, CHACC staff members facilitate communication between different providers participating in a child’s care to ensure effective information transfer and thorough communication of care plans between providers. CHACC staff members, for example, distribute the treatment plan to providers, and also work with community care managers to ensure that primary care physicians receive from the specialty clinic or hospital all information pertaining to mutual patients' care.

After establishing a comprehensive care plan and effectively coordinating a patient’s medical care, CHACC care managers may entrust care coordination responsibilities to the patient’s community care manager in a “warm handoff.” Following this warm handoff, CHACC care managers continue to serve as a resource for community care managers, remaining available to address questions or needs. CHACC care managers again intervene to coordinate the patient’s medical care when specialist visits or declining patient status warrant further CHACC assistance with clarifying and coordinating medical care needs (L. Guerrant, personal communication, April 17, 2013).
In addition to the CHACC care managers’ role of coordinating medical care, CHACC promotes coordination of care in multiple ways. CHACC patient coordinators collaborate with care managers to facilitate patients’ and families’ access to services, assisting families in navigating the complex medical system and associated resources. For example, patient coordinators may help families schedule medical appointments, secure transportation to appointments, and obtain durable medical equipment. Thus, CHACC patient coordinators and care managers work together as a team to meet the comprehensive needs of the patient and family. Additionally, to enhance provider co-management of mutual patients, a web-based communication system allows secure information exchange between providers. Providers may also access a patient’s comprehensive treatment plan using this communication system after CHACC staff members upload the treatment plan into the system (L. Guerrant, personal communication, April 17, 2013). Also, CHACC assembles groups of primary care and subspecialty physicians to develop guidelines for common pediatric chronic conditions, in an effort to assist primary care providers with managing these conditions without subspecialist referral, and to more appropriately refer patients to specialists when necessary (“Child Health Accountable Care Collaborative,” 2013).

The writing of this master’s paper occurs during a tumultuous time in North Carolina’s political arena. Citing a need to reform the current Medicaid system, Governor Pat McCrory recently signed legislation declining to expand the state’s Medicaid program to all individuals below 138 percent of the federal poverty level, as authorized in the ACA (Frank, 2013). As state policymakers contemplated and later reached a decision not to expand Medicaid, substantial controversy developed among health care providers, elected political leaders, and the public (Conover, 2013; Leslie, 2013). Republican leaders of the state Senate and House have agreed
with the Governor that North Carolina must reform its current Medicaid system to create a predictable and sustainable budget, reduce expense, and improve system efficiency; the state’s current elected leaders have begun efforts to institute Medicaid reform ("Governor Pat McCrory Announces Joint Effort," 2013). The state’s health policy leaders and health care professionals anxiously await policymakers’ final determination of details for Medicaid reform, especially the implications of Medicaid reform for CCNC and the possibility of commercial Medicaid managed care companies entering North Carolina. The CHACC program’s implementation, therefore, builds on CCNC’s adept statewide infrastructure, yet occurs amidst ongoing debate about the state’s Medicaid system and its fate, potentially jeopardizing both CCNC and CHACC.

**Methods**

In this paper, I triangulate information from in-depth interviews and a review of the scientific literature to explore CHACC’s implementation. Because CHACC seeks to improve patient care, enable more effective use of health care resources, reduce health care costs, as well as to enhance caregiver satisfaction, I performed a systematic review of the literature to explore how pediatric Medicaid managed care programs affect parent satisfaction. The methods and results of this systematic review are presented in Appendix 1.

After receiving notification that the University of North Carolina Institutional Review Board considered our research study exempt from further review, my advisors and I began recruiting participants for interviews of CHACC key elite stakeholders and staff members. We sent a standardized informational email message presenting the research study to seven key elite stakeholders, six of whom agreed to participate. We also sent a brief email message to 12 CHACC lead care managers, requesting permission to contact CHACC staff members in their
local networks about the study. Five lead care managers agreed for us to contact their local networks with more project details. Next, we sent a standardized informational message to those five lead care managers, in addition to the CHACC staff members within their networks. In total, we contacted nine CHACC staff members, four of whom agreed to participate in interviews. A list of interview participants is provided in Appendix 2.

In this research study, I conducted 10 individual telephone interviews, each ranging from 40 to 60 minutes, using standard interview protocols. I conducted all interviews in May or June 2013. Interview participants included four CHACC medical directors, the CHACC program manager, three CHACC care managers and one CHACC patient coordinator, as well as an additional key elite stakeholder. I used separate interview protocols for the key elite stakeholders and the CHACC staff members, customized to their distinct roles and expertise. Prior to conducting the interview, I read a standard informational notice to introduce myself, describe the project in detail, and obtain permission to audio-record the interview for later transcription. I also sought permission to include the respondent’s name and title, as well as to use direct quotes, in this paper and any publications resulting from the study. I respected requests for anonymity and for participant approval of direct quotes prior to inclusion in this paper or resulting publications. The interview protocols, along with the preceding informational notices, are located in Appendix 3.

After conducting the interviews, I transcribed each interview verbatim and verified the interview participant’s approval of the accuracy of the transcript. I subsequently coded all interviews to identify emerging themes. First, I identified variables present within interview questions as well as in recurrent concepts observed in interviews. Next, using a Microsoft Excel 2010 workbook, I coded interview transcripts using numerical codes when appropriate for the
variable, and classifying data for string variables using textual analysis of participant responses. I used this codebook to analyze the data for common themes and noteworthy confluence or divergence of participants’ responses.

**Findings**

Interview findings reveal several underlying themes that clarify elements critical to CHACC’s implementation. These themes arise from recognition of the setting in which the program evolves, consideration of the environment during the program’s implementation, integration of the program into care management structures and health care systems, and identification of suitable patients for enrollment. Finally, because CHACC seeks to reduce health care expenses by coordinating patient care, I present relevant financial considerations. A summary of themes is provided in Tables 1 and 2.

**Program Setting: Recognizing the State and Local Environment**

A majority of interview respondents emphasized the importance of the environmental context of CHACC’s implementation. Respondents highlighted various specific characteristics of the environment, including the CCNC networks in which CHACC’s implementation occurs, the resources CCNC provides to CHACC, outside care coordination groups with whom CHACC staff members collaborate, and local resources available for families.

Four key elite stakeholders directly emphasized the importance of Community Care of North Carolina (CCNC) as CHACC’s foundation, although they presented differing interpretations of CCNC’s effects on CHACC. The remaining two key stakeholders each described CCNC providing resources essential for CHACC, indirectly attesting to CCNC’s
invaluable role in CHACC’s establishment. Three respondents discussed the infrastructure that CCNC offers for CHACC; Dr. Betsey Tilson, a CCNC network medical director and member of the CHACC advisory committee, specifically cited CCNC’s “Care Management Information System, and provider portal” as assets for CHACC. Dr. David Tayloe, a pediatrician in eastern North Carolina who is also a member of CHACC’s advisory committee, also emphasized CCNC’s infrastructure. Dr. Tayloe said that as a statewide Medicaid program, CCNC provides a venue to “bring everybody in the state together to focus on a single problem,” in a program such as CHACC. Two CHACC advisory committee members elaborated on CCNC’s role in uniting health care providers; in a compelling illustration, Dr. Tayloe described health care providers as “bound into the tradition of Community Care.”

In addition to the benefits of CCNC’s structure, three respondents explained that CCNC’s structure presents challenges to CHACC’s implementation, as well. Dr. Tilson described CHACC’s implementation “drawing from the strengths of the networks and the local resources,” yet also explained that implementing CHACC is “not a very simple, one-size-fits-all” approach. Because networks enact CHACC autonomously, shaping its program-wide goals to their own conditions, independent networks benefit from the ability to establish the local organization in a manner that best suits their environments; however, networks must also devote time and energy to deciding how CHACC will work best in their particular settings. As three stakeholders explained, separate networks conduct work processes differently, such that CHACC’s implementation varies from network to network. Operating a unified organization with common goals and outcomes – but enacting distinct, separate processes in different networks to achieve those outcomes – poses challenges, not least of which is obtaining statewide data “in a
consolidated report” to allow program-wide evaluation (L. Guerrant, personal communication, May 22, 2013).

