Up to three million children in the U.S. have medical complexity, and the current health care system is not equipped to provide them optimal care. With diagnoses that are multiple and varied, they require highly specialized medical care, as well as mental health and psycho-social services. Families of children with medical complexity (CMC) bear the brunt of trying to coordinate the care their children need from numerous providers.

With two million of these children relying on Medicaid, the traditional fee-for-service payment model fragments their care, leading to longer inpatient hospital stays, preventable hospital readmissions and unnecessary emergency department (ED) visits. While these children represent only 6 percent of all children enrolled in Medicaid, they account for 40 percent of Medicaid’s spending on children’s health care.

Coordinating All Resources Effectively—the CARE Award—is a landmark national study aimed at improving quality and reducing the cost of care for CMC enrolled in Medicaid. Funded by the Center for Medicare & Medicaid Innovation (CMMI), the CARE Award is designed to test the concept of a new care delivery system supported by new payment models specific to CMC. Under the CARE Award, 10 children’s hospitals partnered with the Children’s Hospital Association (CHA), eight state Medicaid programs and Medicaid managed care organizations (MCOs), 42 primary care practice sites, and more than 8,000 children and their families.

The enrolled children represent approximately $380 million in annual health care costs. The CARE Award was designed to impact growing costs and reduce family burden by transforming care for CMC through the provision of appropriate, coordinated care in the right setting, along with the development of alternative payment models that more effectively align with the new care model.
With an overall aim to inform sustainable change in health care delivery through new payment models supporting better care, smarter spending and healthier CMC, the CARE Award set out to:

- Decrease caregiver burden
- Enhance patient experience of care and care coordination
- Provide care closer to home and at lower cost
- Create payment models that support high-quality care and rewards savings
- Decrease utilization of health services

The CARE Award targeted care delivered in hospitals, hospital-based complex care clinics and community-based primary care practices. Implementing a combination of evidence-based and best practices consistently across the continuum of care to improve care coordination, the CARE Award set spending and utilization outcome goals taking into account an October 2013 study of the medically complex pediatric population by the firm Dobson DaVanzo. Based on implementation of a new care model, the study projected a three-year reduction in spending by 6.8 percent, a decrease in inpatient days by 40 percent and a reduction in ED visits by 10 percent.

Undertaking such a major transformation of the health care delivery system for 8,000 CMC in Medicaid required an enormous investment and commitment from CMMI, CHA and participating children’s hospitals. This involved three primary project tracks:

- **Data and analytics** – provided the foundation of the work done within the CARE Award by gathering and interpreting information from surveys, care coordination costs, project measurement and health care utilization and spending available in Medicaid claims
- **Care transformation** – dynamic care teams (DCT) devised customized access plans and care strategies complete with patient and family-stated goals, effective transitions of care management across multiple providers and sustainability of high-quality care
- **Payment reform** – involved the research and development of payment model options, partnerships with payers for the implementation of the new models, and ongoing monitoring of payments and costs under the new models.

Insights from this project may contribute to larger-scale innovations and transformation among CARE Award hospitals and, ultimately, many other health care providers for CMC.
Background
Before diving into numbers, it’s important to understand the data sources—provided by eight states including the District of Columbia—and the magnitude of the effort to collect and standardize Medicaid claims data. Of the 8,000 enrolled CARE patients current analysis is available on 3,200 for a period of 12 months to establish a relatively stable cohort of patients exposed to care transformation during the CARE Award period. The initial cohort size is due to data quality and a 5-18 month data delay across the data providers. These preliminary results based on a pre-post analysis reveal a promising start.

Spending and utilization
An important aspect of the CARE Award is optimizing health care utilization while simultaneously reducing overall spend. The project’s results show success in all three target categories (see Figure 1).

