Children with medical complexity (CMC), who have multiple chronic conditions requiring care from several specialists, depend on the coordination of supportive services to achieve maximum health and wellness. Care maps have been a useful tool to communicate the varied touchpoints from a family perspective, with services including primary and specialty care, hospital and emergency department (ED) care, community-based therapies and durable medical equipment, school services and many others.

Families often report fragmented care from a lack of active coordination of services. Fragmented care may include duplicative or unnecessary services, unmet service needs, excessive wait times and lack of information sharing needed to make correct medical decisions.

The American Academy of Pediatrics (AAP) defines care coordination as a patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Notable is the foundational aspect of family-centered care. The child and family experience the entire system of care, which includes medical, educational, legal and advocacy services. A family-centered care foundation ensures care coordination is a collaborative, partnering activity, centered on the needs of the child and family, and engages the entire system of care.

Reflections on Care Coordination

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Care coordination is particularly crucial for optimal health and health care of a CMC. Primary care provides preventive care and first contact for illnesses; specialty care provides condition-specific management. Other services support vital functioning on a day-to-day basis, enhance growth and development, and address social determinants of health (SDH) such as transportation needs, poverty and health inequities.

All services need to be proactively managed and delivered in an efficient manner. No current consensus exists on the optimal model of care coordination. Questions include location of services, such as hospital-based, primary care-based, accountable care organization-based or community-based; degree of staff training and experience; and staff scope of practice, including medical and SDH.

Care coordination was the basis for the better care aim in the CARE Award (see Appendix A) to transform care delivery for CMC.

All participating sites were asked to implement care coordination concepts embodied in the change concepts of a dynamic care team (DCT), access plan and care plan. (See Appendix B)

All sites identified designated care coordinators who were tasked with providing and steering care coordination activities. In the project’s third year, CARE Award staff and faculty surveyed sites to define the roles designated care coordinators played, their training, duties and time commitment. Forty-five practices completed the survey in December 2016 (36 primary care; nine hospital-based complex care).

This paper offers the experiences of designated care coordinators, lessons learned, and steps to build successful care coordination for CMC.

The Care Coordinator Role
Care coordination activities are not limited to one person. Cincinnati Children’s Hospital Medical Center (CCHMC) emphasized that all team members are expected to perform care coordination. However, all sites designated at least one staff person to act as a designated care coordinator, and specific duties were assigned to this person. The most common training background was RN, followed by social worker and physician/nurse practitioner. Other qualifications included LPN, clerical, care coordinator assistant and other—including family navigators, data specialists, medical assistants and community health workers. All complex care programs and most primary care programs used an RN-trained staff member as the designated care coordinator. Prior work experiences varied across programs, ranging from intensive care to care management.

The AAP published 10 functions of care coordinators (at right). While all sites generally reported that care coordinators provided these functions, they also reported the importance of a care coordinator developing a trusting relationship with the family. Families emphasized the importance of having a key point of contact for all issues, and the care coordinator was tasked with addressing or delegating a response.

There remains a lack of consensus for how designated care coordinators are trained. In the CARE Award, on-the-job training for care coordinators varied. Some programs had informal training, while others implemented a standardized training curriculum based on experience. CCHMC used a structured learning collaborative for onboarding new care coordinators across different practice sites. Cook Children’s

10 functions of care coordinators

☐ Provide a specific visit with care coordinator
☐ Manage continuous communications
☐ Complete/analyze assessments
☐ Develop care plans with the family
☐ Manage(track tests, referrals and outcomes
☐ Coach patient/family skills learning
☐ Integrate critical care information
☐ Support/facilitate all care transitions
☐ Facilitate patient/family-centered team meetings
☐ Use health information technology for care coordinators

Source: AAP
Health Care System drew on an external case management curriculum that was not specific for CMC, but built on a case management framework encompassing psychosocial determinants of health.

CARE site quality improvement (QI) teams reported on empanelment metrics for each designated care coordinator. RN care coordinators averaged one FTE per practice and managed an average of 182 patients. Social work care coordinators reported 0.64 FTE and managed an average of 138 patients. The range of patients extended up to 500, although higher numbers were seen in primary care practices with an overall lower acuity of patients on the panel. Some teams conducted risk stratification of patients and accordingly assigned patients with the highest level of medical and psychosocial risk to RN-level care coordinators.