Additionally, each CHACC staff member addressed the critical importance of recognizing and working within the environment. Each CHACC staff member discussed working with available community resources and care coordination services for children and families. Two CHACC staff members explained that by working with another local program that serves children with complex medical conditions, they have been able to learn about local community resources. CHACC staff members’ awareness of additional services allows them to work together efficiently with community-based care coordinators; as one staff member explained, by gaining insight into other care managers’ roles and developing effective processes to integrate services, separate care coordinators avoid service duplication.

Four key elite stakeholders discussed how CHACC care managers complement the roles of existing care managers. Dr. Tilson, for example, described CHACC care managers as “the care coordinators of the care coordinators” and as the “hub” for coordinating children’s specialty care. She explained that CHACC care managers should coordinate children’s specialty care, meanwhile sharing care management responsibilities for those children with community care managers. Likewise, Ms. Lynn Guerrant, the CHACC program manager, emphasized that CHACC care managers should focus on building relationships with their patients’ community care managers, working closely with patients’ existing care coordination teams. Interviews with CHACC staff members provided evidence that they appreciate the necessity to locate and work with other organizations and are striving to accomplish this task; each staff member discussed efforts to integrate and work effectively with other organizations and care managers.
When I asked key elite stakeholders whether they felt that the current state environment had affected CHACC’s development and implementation, many described a general sense of discomfort and tension with respect to the state’s ongoing Medicaid reform debate. Interestingly, though, no respondent believed that the political controversy had harmed CHACC directly. Two respondents did discuss a need to remain focused and avoid allowing the Medicaid debate to introduce distraction from the work at hand, and one respondent stated that the debate had placed additional pressure on the CHACC program to meet goals for reducing health care expenses. Overall, although respondents acknowledged the urgency of the state’s political situation, they also maintained a steadfast determination for CHACC to accomplish its goals and collective belief in its ability to do so.

**Working in the Environment: Defining Roles, Disseminating Information, Engaging Allies**

Interview respondents collectively discussed multiple challenges of fulfilling novel roles within the CHACC program. According to Dr. Marian Earls, a pediatrician in central North Carolina who has been very active with the national American Academy of Pediatrics, CHACC staff members have had to “build the role” – the program’s unique, innovative nature required staff members to determine how they fit in with hospital care managers and network care managers, defining their particular roles. Each staff member described a process of defining staff roles within the existing health care team and network, particularly within existing care management structures. One staff member stated that “getting our process in place… was hard at first,” and described difficulty in establishing “what my role was going to be here… and how to work together with other care managers.” Likewise, Ms. Bobbitt, a lead care manager in CHACC, discussed the coexisting advantage and challenge of “being in a project that’s
evolving,” explaining that this eliminates “barriers” that individuals often face in making forward progress, yet also introduces “trial and error” into the process. Another staff member discussed the necessity to determine where CHACC staff members fit into the current network of community resources, in order to identify any communication gaps and specific care needs that CHACC staff members can fulfill. Similarly, three key elite stakeholders underscored the necessity for the CHACC program to test ideas and adjust strategies accordingly, testing methods to achieve CHACC’s goals and subsequently evaluating their effectiveness. The process of defining new roles thus presents a striking opportunity amidst potential difficulties.

In addition to recognizing CHACC’s environment, four key elite stakeholders and two staff members commented on the necessity to alert those outside CHACC of the program’s existence and goals. Of the four staff members interviewed, two discussed direct efforts to educate other health care team members about CHACC. Staff members have presented information about the CHACC program directly to other care managers in their CCNC networks; to community organizations that offer financial assistance or other resources to patients and families; and to local health care providers. Additionally, Dr. Steven Wegner, the Chairperson of the CCNC Board and Principal Investigator of the CHACC demonstration grant, pointed out that one of CHACC staff members’ roles is to reach out to local physicians. As Ms. Guerrant explained, each CHACC team may elect to spread information about CHACC in the manner most appropriate for its particular context. Similarly, two additional key elite stakeholders discussed the need for outreach to the local networks and communities, helping them understand CHACC’s role. This task, as one of the many components of network-specific implementation, simultaneously presents a challenge and an opportunity for CHACC staff members.
As well as explaining efforts to inform others of CHACC’s purpose and goals, two staff members also discussed challenges they had encountered throughout this process. Early in CHACC’s implementation, staff members’ attempts to communicate with those outside CHACC sometimes revealed confusion about the program’s existence and intentions. In one example, a staff member’s early correspondence with other care managers, in which she sought to collaborate about a potential CHACC patient, precipitated questions about CHACC. Another staff member explained that receptivity toward CHACC in her local community had been quite positive, largely because her CHACC group was able to align itself with another local program serving children with complex medical conditions; she had heard of other CHACC teams, however, struggling to find their own “niche.”

The nature of the CHACC staff members’ roles requires that health care team members outside of CHACC agree to collaborate with CHACC staff and subsequently engage in active, ongoing teamwork with staff members. Each CHACC staff member discussed promoting information sharing between members of the health care team, including other care managers, primary care physicians, and subspecialists; for example, each care manager discussed the creation and dissemination of the CHACC comprehensive treatment plan among the health care team. Each CHACC staff member described productive, positive relationships with other care managers, characterized by open communication that facilitates the care managers’ complementary roles. As one key elite stakeholder pointed out, however, conveying CHACC’s specific goals and assuring other organizations that CHACC seeks to complement – not absorb – their roles and responsibilities can also present challenges for CHACC staff members.
Interview respondents highlighted the need for communication among those involved in a patient’s care in order for CHACC to improve care, as well as CHACC staff members’ key role in facilitating this communication. Three CHACC staff members explained how efforts to inform others about CHACC and collaborate with those outside CHACC fostered teamwork between CHACC and other organizations. One CHACC staff member discussed the benefits of her outreach efforts to others, explaining that after she presented the CHACC program to other care managers, she began to receive referrals from those care managers. Similarly, two CHACC staff members discussed the benefits of weekly conference calls that they held with other care managers who worked with CHACC patients to discuss plans for care. One staff member specifically explained that these conference calls allowed other care managers to understand CHACC’s role and how they could work together with CHACC staff members. Although different interview respondents emphasized distinct avenues of communication, together their responses illustrate a rich, multifaceted network in which CHACC staff members seek to ensure timely, complete, and appropriate information transfer.

The extensive network of individuals contributing to the health care of a child with complex conditions often includes primary care physicians, pediatric subspecialists, multiple care coordinators, other health care professionals, and parents or other family members. Each CHACC staff member discussed her role in facilitating communication among all individuals in this network. One care manager described her role as a “contact point” for families, ensuring that all members of the health care team communicate and collaborate on a plan for the child’s health needs. Each staff member also discussed working together with other care managers to meet the child’s needs effectively, whether those needs relate to community resources, primary
care, or hospital or specialty care. As one staff member explained, her role coordinating patients’ specialty care effectively complements the roles of other care managers who focus on coordinating primary care or community resources. Two staff members discussed holding conference calls with other care managers involved in their patients’ care; in addition to enhanced familiarity with CHACC among call participants, CHACC staff members also noted these discussions’ value for enhancing communication among various members of a patient’s care team.