### Figure 1. Preliminary Results

<table>
<thead>
<tr>
<th>Outcome Measures</th>
<th>3-Year Aggregate Goal</th>
<th>12 mos. 8 hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased inpatient days</td>
<td>40%</td>
<td>32%</td>
</tr>
<tr>
<td>Decreased ED visits</td>
<td>10%</td>
<td>26%</td>
</tr>
<tr>
<td>Decreased spend</td>
<td>6.8%</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

Breakdown of spending and utilization results for one-year of full implementation

- The CARE Award baseline period showed an increase in patient days. Once the change interventions were fully implemented, inpatient days declined to levels expected under successful care transformation.
- ED visits declined; the decrease in ED visits exceeded the three-year aggregate goal.
- Although controlling pharmacy utilization and spend was not a target intervention of the CARE Award, pharmacy did have an impact on overall spend figures. The Dobson DaVanzo study predicted a 10 percent increase in pharmacy spend due to national factors over this time period. Our experience exceeded those numbers, impeding the award’s expected decrease in overall spend.
- Spending decreases in the first year of implementation are in alignment with year one of the original Dobson Davanzo projections.

Family-centered outcomes
Working toward a goal of 2,500 family surveys, CARE Award hospitals experienced a 90 percent follow-up from roughly 1,000 baseline surveys. Families did not indicate adverse impacts during the care model transition—in fact, a statistically significant 1 percent increase in family function was cited. Though the three-year goal was a 10 percent increase, the finding demonstrates that transformational work focused on utilization and spend can be done without creating greater stress on families, and may ease caregiver burden over time.

Care transformation
With a staged implementation of change concepts, best practices and successes spread rapidly across CARE Award teams. As a result, care transformation goals were met or exceeded. Highlights include:

- The first patient was enrolled in May 2015, with the enrollment goal (8,000 children) reached by November 2016.
- Change concepts were fully implemented by May 2016.
- A total of 51 quality improvement (QI) teams were engaged, encompassing more than 265 people.
- Implementation goals were broadly exceeded in 2017, the last year of the award.
- Process measures met or exceeded targets for three key change concepts—DCTs, access plans and care plans.
- Teams developed sustainability plans in the three months following the end of the CARE Award care transformation implementation, September-November 2017.
Using access and emergency plans, UCLA Mattel Children’s Hospital developed after-hours action plans to help families of CMC avoid ED visits. These plans were then embedded in the patient’s EHR to ensure any provider would understand how to manage the child’s care.

Proactively managing overall care and needs when symptoms escalate
The Mattel Children’s team developed an action plan tool for CMC modeled using their successful asthma action plan model. To create each plan, the care team and the family identified issues or diagnoses that would likely lead to a child’s decline and require an ED visit or hospitalization. These conversations then identified actions the family should take when the patient was at baseline (green zone), beginning to deteriorate (yellow zone) or showing severe symptoms (red zone).

It was important these recommendations were consistent with the specialists’ recommendations. When necessary, the team discussed the care plans with the relevant specialist prior to finalizing. Common topics for action plans included respiratory problems, fever, seizure management and equipment issues. The majority of families received one plan, but some received plans for up to three conditions. Families also received personalized information on how to contact providers for issues, as well as clinic and urgent care hours.

Helping families understand action plans
Understanding of, and agreement on, the plans was assessed using teach-back, a way of checking understanding by asking patients to state what they need to know or do about their health. Families received a color copy of their action plan, with one page for each condition, making it clear what to do if they become concerned about a change in their child’s condition. Hospital staff translated the plan for Spanish-speaking families.

Promising approaches for implementing action plans
The CARE Award greatly strengthened plan implementation by helping the team deploy rigorous quality improvement methods to translate good ideas into successful practices. Additionally, insights from CARE Award colleagues offered some promising approaches to embedding action plans into electronic medical records.
St. Joseph’s Children’s Hospital

With a focus on creating comprehensive care plans for all children with medical complexity (CMC), St. Joseph’s Children’s Hospital in Tampa, Florida implemented contingency plans and emergency protocols to reduce preventable emergency department (ED) visits when there was a change in the child’s condition.

Building effective care plans for CMCs
The consistent formatting of a care plan is key to its effectiveness. Today all pertinent patient information is available in one place and in an easy-to-read format. This makes it quickly accessible to the entire dynamic care team (DCT), as well as others involved in the patient’s care, ensuring every provider who interacts with the child has the most accurate information.