**Team Organization: The Dynamic Care Team**

Care coordination is a team-based activity. While all sites designated at least one staff member as a care coordinator, coordinating the roles and tasks of multiple people was critical. Accordingly, the CARE Award’s change package featured a DCT with specific roles for all members in the care of CMC. One site explicitly emphasized that all DCT members were to do “care coordination,” underscoring the importance of the team-based approach to care. Family is the constant on all teams, regardless of the DCT composition.

In the past, the family has often acted as a care coordinator. In part, this is because CMC depend on services from many systems that have different entry points, training, financial support and goals. Under the CARE Award model, families generally worked with a designated care coordinator. It is important to emphasize, however, that family expertise includes the fullest understanding of the care system.

Care mapping visually illustrates the complexity of the care system families encounter and CMC depend on. Different systems are color-coded, such as health, school, support and legal/financial; Figure 1 offers an example care map developed by a CARE-enrolled family. Care coordinators need to have sufficient training and expertise to navigate the different systems and that often is relegated to the family. The location of the designated care coordinator can also affect how team-based care coordination is executed. Many sites emphasized the importance of a single point of contact as a designated care coordinator for families to build relationships and continuity.

CARE Award care coordinators were reported to be based in the primary care practices or hospital-based complex care service, with one site reporting the use of a health plan-based care coordinator system.

![Care Map Example](image)

**Figure 1: Patient Care Map (2016)**

That site had care coordination provided by designated staff that were not in the health care delivery sites, requiring specific communication tools and designated roles within practices. Other organizations which play a prominent role in the child’s DCT should have one or more similarly designated roles to provide...
Many sites emphasized the importance of a “single point of contact” as a designated care coordinator for families.

Care coordination: Part of the change concepts

Dynamic care team (DCT)
- Identified care coordinator, with consideration for RN training, per 150 patient panel
- Standardized training, particularly in social determinants of health
- Family is a key member of the DCT and collaborates with identified care coordinator
- DCT members include key health care, community and educational providers; all are viewed as engaging in care coordination activities

Access plan
- Designated care coordinator acts as single point of contact
- Patient/family knows who to contact, and how, based on their child’s circumstances and characteristics

Care plan with shared goals
- Goals relate to quality of life and every day functioning
- Standardized approach and tools utilized by designated care coordinator
- Team-based approach with care mapping
- Providers and patient/family have same understanding of roles and acknowledge same patient goals

See Appendix B for extended definitions

Care coordination services.

Several sites expanded team member roles to perform care coordination activities. UCLA Mattel Children’s Hospital used non-licensed care coordinators under the supervision of a nurse practitioner. The Children’s Hospital of Philadelphia (CHOP) and Cook Children’s, utilized and expanded the role of community health workers to better address cultural sensitivity concerns. Lucile Packard Children’s Hospital Stanford and Children’s National Medical Center used paid parent navigators to address family needs and provide insight into system issues. CCHMC, CHOP and Children’s Mercy Kansas City implemented the equivalent of a care management service where services cut across specialty care centers and were non-categorical with respect to diagnosis. CCHMC reported mapping a different group of care coordination team members to each family, depending on their level of social and medical complexity.

Communications Tools
Sites reported communications tools and electronic health records (EHR) optimize communication among the different sectors, and enhance team functioning. Tools included the creation of a care coordinator dashboard that would trigger alerts such as new admissions, pending discharges and upcoming specialty visits. Sites that already implemented the longitudinal plan of care module of EPIC’s Healthy Plan did this more easily. Several sites used the patient portals associated with their EHRs for communication and access to action plans. Challenges arose with private practices on different EHRs than the hospital, particularly for specialty care and/or the complex care clinic.

Key Workflows
Care coordination duties entail population management, including identification, stratification, mapping of services on risk tiers and empanelment of high-risk patients. Care coordinators played active roles in identifying children for risk tiers. As part of the CARE Award, CCHMC and Children’s Hospital Colorado began incorporating social complexity, a process that generally requires a personal assessment of needs. In addition, designated care coordinators generally became the point person with practices to create and maintain the CARE Award change concepts.