In addition to communication among the care managers, four key stakeholders emphasized staff members’ instrumental role in improving communication between primary care physicians and pediatric subspecialists. Another key stakeholder indirectly indicated the importance of bolstering this communication between providers, stating that the comprehensive treatment plan and information sharing were important accomplishments of CHACC. Four interview respondents noted the substantial time, resources, and expense a primary care practice must allocate to providing excellent care to a child with complex medical conditions. Moreover, several interview respondents described the primary care physician’s conundrum when a child with complex conditions presents for care – the primary care clinician must devote significantly more time to that patient’s appointment than to most other appointments, while meticulously documenting the extensive visit in order to ensure adequate reimbursement. Patients with later appointments must then wait longer, potentially upsetting those families.

CHACC intends to address these barriers in multiple ways. Three key elite stakeholders explained that as staff members identify children eligible for CHACC, they also reach out to their existing primary care providers. Also, all CHACC staff members discussed their efforts to bolster communication between physicians about patients’ care, illustrating a commitment to
improving this communication. Each care manager discussed sharing the comprehensive treatment plan with different physicians caring for an individual patient, and two staff members discussed assisting with direct communication between physicians. For example, one CHACC care manager described working with a community care manager to ensure that hospital physicians spoke with the primary care physician of a shared patient directly, in order to facilitate communication and discuss any questions the primary care provider had. Four key elite stakeholders applauded the communication that CHACC staff members foster between primary care providers and subspecialists, particularly indicating the substantial value of the shared comprehensive care plan and CHACC’s online communication system. By closing previous gaps in communication, CHACC staff members facilitate the primary care provider’s responsibilities in caring for children with complex medical conditions.

Nearly all respondents addressed the necessity of successful integration of CHACC staff members. Interviews revealed many components of this integration into the system, including assessing the local CCNC network and incorporating into this arena, evaluating local patient resources and working with them effectively, and establishing relationships with physicians involved in their patients’ care. The robust CCNC infrastructure fosters integration of CHACC staff members into existing systems. Three key elite stakeholders explained the importance of the CCNC community-based care managers, with whom the CHACC staff members collaborate to coordinate patients’ care. In addition, each CHACC staff member discussed using CCNC’s Care Management Information System to communicate with other care managers.

Additionally, three key elite stakeholders described CHACC’s role in uniting CCNC networks. According to one key elite stakeholder, CHACC builds on CCNC’s ability to foster communication within networks, promoting communication across distinct CCNC networks. As
Dr. Tilson stated, CHACC seeks to “bridge communication between the hospitals and across networks.” Another key elite stakeholder explained that CHACC is demonstrating CCNC’s ability to establish a statewide program that crosses local network boundaries. Thus, in addition to integrating themselves into their local settings and into the fabric of individuals involved in patient care, CHACC staff members also integrate CCNC’s separate local networks and many traditionally disjoint health care institutions throughout the state.

**Identifying Patients Whom CHACC Can Serve**

Each interview respondent discussed the essential nature of locating well-suited patients to enroll in CHACC; key elite stakeholders pointed to the difficulty of accomplishing this task at a global level, and CHACC staff members offered insight into the extensive practical duties necessary to find and enroll patients. One key elite stakeholder explained that any new care management program experiences challenges consistently identifying patients who will benefit from program services. Three stakeholders explained that although CHACC has been able to identify children with complex medical conditions and extensive, costly health care, considerable difficulty lies in determining which children will benefit most notably from CHACC’s services. As one pediatrician explained, a child with the most significant technological support and the most intensive medical needs may not actually benefit from enrollment in CHACC, and CHACC seeks to determine which groups of children will indeed benefit. Four key elite stakeholders described CHACC’s current effort to develop a predictive model, clarifying which children enrolled in CHACC have benefitted most from the program in order to assist with future enrollment decisions. Another key elite stakeholder felt that CHACC’s development of this
predictive model would help the care management community, even beyond CHACC, to
determine which children could benefit from additional care management support.

Each CHACC staff member described an extensive process, in the absence of that
predictive model, through which staff members identify patients. To locate eligible patients,
CHACC staff members review incoming referrals, examine hospital admission and discharge
lists, evaluate patients in neonatal or pediatric intensive care units, and communicate with care
managers and other health care staff about potential patients. Additionally, two staff members
described a process in which their network periodically reassesses previously reviewed patients’
eligibility, to ensure that patients formerly excluded from the program do not currently need
CHACC’s services. One staff member discussed her network’s process of identifying patients,
in which staff members use multiple standard forms to collect data about potential patients,
synthesizing this information to help staff members decide whether to enroll these children.
Staff members thus devote considerable time and effort to the task of identifying the proper
patients for CHACC.

Financial Considerations

By improving patient care through coordinating service delivery, the CHACC program
also seeks to reduce the state’s health care expenses. When I asked key elite stakeholders
whether the absence of shared savings in CHACC would prevent its ability to reduce cost, no
one believed that the absence of shared savings for CHACC would prevent the organization from
reducing health care expenses.

Three key elite stakeholders indicated that CHACC’s promotion of care coordination and
the ensuing effects on service utilization would allow cost savings. One key elite stakeholder
said that CHACC’s care coordination would be able to affect service use, thereby reducing cost, without a shared savings component; another stated that studies of care management services had demonstrated cost savings, indicating agreement that care coordination in CHACC can similarly reduce health care expense. Likewise, one individual specifically cited CCNC’s proven ability to show cost savings as evidence that CCNC’s strategy of coordinating care and providing performance feedback to practices can reduce health care expenses in the absence of an associated shared savings mechanism. This individual suggested that CCNC’s strategy encourages CCNC providers to engage in actively improving patient care.

Two individuals contended that incorporating shared savings into CHACC may allow the organization to demonstrate greater cost savings for its population, and two individuals said shared savings would likely reduce the financial burden that primary care physicians incur when caring for children with complex medical conditions. One individual stated that the fee-for-service environment limits practices in their ability to provide additional services to patients, and stated that shared savings would provide practices with resources to implement additional services that a fee-for-service model does not support. Another individual stated that shared savings would counteract the loss of revenue that providers experience when devoting additional time to caring for these children. One individual said that CHACC may facilitate the future introduction of shared savings, because in CHACC providers begin to work together to improve patient care. Another individual stated that a shared savings approach could help sustain the CHACC model, although accountable care organizations thus far have been structured to suit Medicare instead of Medicaid.
Discussion

The interviews I conducted and analyzed reveal many concepts important in CHACC’s implementation. These concepts include assessing and working within the local environment; the challenge of defining the novel role CHACC staff members fill; the necessity for complete communication among members of each patient’s health care team; and identification of appropriate patients. Last, I discuss the potential for disseminating the CHACC strategy to those undertaking similar programs, and review the implications of North Carolina’s current political environment for CHACC’s implementation.

Evaluating and Integrating into the Local Environment

A strong emphasis on understanding and working within the state and local environment emerged. The importance of the CCNC program and its infrastructure as CHACC’s foundation surfaced many times. Also, the necessity to evaluate each local network’s structure and resources – thus enabling optimal integration of CHACC – arose in many interviews. Many respondents discussed the benefits and challenges of CCNC’s statewide yet locally administered infrastructure. The emphasis on examining and working with the environment is not surprising, considering that CHACC builds on the CCNC program, which fosters broad collaboration (Steiner et al., 2008). Although interview respondents acknowledged the state’s current political tension, they voiced a necessity for CHACC to forge ahead and avoid the potential distraction that this tension could cause.
Defining Roles in CHACC

CHACC staff members fill a novel role, which has not previously been defined in North Carolina’s health care system. Interview respondents emphasized that CHACC staff must identify an appropriate niche, and ensure that CHACC complements – and does not duplicate – existing resources. CHACC aims to alleviate fragmentation in the care of children with complex medical conditions; to reach this goal, CHACC staff members endeavor to ensure seamless communication about patients’ care. The innovative nature of this responsibility requires staff members to consider how best to fill this role and pursue optimal methods for meeting this goal.