Several change concepts from the CARE Award proved especially helpful for both families and staff. The DCT helped families know who their health care team was and how to contact them, while the staff used this knowledge to improve connections across the continuum of care. The emergency care plans were essential for the families to prepare for any situation that could lead to an ED visit.

New strategies support improving patient care
Simplified models for documenting the care plan demonstrated what worked best for the care of these patients. It is very helpful for families to have the care plan at their fingertips, with the knowledge that it’s updated to reflect current needs at every visit. Because St. Joseph’s and other hospital specialists don’t share the same electronic health record, a written care plan of care is also available and in the patient’s medical binder to bridge the communication gap between care providers.
As a critical element of the CARE Award, Wolfson Children’s Hospital collaborated with the University of Florida (UF) Department of Pediatrics, and community hospice and palliative care to implement a transition program for adults with medical complexity to ensure integrated palliative care services in inpatient, outpatient and community settings. Focused on the care of the young adult transitioning to adult care and palliative care coordination, UF-Wolfson applied change concepts to patients co-managed by their community-based palliative care program.

Care transitions that should be integrated into CMC care models
Inherent to the care of CMC is the commitment to ensure their successful transition into adulthood. Over the past decade, much has been learned about how to structure and implement formalized programs to address the needs and rights of young adults with complex medical, mental health, developmental and social conditions. CARE Award concepts were applied to the UF-Wolfson Jaxhats Transition Program to ensure the successful transition of patients from the UF-Wolfson Complex Care Clinic (birth to age 18) to Jaxhats (ages 16-26). It is critically important that transition medicine be included in the development of all clinical programs, systems and policies related to the care of children and young adults with medical complexity.

Incorporating palliative care as care model element
CMC live, grow and develop within families, child care centers, schools, their homes and communities. The care of these children, siblings and parents must extend beyond the out- and inpatient medical settings if their health and development is to be optimized. The principles and practice of palliative care, and in particular community-based palliative care, must be fully integrated into all models of complex care to fulfill these children’s rights to optimal survival, health and health care. As demonstrated in the CARE Award, integrating community-based palliative care into the continuum of care for CMC also decreases hospitalizations and emergency department visits over-and-above the impact of establishing specialty practices.

Integrating concepts into clinical programs
The CARE Award advanced the effort to fully integrate nurse and social work care coordination, and family advocacy, into the fabric of the hospital’s clinical programs. Two change elements—care coordination and family advocacy—transformed Wolfson’s practice from a medical model and medical home into a community health home.
FAMILY ENGAGEMENT

Engagement of families of CMC as equal care team partners is crucial to optimize hospital utilization. This became evident during the CARE Award, and the importance of inviting families as partners early in transformation work cannot be overstated.

From their unique vantage point as frequent health care consumers, family members shed light on gaps in the care delivery system. Each CARE Award site sought this input by embedding family champions in their QI teams. A prime example of how family input affected process change: CARE Award teams interviewed more than 500 families after ED visits to better understand what led them to take their child to the ED and what could have been done to prevent the visit. Those insights strengthened strategies that would help families avoid future ED visits by informing contingency plans, emergency care plans and family-focused goals.

Recognizing family engagement on a deeper level is an important CARE Award finding. This project illuminated the profound effect families have on health care system redesign, implementation and evaluation. When families are included from the beginning, children’s hospitals gain incredible insights that can change care for all CMC.

Photo: Katherine C. Cohen, Boston Children’s Hospital, Boston, Massachusetts
Using concepts and learnings from the CARE Award, Children’s National Health System in the District of Columbia expanded on its existing parent navigator model and use of telehealth for virtual home visits to improve care for CMC.

Designing the Parent Navigator program
Founded in 2009, the Parent Navigator Program provides peer-to-peer support for families of CMC. Parents are often overwhelmed with the challenges of their child’s care, specifically navigating and coordinating an increasingly complex system of multiple medical specialists, care coordinators, case managers and support services in the health system and community. Parents of CMC are often more comfortable reaching out to peers with questions and to ask for support. At Children’s National, Parent Navigators are active members of the CMC care team, bridging communication and coordination between families, care providers and care team members.

