



CARE AWARD

Photo: Seth Dixon, St. Jude Children's Research Hospital; Memphis, Tennessee

An Important Role: Family-Centered Primary Care Medical Home for Children with Medical Complexity

Children with medical complexity (CMC) typically require care from multiple pediatric subspecialists. A complex care clinic may provide them regular longitudinal care on an inpatient and outpatient basis, sometimes helping coordinate the specialty care they need. While some complex care clinics provide all services associated with primary care, most do not, though some fill a consultation role for primary care teams.

As a result, most families with a CMC seek a separate community or hospital-based source of pediatric primary care to improve access to care. Primary care physicians (PCP) care for the majority of CMC. This aligned with the CARE Award (Appendix A) findings, which showed that 60% of the enrollees were based in primary care practice settings. The definition of roles and care coordination among specialists, complex care clinics, and community-based primary care settings are often unclear and poorly understood by families.



When primary care is present and valued in the delivery system, communities have better public health outcomes and lower health care costs.¹ These results could apply to systems serving CMC. Four fundamental and necessary characteristics for primary care include:²

- First contact for each need.
- Longitudinally involved over time.
- Comprehensive in its services.
- Coordinated in its relationship with the larger systems of care.

The Background: Medical Home Model

The American Academy of Pediatrics and US Maternal and Child Health Bureau elaborated a refined model for pediatric primary care called the Family-Centered Medical Home.³ The medical home model was further developed through a series of primary care practice-based improvement collaboratives. It was later adopted by adult care providers with an emphasis on patient and family-centered approaches, care planning and coordination, improved access, and team-based care. In 2007, several primary care professional organizations created the Joint Principles of the Patient-Centered Medical Home.⁴

Primary Care in the CARE Award Model

The CARE Award acknowledged the importance of primary care teams in caring for CMC and their families, and the value of including them in the family’s dynamic care team (DCT) for care continuity. CARE Award teams worked with families to define the roles and responsibilities of

DCT members, then developed access plans that met their needs. All DCT members followed these shared plans of care. Children with the most complex needs had most of their care managed in the complex care clinic and by specialists while staying engaged with their PCP.

Children with less complex needs received the bulk of their care through their primary care team, with periodic consultation from the complex care team and specialists. First contact for some needs remained with primary care while other needs were managed directly with the complex care clinic.

The CARE Award engaged 10 children’s hospitals in a quality improvement learning collaborative. Nine teams included a children’s hospital-based complex care clinic and one or more primary care practices; one team had complex patient care spread among six community practices with no physical complex care clinic. Primary care practice scenarios included:

- Independent community-based primary care practices
- Primary care practices owned by and within the same health care network as the children’s hospital
- Primary care practices that were part of the same Medicaid managed care organization (without a participating complex care clinic)
- Independent community primary care practices that had a consultative relationship with a hospital complex care clinic.

The CARE Award design provided one Practice Transformation Facilitator (PTF) associated with each team to assist primary care practices with implementation of the CARE Award change concepts (see Appendix B). Table 1 summarizes the primary care practice characteristics of the 10 teams.

Table 1. Primary Care Profile by Children’s Hospital

Site	Patients Enrolled	Number of PCP partners	% of Enrolled Children at PCPs	Type of PCP Relationship
A	972	3	79.5%	PCPs in hospital network
B	644	6	96.4%	PCPs in hospital network
C	1,094	2	91.9%	PCPs in hospital network
D	681	5	46.1%	PCPs in hospital network
E	1,684	5	49.6%	One large PCP in hospital network, one small independent PCP, on FQHC, one large PCP part of a large health care system
F	439	8	100%	No brick-and-mortar complex care program; PCPs in hospital network
G	229	1	4.4%	PCP part of large health care system not owned by hospital
H	711	5	34.7%	PCPs all independent from hospital, some part of large health care systems, some not
I	447	5	28.6%	PCPs all independent from hospital, some part of large health care systems, some not
J	489	2	32.3%	One PCP in hospital network, one independent

Because many key ingredients for a more integrated system of care for CMCs (care coordination, family partnerships, chronic condition management, quality improvement, and data management) are also critical functionalities of a family-centered medical home, a shortened version of the Medical Home Index (MHI) (MHI) was used to track practice transformation in the complex care clinics and primary care practices. Each of the six MHI domains are scored on a scale of 0 to 8, with a higher score reflecting a higher degree of implementation. To aggregate scores across domains, MHI scores are

mathematically transformed to a standard scale of 0 to 100, with a higher score reflecting a higher degree of implementation.