After ensuring that individuals outside CHACC understand the organization’s role, CHACC staff members are able to collaborate with individuals outside CHACC. In fact, as CHACC care managers and patient coordinators begin to interface with others outside CHACC, those individuals observe and more thoroughly perceive that CHACC seeks to improve specialty care coordination and communication. Enhancing others’ awareness of CHACC’s purpose subsequently advances collaboration between organizations. As CHACC develops, staff members should continue to consider the program’s innovative goals, discuss approaches that staff members in different networks have found effective, and adapt their approaches to accomplishing this novel task.

Promoting Communication among the Health Care Team

Another pronounced theme involved the necessity for complete communication. Interview respondents stressed the critical importance of communication among all members of a patient’s health care team, and pinpointed CHACC staff members’ vital role in facilitating and ensuring this communication. The CHACC program bolsters communication among those...
participating in patients’ care in many ways, including through establishment of unified care plans and facilitation of direct physician-to-physician conversation.

Neither North Carolina nor the U.S. overall should accept the compromised health care quality and unnecessary health care expenses that result from insufficient coordination of care. As CHACC staff members continue the endeavor to close gaps in communication, the CCNC program may benefit from applying CHACC’s approach to CCNC’s other patient populations, eradicating barriers preventing communication among providers and institutions for additional patients.

Identifying Patients Likely to Benefit from CHACC Enrollment

Identifying appropriate patients to enroll in CHACC poses a challenge at multiple levels. Key elite stakeholders described the difficulty at a conceptual level – understanding which children CHACC can best serve, and devising methods to determine whether a specific child would benefit from CHACC enrollment prospectively. Staff members offered a pragmatic view of work occurring in the field to ensure CHACC locates these patients quickly and efficiently. Identifying and enrolling proper patients in the organization undoubtedly represents an essential component of effectively implementing this program, and CHACC’s leaders and personnel recognize the urgency of successfully accomplishing this task.

The state should continue to develop methods to identify children best served by care coordination programs, as appropriate patient identification will benefit potential patients as well as improve program administration and resource utilization. If the CHACC model does spread beyond the state of North Carolina, other states should participate in the development and testing
of predictive tools to identify appropriate patients, allowing reliable use of the model in separate settings.

**Financial Considerations for Implementing the CHACC Program**

The prospect of shared savings in CHACC appealed to several interview respondents for its potential to encourage provider involvement and enhance cost savings. Although respondents considered shared savings in CHACC an interesting idea with multiple potential benefits, the state’s ongoing Medicaid debate reduces the likelihood of introducing a shared savings component in the near future. Introducing shared savings for CHACC would require the close cooperation of several stakeholders, including health care providers and, perhaps most importantly, the state’s Medicaid administrators.

The CHACC program promotes collaboration among those involved in caring for a particular population; therefore, although shared savings may introduce additional complexity into CHACC’s implementation, the CHACC program offers a suitable setting in which to investigate shared savings. As policymakers reconsider health care reimbursement methods, testing the effects of shared savings in CHACC would provide valuable information for potential payment structure reform. Also, after the three-year period of federal funding for CHACC, introducing sharing savings for CHACC may provide a mechanism to encourage providers to continue working to improve quality of care, coordinate care with other providers, and reduce service duplication.
Disseminating the CHACC Strategy

Reducing fragmentation of care nationwide remains a goal for the U.S. health care system; fragmentation of care diminishes quality of care for adult as well as pediatric patients. In response to this fragmentation, CHACC leadership should disseminate information about this innovative strategy for improving care. Presentation of the CHACC strategy to those in other states may inspire implementation of similar initiatives to improve care, especially for patients with heightened, intensive care needs. Although the CHACC program benefits immensely from its establishment in a state with a strong care coordination infrastructure (i.e., CCNC and its resources), CHACC does build on specific foundational approaches that other states could adapt to their specific environments.

First, CHACC builds on an existing statewide infrastructure supporting local networks; staff members in each local network, however, have had to determine how best to implement CHACC in their specific setting. When developing similar programs, other states or institutions should likewise consider how to utilize their own specific context and resources to facilitate novel program development and implementation.

Second, as a substantial component of their roles, CHACC care managers develop and disseminate comprehensive treatment plans for each patient. Specialty care managers in other settings could similarly work with providers and other members of the health care team to develop treatment plans, thereby offering consistent information and guidance to each individual caring for particular patients with complex conditions.

Third, the CHACC program benefits from multiple web-based communication systems, allowing direct secure communication among care managers as well as between providers. Admittedly, CCNC had previously established the online infrastructure that houses these online
portals, simplifying the work necessary for CHACC to institute these systems. Nevertheless, others seeking to implement similar care coordination initiatives should consider the resources that may assist in implementing communication systems within their own specific context.

Fourth, CHACC arose, in part, from the knowledge that a small proportion of the state’s children contributed a substantial fraction of its pediatric health care expenses; others implementing similar programs should evaluate which patients with complex medical conditions would benefit from such a program to improve care while reducing cost. Similarly, CHACC has had to establish extensive methods to identify appropriate patients, and other organizations seeking to serve similar populations will need to locate or create methods to identify proper patients, as well.

Additionally, the U.S. Secretary of Health and Human Services has the authority to expand the scope of promising programs funded by the Innovations Center. If the CHACC program or other attempts to streamline patient care and reduce fragmentation prove successful, then the U.S. Secretary of Health and Human Services should also consider expanding the scope of these programs.

Effective Implementation amidst Political Tension

Finally, the CHACC program’s implementation occurs in the midst of political strife in the state. As state legislators consider Medicaid reform, the future of CCNC – the organization on which CHACC was founded – remains undetermined. The CHACC program arises from a three-year federal grant to CCNC, awarded one year prior to this writing; thus, funding exists to continue CHACC for at least two more years.
Beyond federal funding, however, the political arena raises concern. CHACC’s demonstration of improving patient outcomes would gain support for CHACC from additional stakeholders, including health policy experts and medical professionals. Proponents for CHACC in these fields would likely advocate for the program.

Considering the state’s turbulent political setting, CHACC will be more likely to thrive if the program captures the attention of policymakers by achieving its anticipated outcomes, improving patient care while reducing health care expenditures. Those outcomes are, after all, also the current state administration’s goals for Medicaid reform, as well as the national administration’s goals for the ACA. Thus, CHACC’s achievement of these goals would fulfill the hopes of CHACC’s leaders, the goals of the state’s current elected leaders, and the intentions of the current national administration in enacting its defining health care reform.

Conclusion

The CHACC program is one particular example of carrying out the ACA’s broader goals to improve quality of care while reducing cost. CHACC intends to improve care for a specific population, however – pediatric patients with complex medical conditions. The program’s implementation occurs at a turbulent time in North Carolina’s political arena, presenting potential challenges in CHACC’s implementation, but CHACC does have an appreciable possibility for success.

CHACC builds on the foundation of CCNC, an organization that has demonstrated its ability to improve patient outcomes while reducing cost. CHACC’s foundation in CCNC, in addition to the success of other programs that seek to improve care for children with complex medical conditions (Casey et al., 2011; Cohen et al., 2010; Gordon et al., 2007), suggest that
CHACC can succeed in its goals to improve care while reducing cost for this population. If Medicaid reform ultimately threatens CCNC, however, CHACC will likewise experience similar danger, due to its close connection with CCNC and dependence upon the organization.

In summary, the CHACC program builds on a strong CCNC foundation but evolves in an unpredictable political environment. CHACC’s goals for health care reform align closely with those of the ACA as well as the current state administration. The themes identified in this study suggest that CHACC leaders and staff members have implemented a new strategy for health care reform, which fills a former void in the health care system and which others undertaking similar initiatives may also find helpful.
References


Figure 1. The “New” Health Care System.