Recommended parent program elements
The Parent Navigator program expands and enriches evolving programs to better address care coordination and case management for children with acute and ongoing medical complexity. Key to this is peer-to-peer engagement and communication. While not required, all Parent Navigators have personal experience with children with significant health concerns. They offer a safe listening ear for parents to voice fears, worries or frustrations, which creates opportunities to better identify parental stress and improve communication and coordination among the care team. The Parent Navigators participate in operational, management and care team meetings across the care continuum, including complex care, primary care medical home redesign and hospital Parent Family Advisory Council. This brings the parent perspective to care delivery, planning and operations.

Funding options for this parent partnership model
The program was launched with state funding from both the District of Columbia and Maryland to better address the needs of children and youth with special health care needs. Children’s National has provided additional funding support from philanthropy and both primary care and complex care operations. As children’s hospitals increasingly invest, and expand resources and infrastructure to better coordinate and support the care of CMC, Parent Navigators are a valuable resource.

Using telehealth to enhance family engagement at home
The hospital has begun to incorporate telemedicine and telehealth to improve care and coordination for CMC. They’ve successfully piloted and validated key use cases for CMC including direct medical care visits (particularly with technology-dependent children) for both post-discharge and interim visits as well as joint visits involving child, parent and other participants like primary and complex care providers, case managers, care coordinators, home care nursing services and parent navigator partners. Payment for provider-to-home telemedicine is evolving in local markets; however, several large Medicaid MCOs and commercial payers are currently recognizing and reimbursing for telemedicine visits. Scheduling and supporting telemedicine visits still requires significant pre-visit staff and technology resources. But staff and families are becoming increasingly comfortable with the technology. Families with CMC especially value avoiding travel and appreciate the ability to virtually assemble health care team visits.

As pediatric health systems move into new payment models for attributed populations, particularly CMC, telemedicine offers significant potential to improve virtual access and better coordinate care with the child, family, and multiple providers and services.
To better understand all factors that affect the health of a CMC and meet needs that extend beyond health care services, Children’s Hospital Colorado in Aurora, Colorado used the CARE Award as a springboard to integrate social risk assessments into the CMC family profiles and patient care plans.

Assessing for social risks with families
Children’s Colorado assesses social risk in a number of ways, starting with awareness by all team members of the importance of social determinants of health (SDOH) on health outcomes. Families began completing a 14-question tool to identify issues that may impede family function. As the team developed care plans (now incorporated into EPIC’s Longitudinal Plan of Care) and worked with families to set goals, there was a high frequency of social issues such as housing, hunger, parental access to health care and employment that emerged as family goals.

As the team was assessing risk using a medical and utilization model in the CARE Award, care coordinators noticed that when the quantitative tool was incorrect, it was often due to social factors that could not be seen in the claims data driving the Clinical Risk Group (CRG)-based score. The questionnaire is completed by the parent at each annual visit and scored by the provider. The medical assistant then uses the result to connect the patient with a family navigator, social worker, mental health worker or other relevant services. Depending on the nature of the problem, the assessment can be completed by the appropriate team member.

Support for developing process to identify needs
The CARE Award drove the development of this process in several ways: First, assessing risk using a claims-based risk score forced the hospital to address the need for augmenting the CRG-driven risk scores with SDOH data. It would be impossible to identify high-risk patients without it. Second, as care coordinators began working with families to set family-centered goals, it was clear that a system was needed to address both social and medical needs to improve family quality of life. Finally, as the screener was implemented across specialty care and primary care practices, providers could address many of those needs without overwhelming the system.

Incorporating social risks into the shared plan of care for CMC
Strategies to address SDOH identified in the screener are part of the longitudinal plans of care, but often involves making a connection to a community agency for additional family support. There is currently no method to ensure that outside referrals are completed; this feedback loop needs to be strengthened into the future.

Lessons from the CARE Award experience
Several takeaways came from Colorado’s participation in the CARE Award, including:

1. Address SDOH as a routine part of caring for CMC. Health risk is driven by social factors as well as biology;
2. Take a thoughtful, systematic approach in collaboration with families to identify areas of focus within the SDOH screener and intervention; and
3. Don’t let perfect be the enemy of good.
The CARE Award project has been a significant journey with important insights.