MHI scores were obtained at baseline and three additional intervals during the CARE Award. All MHI domains showed significant improvements over the course of the project, with Chronic Condition Management showing the most improvement overall (see Chart A). Community Outreach showed the greatest improvement for primary care practices (see Chart B). Table 2 shows aggregated MHI scores throughout the CARE Award for each site.

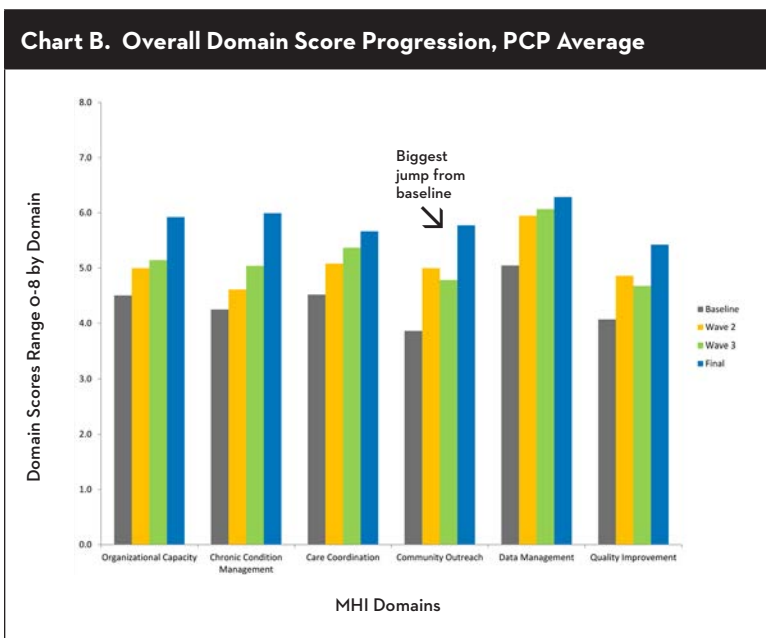
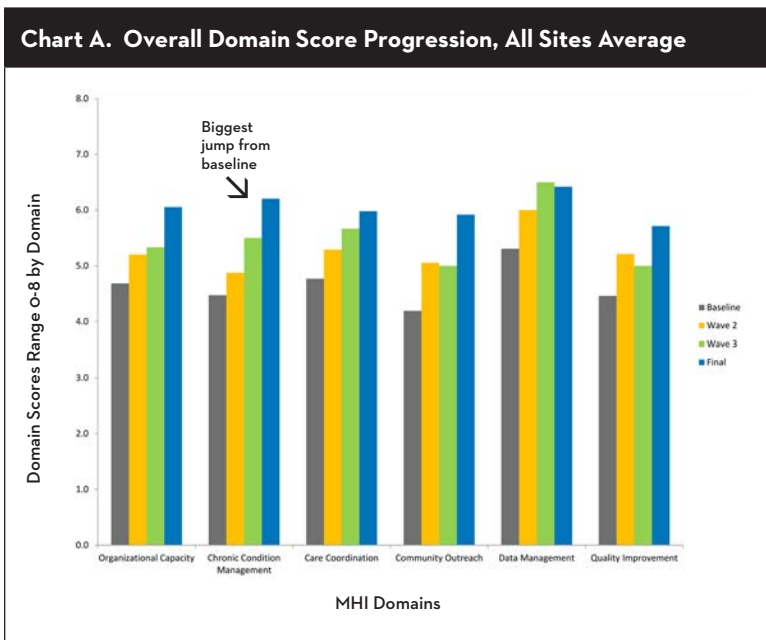


Table 2. Medical Home Index Results by Site

Site	Survey	Total (max: 100)
A	Baseline	56.1
	Final	78.3
B	Baseline	60.3
	Final	75.8
C	Baseline	44.9
	Final	68.7
D	Baseline	57.5
	Final	73.6
E	Baseline	52.4
	Final	73.6
F	Baseline	43.6
	Final	64
G	Baseline	65.8
	Final	72.4
H	Baseline	57
	Final	81.6
I	Baseline	39.2
	Final	62.2
J	Baseline	65.8
	Final	79.9

Domain scores range 0-100 when aggregated by site

CARE Award Implementation

The change concept process measures include implementation of a patient registry at each site for assessment and management of the population of CMC, and development of a DCT, access plan, and care plan with each child and family (see Appendix B). Teams implemented the concepts in a different sequence and at different rates. Charts C-E show uptake for the three key change concepts: DCTs, access plans and care plans. While primary care practices showed lower initial uptake of these change concepts, their progress quickly paralleled, equaled or surpassed that of the complex care clinics.