The United States health care system consists of separate institutions, often lacking essential communication. Integrating and fostering communication between separate institutions, however, can facilitate better coordination of care. *Figure adapted from Dr. Alan Stiles, personal communication, May 2013.*
<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of Respondents</th>
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</thead>
<tbody>
<tr>
<td><strong>Program Setting</strong></td>
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<tr>
<td>CCNC as CHACC’s foundation</td>
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<tr>
<td>CCNC provides essential resources for CHACC</td>
<td>2</td>
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<tr>
<td>Infrastructure of CCNC as a strength for CHACC</td>
<td>3</td>
</tr>
<tr>
<td>Challenges of CCNC’s structure for implementing CHACC</td>
<td>3</td>
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<tr>
<td>CHACC care managers complement existing care managers’ roles</td>
<td>4</td>
</tr>
<tr>
<td>Need for focus amidst ongoing Medicaid reform debate</td>
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<tr>
<td>Medicaid reform debate placing additional pressure on CHACC</td>
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<td><strong>Working in the Existing Environment</strong></td>
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<tr>
<td>Need for testing ideas and adjusting strategy when appropriate</td>
<td>3</td>
</tr>
<tr>
<td>Disseminating information about CHACC</td>
<td>4</td>
</tr>
<tr>
<td><strong>Communication and Integration</strong></td>
<td></td>
</tr>
<tr>
<td>CHACC staff members improve communication between primary care and subspecialty providers</td>
<td>4</td>
</tr>
<tr>
<td>CHACC staff members collaborate with CCNC community care managers</td>
<td>3</td>
</tr>
<tr>
<td>CHACC unites CCNC networks</td>
<td>3</td>
</tr>
<tr>
<td><strong>Identifying Patients</strong></td>
<td></td>
</tr>
<tr>
<td>Explaining difficulty in determining which patients may benefit</td>
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</tr>
<tr>
<td>Need for a predictive model</td>
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</tr>
<tr>
<td><strong>Financial Considerations</strong></td>
<td></td>
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<tr>
<td>Care coordination and its effects on service use allow cost savings, even in absence of shared savings</td>
<td>3</td>
</tr>
<tr>
<td>Shared savings may alleviate PCP’s financial burden when caring for children with complex conditions</td>
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<tr>
<td>Future shared savings approach could help sustain CHACC</td>
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Table 1. Themes arising in interviews with *key elite stakeholders*, and number of stakeholders who addressed each theme.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of Respondents</th>
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<tr>
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<td><strong>Working in the Existing Environment</strong></td>
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<tr>
<td>Defining staff roles</td>
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<tr>
<td>Disseminating information about CHACC and challenges therein</td>
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<tr>
<td>Promoting sharing of information among health care team</td>
<td>4</td>
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<tr>
<td><strong>Communication and Integration</strong></td>
<td></td>
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<tr>
<td>Promoting collaboration by disseminating information about CHACC</td>
<td>3</td>
</tr>
<tr>
<td>Facilitating communication among those participating in child’s care</td>
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<tr>
<td>Working together with other care managers to meet needs of patient and family effectively</td>
<td>4</td>
</tr>
<tr>
<td>Working to improve communication between physicians</td>
<td>4</td>
</tr>
<tr>
<td>Using CCNC’s Care Management Information System to communicate with other care managers</td>
<td>4</td>
</tr>
<tr>
<td><strong>Identifying Patients</strong></td>
<td></td>
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<tr>
<td>Network conducts extensive process of patient identification</td>
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<tr>
<td>Periodically reassessing eligibility of patients who were previously evaluated</td>
<td>2</td>
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</table>

Table 2. Themes arising in interviews with *CHACC staff members*, and number of CHACC staff members who addressed each theme.
Appendix 1: Does Medicaid Managed Care Affect Parent Satisfaction with Care?  
A Limited Systematic Literature Review

Introduction

During the mid- to late-1990s, many states attempted to curb health care costs by instituting managed care for their Medicaid populations (Baker & Afendulis, 2005). Managed care plans seek to contain health care costs by utilizing resources more effectively, potentially improving access to care and quality of care as well. Following managed care implementation, health policy analysts studied the effects of managed care on multiple health outcomes, including patient satisfaction with care.

A particular area of study examines the effects of managed care on pediatric populations. Children depend on others to meet their needs, including health care provisions. Pediatric health advocates have therefore articulated concerns about potential detrimental effects of managed care on children’s health outcomes; for example, concerns exist that managed care may limit children’s access to necessary health care (Davidoff, Hill, & Adams, 2008; Szilagyi, 1998). Researchers interested in pediatric health care have sought to elucidate these outcomes among pediatric populations in managed care plans.

The North Carolina Medicaid system has provided care management services to the state’s Medicaid population since 1995, through the Community Care of North Carolina (CCNC) program (Steiner et al., 2008). The Child Health Accountable Care Collaborative (CHACC) arises from a Center for Medicare and Medicaid Innovations award to CCNC, aiming to improve children’s health care quality in North Carolina ("Child Health Accountable Care Collaborative," 2013). CHACC fosters novel specialty care coordination for children with complex, chronic conditions. Among numerous measures to evaluate the program’s performance, CHACC
measures parent satisfaction with care coordination services at baseline and at six-month intervals thereafter. Although CHACC is not a managed care plan, its goals are similar to those of managed care plans.

In this limited systematic review, therefore, I examine satisfaction of parents whose children are enrolled in Medicaid managed care. To explore parent satisfaction after managed care enrollment, this limited systematic review investigates the difference between parents’ satisfaction with their children’s health care either: (1) before and after the implementation of Medicaid managed care in a given population, or (2) when comparing parents of children enrolled in Medicaid managed care to parents of children outside Medicaid managed care (i.e., children who are uninsured, insured in traditional Medicaid plans, or privately insured).

Search Strategy

On May 7, 2013, I searched the PubMed database using the following query: “Medicaid AND patient satisfaction AND pediatric.” This search yielded 34 articles. I excluded 13 of those 34 articles by reviewing titles and determining that these 13 articles did not specifically address parent satisfaction in pediatric Medicaid managed care programs. Abstract review for the remaining 21 articles demonstrated that two articles compared parent satisfaction with pediatric Medicaid managed care programs either to (1) parents’ satisfaction with their children’s health care before enrolling in Medicaid managed care, or to (2) satisfaction of parents whose children were not in Medicaid managed care. I excluded studies of satisfaction with Medicaid managed care including both children and adults that did not stratify analysis for children alone; studies that focused only on parent satisfaction with dental care; and studies that did not compare
satisfaction of parents with children in Medicaid managed care to satisfaction of parents whose children were not enrolled in Medicaid managed care.

After reviewing MeSH terms for the most relevant articles from the primary search, I performed a second PubMed search on May 14, 2013 using the following query: “Medicaid [MeSH] AND child [MeSH] AND patient satisfaction [MeSH].” This search yielded 35 articles, five of which I excluded based on title review. I reviewed abstracts using the same inclusion and exclusion criteria previously described, eliminating 18 articles. After reviewing the remaining articles, I excluded one article because it was a brief research letter; three were excluded because they did not provide stratified analysis for parent satisfaction with their children’s health care. Three articles compared parent satisfaction for Medicaid-enrolled children and SCHIP-enrolled children; I excluded these articles because the Medicaid and SCHIP programs were structured similarly, offering identical provider networks to enrollees in either Medicaid or SCHIP. This yielded five articles for review, one of which the initial search had identified.

Results

Altogether, this systematic review appraises and summarizes six articles investigating parent satisfaction with pediatric Medicaid managed care. Each of the six articles uses survey data to assess parents’ satisfaction with their children’s health care. Most studies also evaluate changes in other outcomes, such as access to care and health resource utilization, when comparing Medicaid managed care plans to non-managed care plans. Table 1 provides appraisals of each study, and detailed descriptions of each study are provided below.
In light of the growth of Medicaid managed care plans in the late 1990s, Baker and Afendulis sought to clarify the effects of Medicaid managed care enrollment on children’s health. Using repeated cross-sectional survey data, authors analyzed how changes in the market share of Medicaid managed care affect children’s health care access and utilization, as well as parents’ satisfaction with their children’s care. The authors used Community Tracking Study Household Survey data from the 1996-97 and 1998-99 surveys, including data for Medicaid-enrolled children in 24 states. Authors analyzed the relationship between changing Medicaid managed care enrollment rates within states and differences in mean access, utilization, and satisfaction measures for children.