**CARE TRANSFORMATION**

Transforming care models is a journey, not an operational template. Existing complex care programs can adapt their model, while new programs can use CARE Award successes to establish buy-in for development of, and a foundation for, their program.

An optimal care delivery model creates shared goals across the care system that center on the child and family. It should focus on formulating easy-to-understand patient treatment plans based on families’ wishes and concerns—it’s at the heart of quality care coordination.

Limited resources can be problematic for primary care physicians (PCPs) engaged in caring for children with CMC. PCPs are paramount to care coordination, and they need more support to engage in QI efforts that transform care. CARE Award funding provided resources, education and paid time and expenses to support PCPs in developing the concept of a medical home. Practice transformation facilitators at each hospital built critical relationships with PCPs, and were essential to change concept implementation at that level.

Strong provider and family partnerships in caring for CMC extends knowledge of the child’s conditions, and creates family-centered and proactive care plans that improve the child’s health outcomes.

Photo: Olaf Starorupsinski, Lehigh Valley Children’s Hospital, Allentown, Pennsylvania
The CARE Award was an important catalyst in the growth of Children’s Hospital of Philadelphia’s (CHOP) care management activities. Using analytics and clinical quality improvement from the CARE Award led to a service line approach and supporting technology for care coordination.

Collaboration led to standardizing care plans and strengthening connections
The change concepts and collaboration across health systems provided a vision for how to standardize longitudinal plans of care for CMC and improve communication across care teams. Even more importantly, the salary support and institutional investment that came from the CARE Award’s visibility was instrumental in aligning early development of care management tools with CHOP’s electronic health records to support primary care medical home activities, and the complex care program, Compass Care, which was available for the most resource-intensive children. This program has had a measurable effect on patients and their families.

Using analytics and clinical quality improvement to transform care
The focus on analytics and quality improvement, which is foundational to CHOP’s programs, helped develop a model of care coordination that was responsive to efficiency measures (e.g., reducing length of stay and emergency department visits) as well as patient and family-reported outcomes. Regular team huddles became the norm, leading to great gains in outcomes across patient populations. The combination of organizational and leadership development that occurred during the CARE Award ultimately led CHOP to devote a new service line for care management within its operational structure.

Clear and consistent demonstration of value through outcomes dashboards led to institutional development, as well as payer investment, in the primary care medical home models for CMC.

As CHOP looks toward the future, learnings from the CARE Award and CMMI’s investment will be seen as a turning point for care coordination for CMC.
At the same time Cincinnati Children’s Hospital Medical Center (CCHMC) became involved in the CARE Award, the hospital launched a care management program focused on the highest-risk patient population across four care centers. This provided the organizational structure and technology support to integrate care coordination competencies across the continuum.

**Aligning care coordination model within the continuum of care**

Care coordination was historically housed in specialty clinics with nurses or social workers focused on a specific disorder or condition, or inpatient units to support patients at discharge. Anchoring the complex care and care management model within primary care supports the Primary Care Medical Home model where primary care practice serves as a hub for care coordination. The tools and model were developed within primary care, and scaled and spread from there. This created a centralized place to support programs like Transitions of Care from Hospital after admission to home.

**Adoption of a system-wide model**

Some factors spurring adoption of this model came from the larger landscape within and outside the organization. Inside was the redesign of CCHMC’s primary care system, redesign of chronic disease and complex patient management, and launch of an accountable care organization-like health model. Each tactic was in progress and elevated the role of care coordination to care for high-risk and high-cost patients with medical complexity. Finally state payment models like Comprehensive Primary Care were supporting the concept of risk stratification and care coordination for high-risk and high-cost payments, which further supported the model adoption.

**Transformation aspects needed to assure continued delivery system evolution**

The use of, and contribution to, the Longitudinal Plan of Care (LPOC) across CCHMC will be helpful as a source of core information about patients and families, their goals and key aspects of care. The CCHMC team will further promote using the EPIC-based tools to support care coordination outside of primary care, ensure access and emergency plans are easily available for all team members—including My Chart for patient and family access—provide continued revision and refinement of care management practice guidelines that define roles, and monitor how interactions occur between primary care and specialty providers.