The y-axis in charts C-E reflect a quality score that combined the overall adoption of the change concept, as well as the number of core elements adopted. The quality score could exceed 100 percent if teams exceeded the goal threshold for number of core elements adopted.

Moving to Integrated Systems of Care

The CARE Award expected that all hospital teams would follow family-centered principles and actively partner with families in care delivery and improvements. While full and consistent engagement of families was a challenge for some sites early in the collaborative, the importance of tools and processes that worked for families was demonstrated repeatedly. (See the “8 Vital Actions to Support Primary Care Teams” tip sheet.)

Two characteristics families frequently requested: effective communication between providers, and access to the care they need, when they need it, from trusted providers familiar with their child. The CARE Award addressed effective communication by working with families to identify a DCT where the team members had defined roles, a comprehensive shared plan of care available to all team members, and an individualized access plan families could easily follow. One of the most useful communication tools, the electronic health record (EHR), was often constrained by the inability of different EHR products to share information.

Access to Care: The Challenge for PCP

Access to care for CMC and their families proved to be challenging. For many families, access to appropriate care is measured against the immediate availability of the emergency department (ED) with its comprehensive evaluation and treatment resources.

Whenever access plans fell short of immediate and useful responses, families were more likely to opt for the ED. Even though more than half of the families interviewed after ED visits said they would have trusted their PCP, they still chose to go to the ED.

Chart C. Dynamic Care Teams: Progress Towards Goal

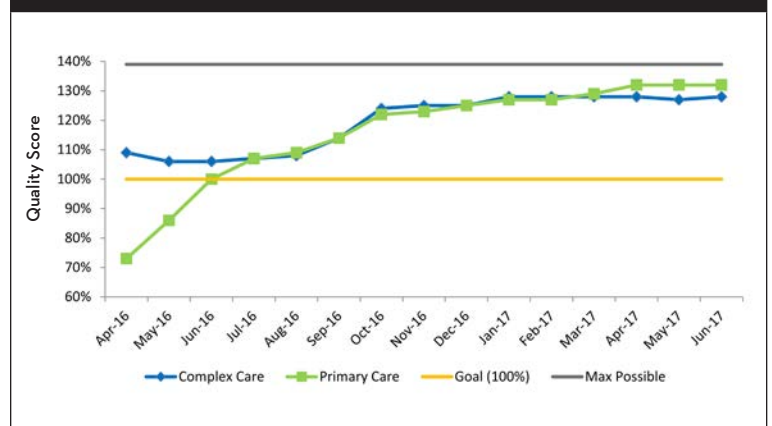


Chart D. High Quality Access Plans: Progress Towards Goal

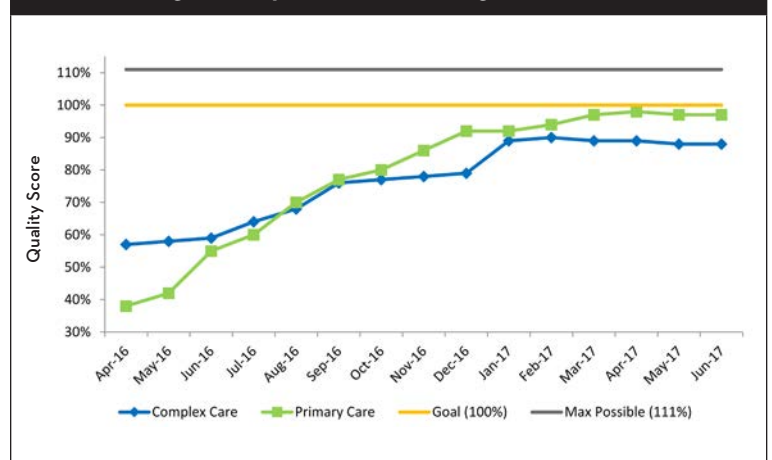
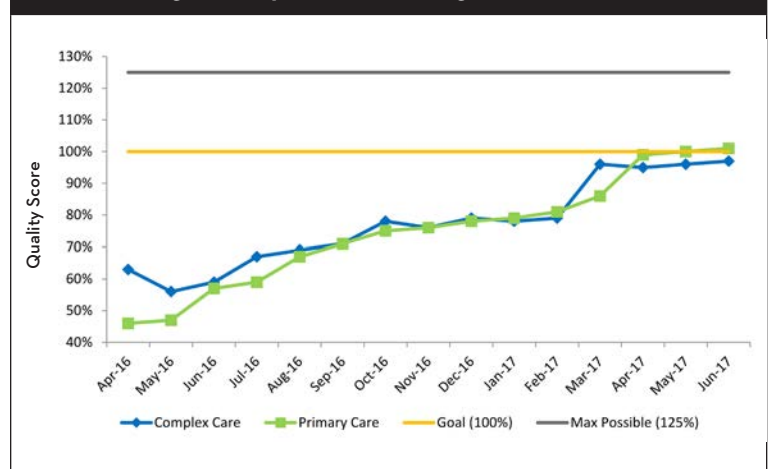