Results for managed care effects on children’s health care indicated varying, somewhat mixed effects on access, utilization, and satisfaction. Increasing Medicaid health maintenance organization (HMO) market shares were associated with fewer emergency department visits, more outpatient visits, and fewer hospitalizations. Growing HMO market shares were associated with parents reporting higher rates of delaying care, but other access measures (e.g., reporting unmet medical needs, reporting usual source of care) did not demonstrate a significant association with HMO growth. Although increasing HMO market share was associated with lower satisfaction with child’s most recent physician visit, parents reported no change in overall satisfaction with the family’s health care or with choice of provider for the child.

Growth of the primary care case management (PCCM) market share was associated with more common outpatient visits. Satisfaction measures were not significantly associated with changing PCCM market shares. Growing PCCM market shares were associated with higher reporting of unmet medical needs and lacking a usual source of care.
Authors concluded that utilization measures tended to change in predictable ways when states introduced Medicaid HMOs – HMO growth was associated with less frequent emergency department visits and hospitalizations, as well as more common outpatient visits – although these results were less clear with PCCM programs. Access measures, however, sometimes indicated access hindrances associated with managed care growth, a finding that warrants future exploration. Finally, satisfaction measures indicated that families maintained overall satisfaction with care and with provider choice, although increasing HMO presence was associated with declines in parent satisfaction with the child’s most recent visit.

Study strengths include the study design’s ability to account for potential selection bias, as the authors evaluated the association of population-wide changes in outcomes with changes in the managed care market share. On the other hand, however, the study analysis did not account for differences in state Medicaid organizations (e.g., voluntary or mandatory managed care enrollment); survey responses may have varied in different Medicaid plan arrangements.


Because New Mexico implemented mandatory managed care for nearly all Medicaid enrollees, this study sought to elucidate the effects of Medicaid managed care on low-income individuals in this state. Study authors used a random-digit-dialed telephone survey to assess outcomes including patient access, use, satisfaction, provider-patient communication, and barriers to care. Data for children pertained only to the child in the home with the most recent birthday. Most survey questions were from the Consumer Assessment of Health Plans Survey. The survey took place in summer 1998, approximately one year after Medicaid managed care began in New Mexico; the survey asked respondents to answer questions related to their current
experience as well as their experience one year before the survey (i.e., prior to Medicaid managed care implementation).

The authors found that unadjusted data showed no difference in parent satisfaction with care when comparing parents of children enrolled in Medicaid to parents of children with private insurance or to parents of uninsured children. Additionally, authors observed no changes in unadjusted data for parental satisfaction with care before versus after Medicaid managed care implementation. Statistical models created using principal components factor analysis demonstrated that parents of Medicaid-insured children were more satisfied with their children’s care than were parents of children in other insurance categories. Additionally, parents of Medicaid-insured children tended to respond positively to questions about access and use more often than did other parents. Importantly, authors found no significant differences in Medicaid parents’ reports of access and use, satisfaction and communication, or barriers to care before versus after implementing Medicaid managed care, suggesting that managed care did not compromise these health care outcomes.

Study limitations include the use of a telephone-based survey, which excludes potential participants lacking telephones. Also, the survey asked respondents to assess experiences with care currently and one year prior, introducing potential for recall bias; however, a pilot survey that the authors conducted one year prior to the study survey mirrored respondents’ later reports of their previous experiences, reducing concern for recall bias. Because this study focused on residents of one state, authors could better determine the effects of managed care within that particular state, although results may be less generalizable to other locations.

In 1995, the state of Minnesota expanded the reach of Medicaid managed care to rural areas. Long and Coughlin used a 1998 population survey to compare health care experiences for Medicaid recipients with fee-for-service Medicaid plans to those in Medicaid managed care plans. The study included children in six rural counties that had switched to mandatory Medicaid managed care, as well as children in 18 counties the authors chose for comparison, which retained fee-for-service Medicaid plans. Using computer-assisted telephone interviewing, researchers administered the survey to the adult in the home most knowledgeable about the child’s health care. The survey asked parents about the child’s recent use of health care services, as well as their access to and satisfaction with care.

The authors found that children enrolled in Medicaid managed care exhibited similar use of services as those in fee-for-service Medicaid. Children in either Medicaid plan were equally likely to have had a health care visit in the previous year and to have received preventive care, specialty care, dental care, or emergency room care. Children in fee-for-service Medicaid, however, were more likely to have had more than one hospital stay in the past year. Likewise, the authors observed few differences in access to care. Nearly all children in either managed care or fee-for-service plans had a usual source of care, although children in fee-for-service Medicaid were significantly more likely to have a usual source of care (95.0% vs. 98.3%). Parent ratings of satisfaction with their child’s care did not differ by Medicaid plan arrangement. Additionally, on most measures, at least 80 percent of parents of children with either managed care or fee-for-service Medicaid rated their child’s care as good, very good, or excellent.

Study strengths include the authors’ matching of counties based on poverty rates, population density, and health care provider supply, ensuring that the managed care and fee-for-
service populations were similar on measures other than insurance plan type. Additionally, authors adjusted for differences in baseline measures between the two populations. The authors presented predicted levels for each measure, in which they predicted results for each outcome measure, assuming that all children were either fee-for-service enrollees or managed care enrollees. This strategy allowed them to control for potential confounders and to ascertain the differences in outcome resulting from insurance plan alone; however, the authors did not present raw data, which would have offered additional information. Additionally, authors did not provide details about the survey’s validation.

Moreno L. & Hoag S.D., 2001

In 1994, the state of Tennessee created TennCare, implementing managed care in Medicaid in order to expand Medicaid coverage to impoverished uninsured and uninsurable state citizens. Moreno and Hoag assessed TennCare’s effect on access to care and satisfaction with care, comparing measures for TennCare beneficiaries to measures for the uninsured or uninsurable. They sought to evaluate TennCare’s effect among beneficiaries eligible for TennCare specifically under the Medicaid expansion. Study data resulted from two random-digit-dialed, computer-assisted telephone surveys, pooling data collected in 1998 and 1999.

Parents of children covered by TennCare were more satisfied than were their uninsured counterparts on all measures of satisfaction, although only five of 12 satisfaction measures were significantly different. Measures revealing significant differences assessed satisfaction with time to obtain an appointment, time spent with health care staff, explanations of medical care, ability to obtain medical help or advice quickly, and availability of medical care in emergencies. Access measures also demonstrated favorable effects of TennCare. Children covered in
TennCare were more likely than were the uninsured to have a usual place of care, to receive appointments promptly, and to visit the same health care provider consistently. TennCare-insured children also incurred less health care expenses than did uninsured children.

Study strengths include that authors adjusted for numerous potential confounders, including participants’ attitudes toward health care. Those attitudes likely affected whether or not persons eligible for TennCare under the expansion ultimately decided to enroll in TennCare. Nevertheless, other potential confounders may remain, for which authors were unable to adjust. Authors of this study provided predicted levels for each outcome measure, similarly to methods used in the study by Long and Coughlin, thus introducing similar strengths and weaknesses into this study.