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**Takeaways from the CARE Award**

There is tremendous variation in how and where care managers document their practice. Learnings from the other awardees helped to inform work around optimizing EPIC tools, updating Care Manager Practice Guidelines and providing supportive accountability in supervision. Input from CARE Award sites on their model and practices also allowed opportunities for more proactive practice with respect to continual assessments. They shared that every interaction is an opportunity, encouraged dynamic care team core members to be included on the access plan and integrated with the care delivery team, offered ideas for transitions of care between in- and outpatient settings, and supported the creation of Care Manager EPIC Dashboard.

**Family engagement in the new care model**

The CCMHC team focused on 1) family relationship development with the care managers and 2) testing and implementation of the change concepts. Family relationship development was an ongoing process, and emphasized the importance of developing collaborative partnerships between patients, families and care managers. Families were involved one-on-one with care managers, actively engaged in Plan-Do-Study-Act (PDSA) activities in real-time, and their feedback incorporated into all PDSA cycles.

Family feedback was used in planning and practice guideline development, and parents served as either intermittent or continuous reviewers of PDSA cycles. They were engaged at visits by one of their primary care team members, and then received follow-up calls. Their providers explained care management services, and that parental involvement were essential.

Families were also engaged through coproduction of patient-stated goals for the LPOC that allowed reinforcement of patient and family preferences. Families were appreciative of access planning, which gave them more confidence in managing their child’s care. Having an accountable point of contact improved the family’s connection to their clinics and ensured their needs were addressed. Parents on the project team confirmed that family input is important and brings a different and valued lens to patient care. Families shared feedback that validated the utility and value of the current care management model, its practices and the importance of establishing sound relationships with care managers, providers and care team members.
With the implementation of the CARE Award change concepts in collaboration with the system health plan, Cook Children’s Health Care System in Fort Worth, Texas developed an integrated case management model for both medical and behavioral care.

**Engaging broader delivery system without an established complex care clinic**

Collaboration and ongoing communication with primary care and specialty providers was key for the Cook team. But it was not until the team engaged individual clinics in developing single patient care teams and care action plans that the process began to work effectively. It was the provision of clinic-specific care coordinators and managers that helped the clinic staff and physicians appreciate the value of these individuals in removing existing barriers of time and the personnel required to coordinate care away from other clinic staff duties.

This is more than coordinating with inpatient care. That’s a prerequisite, but not likely to work unless there is a coordinated care management effort that encompasses care before, during, and after inpatient care.

**Moving the CMC population into managed care**

The team started to prepare for the transition by clarifying the deficiencies present in baseline systems of care, which allowed time to address them prior to managed care being implemented for the high-needs, chronic medical condition pediatric patient population by the state Medicaid program. One example is the establishment of medical home practice principles, including communication and care transition processes between primary care physicians, hospitalists and subspecialists.

**The role of families in improvement**

A physical complex care clinic was not necessary to provide best practices to this high-needs population as long as a coordinated and transparent approach to care delivery and utilization monitoring was in place. While families benefited from the care coordination improvements, the team learned that none of it was effective without parents actively engaged and willing to participate in their children’s care.
There are a number of sustainable alternative payment models with payers that children’s hospitals may consider, though it’s uncertain if the risk and amount needed for care coordination costs can be covered.

The CARE Award is unique among the CMMI awardees focused on CMC in its ability to implement multiple types of payment models across states and Medicaid MCOs. Five children’s hospitals developed and implemented new payment models within the CARE Award, serving as an example to others on possible models. Three other children’s hospitals are currently in discussions with their respective states and payers regarding the creation of new payment models for CMC.

The CARE Award demonstrated that new payment models can drive and sustain changes to the care delivery system when they include:

- Infrastructure support to coordinate care designed to provide a medical home for CMC. The medical home model prioritizes the development of family-stated goals and shared plans of care including contingency, emergency and access plans, and enables after-hours access to providers familiar with the child/family

- Resources for providers who directly manage the child’s care
Using a state health home in behavioral health as a platform for transforming care delivery for CMC, Children’s Mercy Kansas City implemented a state health home per member per month to support service integration across providers. Missouri’s Primary Care Health Home initiative provides intensive care coordination and care management, and addresses social determinants of health for this complex patient population.