Chart E. High Quality Care Plans: Progress Towards Goal



The CARE Award demonstrated that primary care practices can effectively care for CMC in close coordination with a complex care program.

A gap for primary care practices in this situation is providing 24/7 access to providers that families trust. Many primary care practices relied on triage call nurses, which in some cases, were contracted services. Primary care practices were also challenged to respond in a timely manner to calls from parents, often sharing on-call responsibilities with providers who were either unfamiliar with CMC patients or uncomfortable with their needs.

For families worried about a change in their child's health status, response delays would result in seeking alternatives, usually a trip to the ED. Some families preferred to go to the ED where they could get all their tests and imaging done in one place (i.e. all the specialists came to them). Access plans were more effective for families when they included common contingency plans that identified where and when to seek care when a problem was urgent.

Care coordination is central to the effective delivery of care, and supports clear and consistent communication between families and all providers. This may be augmented for CMC, for example, with stronger social work services. Fragmented care leads to redundancy, unnecessary services, incorrect assumptions, and added stress and uncertainty for patients and their families.

Primary care practices with care coordination functionalities, either through prior medical home transformation efforts or by belonging to a hospital-based network with a well-developed care coordination service, were more equipped to implement CARE Award core elements and meet the families' needs. However, sustaining care coordinators in primary care practices is difficult because of nonexistent or insufficient payment arrangements for care coordination services.

Some families and complex care specialists believe the needs of CMC are "too complex for primary care." Some PCPs are uncertain they have the skills to care for these patients. And there are consequences of these perspectives. Highly-trained resources familiar to the family and community in which the family lives are left without a role in the care of this population, while families are left with uncertainty about if they should seek care from their PCP. DCT clearly defined roles for team members and shared plans of

care that explicitly allocate responsibility for action steps. This ensured that all care team members can contribute at their highest level of ability.

Mechanisms to deliver training to primary care teams in the management of CMC could raise levels of skill, knowledge and confidence at the primary care level. Distributing primary condition management responsibilities according to levels of complexity could direct the children with the most complex needs to the complex care clinic. Those with somewhat less complexity would receive more care from their PCP. Finally, more effective and widespread use of telehealth consultations between complex care teams and primary care practices could permit efficient and timely access to point of care decision support, as well as facilitating better coordination of care.

To improve and sustain the delivery system, payment arrangements for primary care practices as part of the care coordination model are necessary.

Coordination: Essential for Successful Medical Homes

The CARE Award demonstrated that primary care practices can effectively care for CMC in close coordination with a complex care program. These practices also showed they can rapidly implement change concepts that are essential to providing a medical home for CMC.

But challenges still exist for PCPs in caring for CMC. Many of these practices do not have easy access to important members of the child's health care team, such as care coordinators, social workers and nutritionists.

For most PCP practices with limited resources, after-hours care is frequently delegated to clinicians who are not necessarily the trusted providers for the families of CMC, which leads to an increased likelihood that family will use the ED for care. Financially, PCPs are not reimbursed for the care coordination for these families, placing a time and resources burden on the practice as the PCP tries to balance care for all patients.

In the future, it is likely the majority of CMC will continue to have their medical home in a PCP practice. For these children to receive high-quality care and care coordination, it will be important for hospital-based complex care programs to work closely with PCP practices and networks to ensure comprehensive, coordinated, longitudinal, and first-contact care are cornerstones of the pediatric medical home.