Conover, Mah, Rankin and Sloan also sought to elucidate TennCare’s effects on satisfaction with care. The authors compared satisfaction for Tennessee residents after TennCare’s implementation (i.e., in 1995) to that of Tennessee residents before TennCare’s establishment (i.e., in 1993), as well as to that of North Carolina residents in 1993 and 1995. At the time, North Carolina had very little Medicaid managed care. Researchers surveyed parents of infants born in 13 Tennessee hospitals and in 10 North Carolina hospitals, chosen as controls for the Tennessee institutions. The survey used questions from validated instruments to assess parents’ satisfaction with their child’s overall care, waiting time for an appointment, waiting time during the appointment, answers to questions about the child’s care, and access to all care the parent thought necessary.
Parents of TennCare recipients were consistently as satisfied with their child’s care as were parents of children in traditional Medicaid. On one measure (child’s overall care), TennCare parents were significantly more satisfied than were parents of children in traditional Medicaid. TennCare parents were more satisfied with care than were parents of uninsured children, although parents of privately insured children were the most satisfied group of all. Controlling for potential confounders, authors observed no statistically significant differences between TennCare parents’ satisfaction and traditional Medicaid parents’ satisfaction. Also, after controlling for potential confounders, parents of uninsured children were less satisfied than were other parents, and parents of privately insured children were again the most satisfied.

Study strengths include the use of a fairly similar control state for comparison, as well as a reported high response rate for this study population. Additionally, authors controlled for several potential confounders. A potential weakness of this study includes potential recall bias, especially for parents of infants born in 1993, as the survey administration occurred in 1996-97. The study focuses on Medicaid managed care in one state, thus limiting its generalizability to other states, but providing the possibility to make meaningful conclusions about managed care in the state of Tennessee.


In 1995, Ohio developed the Access to Better Care Program to test managed care delivery in populations with disabilities. Program enrollment was voluntary. Grossman, Rich, Michelson, and Hagerty sought to evaluate this program’s effect on satisfaction with care, access to care, and resource utilization, as well as the quality of the program’s services. A research assistant interviewed families by telephone or in-person during health care visits. Parents rated
service quality and access, as well as their satisfaction with health care, both before and during enrollment in the program. Study authors designed the survey instrument.

Parents generally rated program quality and access to services quite highly. Parents rated service quality and access on a scale from A to F, and almost all health care services obtained median ratings of “A.” When comparing their children’s health care after enrolling in the managed care program to that prior to enrollment in the program, 18 of 46 parents stated care had improved, and 21 of 46 stated quality of care had not changed. Merely three of 46 respondents reported a decline in satisfaction with care following enrollment in the managed care program. Authors found no significant difference in cost of care prior to versus during enrollment in the managed care program, although authors observed significantly fewer hospitalizations and hospital days after the program began.

This study’s exclusive focus on children with special health care needs poses both strengths and limitations: the study demonstrates the effect of managed care for this population alone, but also has limited generalizability to children outside this population. Additionally, enrollment in the managed care program was voluntary. Moreover, only 62 of 3,000 eligible children enrolled in the program, raising concerns about the potential differences between those choosing versus declining to participate in the program.

**Conclusion**

This systematic review set out to explore the effects of Medicaid managed care on parents’ satisfaction with their child’s care, also reviewing additional data about health outcomes that studies had evaluated. Of the six studies in this systematic review, five suggest that Medicaid managed care does not, in fact, harm pediatric health outcomes. Contrary to this
concern, which children’s health advocates raise, most of the studies suggest that children enrolled in managed care experience equally good – sometimes superior – health outcomes, as compared to those outside managed care settings. Most studies in this review suggest that implementing managed care within a state’s Medicaid system does not compromise parent satisfaction with health care, health resource utilization, quality or accessibility of care.

When comparing parents of children in Medicaid managed care plans to parents of children outside these plans, parents whose children were in managed care tended to report equal satisfaction with their child’s care. Importantly, parents of children in managed care often reported significantly greater satisfaction with their child’s care, as compared to parents of uninsured children. Parents’ satisfaction with care did not tend to diminish after their children had newly enrolled in managed care.

The 2005 study by Baker and Afendulis, on the other hand, did suggest that enrollment in HMOs may reduce parents’ satisfaction with their children’s care, in addition to potentially hindering access to care. The study only demonstrated reduced parent satisfaction with respect to the child’s most recent physician visit, however; parent satisfaction with the family’s overall health care and choice of pediatric provider did not change. Future studies would likely benefit from collecting data for additional satisfaction measures, to facilitate richer understanding of various components of parent satisfaction. Also, this study analyzed data from several states, a noteworthy difference in study design, as other studies focused on a single state. The fact that the most recent study aggregated data from numerous states may potentially lend more credence to the study, as results may be more generalizable; on the other hand, Medicaid plan arrangements did differ from state to state, thus combining these data may have introduced flaws because of inconsistencies in the data being compared.
Overall, the results of this systematic review suggest that children in Medicaid managed care do not experience compromised care because of their enrollment in managed care plans. Future studies should continue to explore this question in additional states, with attention to the distinctions between varying managed care plans during study development, data collection, and analysis of results.
<table>
<thead>
<tr>
<th>Citation</th>
<th>Study Question</th>
<th>Study Design</th>
<th>Study Population (Number of Participants)</th>
<th>Results</th>
<th>Strengths (+) / Limitations (-) / Comments</th>
</tr>
</thead>
</table>
| Baker, 2005   | How does a growing Medicaid managed care (MC) market affect children’s health care utilization, access, and satisfaction? | Repeated cross-sectional survey Two multi-state Community Tracking Study (CTS) surveys, 1996-97 and 1998-99 | Medicaid-covered children included in CTS surveys (n=2,602) | MC market share: not associated with overall satisfaction with health care or with provider choice. As HMO market share grew, satisfaction with physician thoroughness, listening, and explanation at child’s most recent visit fell. PCCM market share not associated with changes in satisfaction. | +: minimizes potential selection bias by evaluating assoc’n of population-wide changes with MC market shares  
+: includes many states  
+: adjusts for many potential confounders  
--: does not control for variation in MC rules by state  
--: response bias possible |
| Waitzkin, 2002 | How does Medicaid MC affect health care access, use, communication, satisfaction, and barriers to care? | Cross-sectional survey Population-based survey, conducted in low-income zip codes, in summer 1998 | Children in 2 NM counties – 1 rural, 1 urban; all Medicaid-insured, uninsured, or total household income less than $20,000 (n=267) | Parents of Medicaid recipients, as compared to those in other insurance categories, more often responded positively to satisfaction questions. During transition to Medicaid MC, satisfaction with care did not change. No difference in unadjusted results for parent satisfaction with care by insurance category. | --: no correction for multiple comparisons  
--: adjusts for relatively few potential confounders  
--: potential recall bias  
+: transition to mandatory MC in Medicaid → can better isolate effects of mandatory MC  
--: limitation to one state reduces generalizability |
| Long, 2001    | How does switching from fee-for-service to MC Medicaid affect access, use, and satisfaction with care? | Cross-sectional survey Population-based survey, conducted in counties with traditional fee-for-service Medicaid or novel Medicaid MC | Medicaid-covered children in rural MN counties operating either Medicaid MC or fee-for-service Medicaid (n=1,606) | Parent satisfaction with child’s care did not differ based on whether child was enrolled in Medicaid MC or fee-for-service Medicaid plan. For most satisfaction measures, at least 80 percent of parents reported care was good, very good, or excellent. | +: adjusts for many potential confounders  
--: potential response bias  
+: used sample weights to account for response bias  
--: survey validation unclear  
+: studies mandatory transition to Medicaid MC, minimizing sel. bias potential |
| Moreno, 2001 | How does Medicaid MC in Tennessee affect access to care and satisfaction with care, as compared with uninsured children? | Cross-sectional survey | Medicaid-insured children and uninsured children; uninsured children lived in homes with income <250% poverty (n=315) | Parent satisfaction was higher for children enrolled in TennCare than for uninsured children, on each measure of satisfaction; statistically significant differences arose for five of 12 satisfaction measures. | --: uninsured vs. TennCare groups differed on many baseline characteristics +: adjusts for many potential confounders, including attitudes toward health care --: no correction for multiple comparisons +: used sample weights to adjust for nonresponse --: survey validation unclear |
| Conover, 1999 | How does Medicaid MC in Tennessee affect satisfaction with care? | Survey | Parent satisfaction was higher for children enrolled in TennCare than for uninsured children, on each measure of satisfaction; statistically significant differences arose for five of 12 satisfaction measures. | --: voluntary enrollment in TennCare may introduce selection bias --: survey validation unclear --: potential recall bias --: small sample size +: specific to children with special health care needs, providing information for this particular population |
| Grossman, 1999 | How does enrollment in a voluntary Medicaid MC program affect care satisfaction, quality, access, and utilization for families of children with special health care needs? | Survey | Mean parent satisfaction with medical care was fairly high before the program began, and rose after the program onset. Of 46 respondents, 18 stated that care had improved after the program’s onset, and 21 stated care had not changed. | --: voluntary enrollment in program may introduce selection bias --: survey validation unclear --: potential recall bias --: small sample size +: specific to children with special health care needs, providing information for this particular population |