A complex care model that addresses cost and utilization
Medicaid participants who have two or more chronic health conditions benefit from these comprehensive care management services. The program also integrates primary care and behavioral health care to achieve improved health outcomes. One program component is the Patient Centered Medical Home model, which has shown decreases in emergency department utilization, inpatient admissions and inpatient length of stay.

Evolving delivery system strategy and contracting
Children’s Mercy’s experience in the CARE Award informed the expansion of global capitation agreements to include CMC. In November 2017, CMC were part of Children’s Mercy’s first global capitation agreement for Kansas Medicaid. The knowledge they gained also contributed to the development of bundled payments for episodes of care in targeted specialty areas and within global capitation agreements to design new specialty payment models.
In partnership with a local Medicaid MCOs, Lucile Packard Children’s Hospital Stanford in Palo Alto, California implemented a care management monthly service fee per child in the CMC case management program.

Cost of care findings in claims data evaluations
The Lucile Packard team found interventions decreased hospital admissions and inpatient days significantly, but did not lower the cost of inpatient care. This was likely due to a change in reimbursement methodology that occurred outside the CARE Award. Prescription drugs were the second highest category of spend, with a cost per beneficiary increasing by 70 percent for an unknown reason. Durable medical equipment was the third highest category of spend.

Home health care spend was low due to unavailability of services, and Lucile Packard decreased office visits by using phone and text check-ins. This saved little money because office visits, which are paid at a low rate, are only 1 percent of the total spend per beneficiary. However, this was more convenient for families and prevented extra office visits.

Using clinical, financial and government relations expertise
Payment market forces were in play independent of the CARE award. The state and local managed Medicaid plan moved from per diem to APR-DRG reimbursement, which more accurately reflected high patient acuity and paid better than per diems. Because the state was not willing to do any special payment pilots, Lucile Packard built a trusted relationship with a local managed Medicaid plan to contract for case management services for the highest acuity CMC. The team shared CARE Award data while showing them the case management model and its costs, which led to a three-figure per member per month case management fee. This plan capitated for all care, but both sides acknowledged the total eligible members (less than 500) were too low.

Aligning incentives that support care management and stabilize costs
The number of children needed under management is fairly large; it can be hard to contract for a sufficient number of CMC to have a viable model for full capitation of total care costs. But it’s incredibly valuable for patients and families, and decreases emergency department visits and hospitalizations. Fewer ambulatory visits are possible with tighter coordination using parent education and self-management training and technology tools like telehealth, smartphones and texting.
The CARE Award made significant strides in transforming health care delivery and payment models for CMC. Though not intended to be a complete implementation playbook, the project provides examples of what practices are effective and replicable to help children’s hospitals initiate sustainable changes in health care delivery supported by new payment models.

Incorporated into the CARE Award was a multidimensional approach for teams to recognize and analyze factors known to be critical to sustaining improvement. With the ultimate goal for teams to develop an effective sustainability plan, the four-step process helped teams:

- Understand each organizational system affecting sustainability and its components’ importance to sustaining success
- Determine change concepts that were most essential to sustaining work
- Identify required resources within organizational systems necessary for long-term improvement sustainability
- Develop a comprehensive sustainability plan

Expediting payment models

There are a variety of payment model options hospitals may pursue to better serve this patient population long-term. But given the administrative burden on payers in creating new models for small populations, the optimal route for expediting the movement to alternative payment models for this population is integration into state managed care, or Centers for Medicare & Medicaid Services (CMS) emerging models. State Medicaid programs and CMS are piloting new payment models for adult populations, such as health home models. These models will require adjustments for pediatric populations, but may serve as a more feasible starting point with payers.

Resources available to support transformation for CMC

The CARE Award website—childrenshospitals.org/care—offers detailed information to support health care organizations in transforming care for CMC.

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