Eighty-three percent of the teams responding to the care coordination survey reported the care coordinator made proactive contact with patients at most risk, and 89 percent reported care coordinators provided direct access to patients/parents, with the majority reporting less than one day wait time for a response.

The RN care coordinator was the most frequently designated and
hired person reported by CARE teams. The following tasks were reported by over three-quarters of sites for that position: monitoring/revising/working with DCT (including family) to revise goals and plan as needed; collaborating with other case managers to ensure continuity of care; and identifying family priorities in resolving discrepancies. These results generally reflect an individual contact and case management approach. Less frequently noted were standardizing processes and assessment tools (73 percent), teaching/modeling self-care (64 percent), addressing available resources (58 percent) and maintaining patient registry (51 percent).

Sites noted other persons performing care coordination tasks not performed by RN care coordinators, but there was no clear consensus as to who did what duties. Social workers were more often linking families to community resources, maximizing family resources and addressing SDH. Duties more frequently performed by non-licensed personnel (clerical and care coordination assistants) include maintaining the patient registry, tracking tests and referrals, and assisting with making appointments. Two sites, CCHMC and Lucile Packard, reported care coordinators accompanying families on specialty care visits.

Survey respondents noted multiple people performing overlapping duties. Thirty reported an RN performed written communication to access services; 30 reported an MD/NP performed this task; and 24 reported a social worker performed this task. Other duties performed by multiple positions included linking families to relevant community providers, assisting families in ordering medications and services, and making appointments with other providers. Teams revealed a sense that roles were shifting as positions were filled and duties clarified—both directly related to the CARE Award and outside the project’s scope.

Supporting and Monitoring Ongoing Effectiveness
CARE Award sites used a care coordination needs and assets survey to identify care gaps and drive goal development. These surveys tracked things like enrollment, duration of care management, no-show rates, referrals, and number of appointments made by care coordinators. Outcome measures were reported to be linked with those measured by accountable care organizations and insurers, such as ED and inpatient use, and immunization rates and well-child checkups. Teams often used QI methodology to implement and evaluate care coordination processes and outcomes.

Sites reported up-front care coordination payments—or payments to support hiring of staff for these services—would be linked to specific population metrics. St. Joseph’s Children’s Hospital negotiated a care management fee per enrolled patient; Cook Children’s set up shared savings across three entities (physician group, health plan and hospital); Lucile Packard negotiated a per member per month (PMPM) for care coordination with their local MCO; and CHOP negotiated an up-front payment for care coordination staff at one clinic. Support payments are ongoing, and over the long-term, will allow for outcome measurement related to utilization and spend.

Families were surveyed on their experiences with care coordination as a part of the overall CARE Award family experience survey. More than 900 families were surveyed at baseline and at the end of the CARE Award. Only one site showed a statistically significant increase in experiences with care coordination.

Questions in the care coordination services domain were compared to each other and notably, there were well-performing reports on providers being up-to-date with care needs, supporting decisions and being informed about needs. Direct assistance to help manage care was below expected at baseline and at the CARE Award’s conclusion.

Teams shared findings from parent interviews about care coordination and the change concepts. One parent from a primary care physician (PCP) partner of Children’s Colorado indicated “...the amount of contact information can become overwhelming at times,” and the informal connection with the clinic’s care coordinator was more beneficial than the formal relationship with the provider. Families from St. Joseph’s PCP partner indicated they appreciated the pre-visit planning phone call performed by care coordinators. Families interviewed by Wolfson Children’s Hospital indicated that because of the care coordination team, they felt less intimidated and more likely to share their concerns. The relationships built by the care coordinators and parent support team created a safe environment for them.
Developing the Case for Care Coordination

Throughout the CARE Award, effective care coordination was most often found to be a collaboration between the family and a designated care coordinator, although a team-based arrangement was viewed as necessary to be effective. Designated care coordination has many reported benefits for CMC and their families. Families overall reported providers were well supported with information, and the sites used designated care coordinators to implement specific change packages to improve care for CMC.