Abbreviations: HMO = health maintenance organization; MC = managed care; MN = Minnesota; NM = New Mexico; NC = North Carolina; OH = Ohio; PCCM = primary care case management; TN = Tennessee
References


Appendix 2: List of Interview Participants

Patricia Bobbitt, R.N., B.S.N.
CHACC Lead Specialty Care Manager

Marilyn Brady, R.N.
CHACC Lead Specialty Care Manager

Marian Earls, M.D., F.A.A.P.
Member, CHACC Advisory Committee
Lead Pediatric Consultant, Community Care of North Carolina

Lynn Guerrant, R.N., M.S.
Program Manager, CHACC

Starla Hatley, R.N.C., B.S.N.
CHACC Lead Specialty Care Manager

David Tayloe, Jr., M.D., F.A.A.P.
Member, CHACC Advisory Committee
Former President, American Academy of Pediatrics

Elizabeth Tilson, M.D., M.P.H.
Member, CHACC Advisory Committee
Medical Director, Community Care of Wake and Johnston Counties

Steven Wegner, M.D., J.D.
Project Director, CHACC
Chief Medical Officer, Community Care of North Carolina

Jenna Welch
CHACC Patient Coordinator
Appendix 3: Interview Protocols

Key Elite Stakeholder Interview Protocol

Hello, ____________, and thank you for your time!

Before we begin, I would like to provide you more information about myself and my research project. I am a rising fourth year medical student at the University of North Carolina. I have taken a leave of absence from medical school to pursue a Master of Public Health degree. As part of my public health study, I have been working as a research assistant for the Child Health Accountable Care Collaborative – or CHACC, for short.

As part of my research with CHACC, and for my Master’s Paper, I am collecting information about CHACC’s implementation. I asked for the opportunity to interview you because of your distinct knowledge about CHACC.

Dr. Sue Tolleson-Rinehart is my faculty advisor. She is a faculty member at UNC’s Schools of Medicine and Public Health. She and I hope this research study will provide new information about policy implementation. We believe this information will be useful to others interested in implementing new health policy strategies, like CHACC. We expect this analysis to help policymakers with similar future projects. We hope to publish the results of this study.

The interview has several open-ended questions. I expect the interview to last anywhere from 15 minutes to one hour, based on your availability and how much information you wish to share. With your permission, I would like to record this interview using a digital voice recorder. If you do grant permission for me to record the interview, you may revoke permission for recording at any time during the call. You may also discontinue the interview at any time. I will later transcribe the interview and email you a copy of the transcript.

Do you have any questions at this time?

Now, if we may proceed, can you please agree to any or all of the following statements that I am about to read?

I agree to have this interview tape-recorded using a digital voice recorder. (Yes / No)

I agree for the following information to be included in publications resulting from this study:

    My name (Yes / No)  My title (Yes / No)  Direct quotes from the interview (Yes / No)

Participant Name: ______________________

Date: _________________________________
I appreciate the opportunity to discuss your knowledge about implementing CHACC. Let’s get started.

As you know, CHACC has many parts. CHACC’s success will depend in part on CHACC care managers and patient coordinators accomplishing their responsibilities. How do you think the CHACC care managers and patient coordinators perceive their roles in CHACC? How do you think they would describe their place in CHACC?

Do you think they appreciate their significance to CHACC success?

Why do you think so?

Do you think CHACC care managers and patient coordinators can offer their client families appropriate resources -- from CHACC, as well as from local communities?

   IF YES: How do CHACC staff gain access to these resources?

   IF NO: How might CHACC staff gain access to the resources they need?

How do North Carolina health care providers perceive CHACC?

How can CHACC best identify the pediatric providers who will be most willing to participate in CHACC?

What do you think CHACC’s most important accomplishments have been thus far?

Do you think that the current state environment has affected CHACC’s development and implementation?

   Why/why not? And are there other barriers you see standing in CHACC’s way?

Is there anything else I should have asked you about that I haven’t already? Do you have any other ideas about CHACC’s implementation as an organization that we haven’t addressed here?

Thank you so much for taking the time to answer my questions! I very much appreciate you sharing your thoughts with me.

If you have a few more minutes, would you be able to discuss 3 more short questions with me? I would appreciate the chance to discuss a few other ideas with you, briefly, if you have the time.

Do you think North Carolina health care providers believe that CHACC will accomplish its goals? Why or why not?

Has CHACC been effective at identifying the appropriate patients to enroll? Why or why not?
As you know, their proponents hope Accountable Care Organizations will work by creating sharing risks or savings while meeting quality benchmarks. CHACC doesn’t yet have a shared-savings mechanism. In your view, will that prevent CHACC’s ability to reduce cost?
CHACC Staff Member (Care Manager / Patient Coordinator) Interview Protocol

Hello, ____________, and thank you for your time!

Before we begin, I would like to provide you more information about myself and my research project. I am a rising fourth year medical student at the University of North Carolina. I have taken a leave of absence from medical school to pursue a Master of Public Health degree. As part of my public health study, I have been working as a research assistant for CHACC.

As part of my research with CHACC, and for my Master’s Paper, I am collecting information about CHACC’s implementation. I asked for the opportunity to interview you because of your work with CHACC.

Dr. Sue Tolleson-Rinehart is my faculty advisor. She is a faculty member at UNC’s Schools of Medicine and Public Health. She and I hope this research study will provide new information about policy implementation. We believe this information will be useful to others interested in implementing new health policy strategies, like CHACC. We expect this analysis to help policymakers with similar future projects. We hope to publish the results of this study.

The interview has several open-ended questions. I expect the interview to last anywhere from 15 to 30 minutes, based on your availability and how much information you wish to share. With your permission, I would like to record this interview using a digital voice recorder. If you do grant permission for me to record the interview, you may revoke permission for recording at any time during the call. You may also discontinue the interview at any time. I will later transcribe the interview and email you a copy of the transcript.

Do you have any questions at this time?

Now, if we may proceed, can you please agree to any or all of the following statements that I am about to read?

I agree to have this interview tape-recorded using a digital voice recorder. (Yes / No)

I agree for the following information to be included in publications resulting from this study:

My name (Yes / No)   My title (Yes / No)   Direct quotes from the interview (Yes / No)

Participant Name: ______________________

Date: _________________________________
I appreciate the opportunity to discuss your knowledge about implementing CHACC. Let’s get started.

In CHACC, are you a care manager or patient coordinator?

I’d like you to envision your role in CHACC. How would you describe your role, and your goals? [prompt]: please just describe your role the way you see it.

Do you have ways to offer the resources you need to offer families, either from CHACC or from the community?

How have you found working with CHACC family members? Has it been easy or hard?

And what about other care managers outside CHACC – are they easy or hard to work with?

Thank you so much for taking the time to answer my questions! Is there anything else I should have asked you about that I haven’t already?