CARE Award Defined

The Coordinating All Resources Effectively (CARE) Award is a landmark national collaborative project aimed at improving quality outcomes and reducing the cost of care for children with complex medical conditions enrolled in Medicaid funded by the Center for Medicare and Medicaid Innovation. Children’s Hospital Association partnered with 10 of the nation’s leading children’s hospitals, eight state Medicaid programs and Medicaid managed care organizations, more than 40 primary care practice sites, and 8,000 children and their families.

The CARE Award was designed to transform care through the provision of appropriate, coordinated care in the right setting, and develop alternative payment models that more effectively align with the new care model.

Participating Sites

Children’s Hospital Colorado (Aurora, Colorado)
Children’s Mercy Kansas City (Kansas City, Missouri)
Children’s National Medical Center (Washington, D.C.)
Cincinnati Children’s Hospital Medical Center (Cincinnati, Ohio)
Cook Children’s Health Care System (Fort Worth, Texas)
Lucile Packard Children’s Hospital Stanford (Palo Alto, California)
UCLA Mattel Children’s Hospital (Los Angeles, California)
St. Joseph’s Children’s Hospital (Tampa, Florida)
Children’s Hospital of Philadelphia (Philadelphia, Pennsylvania)
Wolfson Children’s Hospital (Jacksonville, Florida)

CARE Award Change Concepts Defined

Care transformation in the CARE Award was built on a set of closely related change concepts designed for families and providers to develop jointly.

1. Each CARE site will have a patient registry.

Registries are essential tools for population assessment and management and quality improvement, both within individual practices and across the continuum of care.

2. Every child/family will have a dynamic care team (DCT)

Care of children with complex needs requires an effective, informed and coordinated team. The family drives the composition of the DCT and is a critical partner to other members of the team. DCT membership is representative of the care continuum that includes health care and community and educational providers. DCT members recognize each other by name and role, and have effective systems for timely communication among team members.

3. Every family will have an access plan containing three components:

a. An after-hours access plan that describes how and when to contact the appropriate clinical provider for health care issues. Every patient and family needs to know who to contact and how to contact them to access the right provider for the right care. A provider must be available 24/7. The access plan should include a listing of all DCT members with contact information and preferred method of contact to expedite access to care.

b. A contingency plan that contains instructions for parent action when the child experiences a change in condition. It describes how and when to contact the appropriate clinical provider for health care issues. These plans are developed from scenarios suggested by families that are likely to result in their child going to the ED. The contingency plan should contain actions to prevent an acute exacerbation, actions if an exacerbation occurs, and what to do if the child does not improve, e.g. when to call 911 or take the child to the ED. It would also outline the accommodations needed for other children in the house, notification of family members, etc.

c. An emergency care plan that provides essential information for emergency responders or ED personnel who are not familiar with the child to expedite effective treatment and communication with the child's medical home/subspecialty providers. This includes a brief medical history and description of child's baseline condition, current medications, common presenting problems with suggested diagnostic studies and/or treatment, procedures to avoid, important family preferences, a list of the child's physicians/their contact information and an advanced directive form.

4. Each family will have a care plan based on patient/family goals developed via a shared process between clinicians and child/family.

There is a standardized approach (including standardized documents) to care planning used with every child and family. Goals are developed from the assessment of family needs and assets for care planning. Providers and the child/family have the same understanding of roles and acknowledge the same patient goals. Care plan includes action steps to assist child/family attainment of goals. Families and providers across the care continuum have access to the care plan.

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Acknowledge

Acknowledge the importance of primary care as part of all integrated systems of care



Ensure

With the consent of families, ensure that a family's primary care provider is a valued member of their dynamic care team with a defined role and set of responsibilities



Cultivate

Cultivate personal relationships among hospital-based and community/primary care-based dynamic care team members



Communicate

Develop reliable multi-directional means of communication and sharing of information that include each child's primary care team particularly in the presence of different EHR systems

8

VITAL ACTIONS TO SUPPORT

Primary Care Teams

IN THE CARE OF CMC

Utilize

Utilize primary care as a family's "first contact" and as a valued expert to triage problems and concerns as they arise



Facilitate

Facilitate the development of care coordination systems with "nodes" of connection among families, complex care clinics and other hospital-based resources, and primary care teams



Distribute

Distribute locus of management responsibilities according to levels of complexity and to the preferences of families between complex care clinics and primary care settings

Train

Provide regular training opportunities to primary care teams in the management of children with medical complexity as well as access to "point of care" decision support resources