Preliminary CARE Award results show improvement in patient experience and reductions in medical utilization and spending that could be useful for making the care coordination case. There remains variation in experience, training and designated roles for care coordination, and it is not clear yet that one person can perform all care coordinator duties. A team-based approach for overall care coordination in a system is needed, including the incorporation of team dynamics and an understanding of the system of care through care mapping exercises.

There is a high likelihood that one person needs to understand the system, and act as a facilitator and a point of contact for CMC and their families. QI methodologies can use the process and outcome measures for measurable, targeted improvements within and across systems.

The RN care coordinator as a single point of contact is essential for CMC, particularly when a child is identified with a risk stratification method. However, a team approach with defined roles is key, as the RN may not be able to perform all tasks. Social worker and clerical support may be needed in a care team-based approach. Most teams easily designated the RN, but the multiple roles utilized for different tasks suggests that practices have not universally sorted out how to ensure staff are working at the top of their license in team-based roles.

Finally, addressing SDH appears to remain somewhat inconsistent among sites. Innovative methods included use of community health workers and other non-licensed workers under the supervision of a nurse or nurse practitioner. This approach was intended to resolve issues related to cultural competency and community presence.

Conclusion

Care coordination as a family-centered, team-based activity is necessary but not the only step needed to achieve care integration and optimal outcomes for CMC. Success and change was achieved with the designation of an RN-level care coordinator, and this may be essential for success in caring for CMC. Families continued to report the need for more help to manage their child’s care.

Findings from project surveys and process measures were augmented by direct family interviews, providing confidence that the burden of care can be reduced. Findings also suggest further steps for care coordination include development of formalized, standardized training; understanding of care coordination as a team-based activity with designated roles, particularly with addressing SDH; and finally, affirming the family role within the team-based activity, particularly with support for self-management and family health.
Care coordination activities aren’t performed solely by one person. It’s a team-based partnership with the family; additional people serve various care coordination roles when needed.

Children with medical complexity (CMC) benefit from a designated central care coordinator acting as the single point of contact. The average of most programs within the CARE Award (with varying levels of complexity) was about 150-200 patients per care coordinator. Some programs recommend 50-100 for children with the highest level of complexity.

Previous education and clinical experience differs among care coordinators; standardized training on the range of services that CMC require should be done at the beginning of the role, and throughout tenure, to assure understanding and competency.

Care coordinators are often most valued for their reach well beyond the medical sector. Identify what services are most crucial to your patient population, then how care coordinators can support these services.

Centralized electronic communication tools, assessment tools and EHRs help with care coordination activities, including a care coordination dashboard.

Key Care Coordination Takeaways

1. Care coordination activities aren’t performed solely by one person. It’s a team-based partnership with the family; additional people serve various care coordination roles when needed.

2. Children with medical complexity (CMC) benefit from a designated central care coordinator acting as the single point of contact. The average of most programs within the CARE Award (with varying levels of complexity) was about 150-200 patients per care coordinator. Some programs recommend 50-100 for children with the highest level of complexity.

3. Previous education and clinical experience differs among care coordinators; standardized training on the range of services that CMC require should be done at the beginning of the role, and throughout tenure, to assure understanding and competency.

4. Care coordinators are often most valued for their reach well beyond the medical sector. Identify what services are most crucial to your patient population, then how care coordinators can support these services.

5. Centralized electronic communication tools, assessment tools and EHRs help with care coordination activities, including a care coordination dashboard.
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, CO)
Children’s Mercy Kansas City (Kansas City, MO)
Children’s National Medical Center (Washington, DC)
Cincinnati Children’s Hospital Medical Center (Cincinnati, OH)
Cook Children’s Health Care System (Fort Worth, TX)
Lucile Packard Children’s Hospital Stanford (Palo Alto, CA)
UCLA Mattel Children’s Hospital (Los Angeles, CA)
St. Joseph’s Children’s Hospital (Tampa, FL)
Children’s Hospital of Philadelphia (Philadelphia, PA)
Wolfson Children’s Hospital (Jacksonville, FL)
CARE Change Concepts Defined

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

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 at all times. 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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