Invoking the Power of Family Partnerships to Improve Outcomes for Children with Medical Complexity

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Effective Family Partnerships

10 VITAL ACTIONS FOR

**Engage**
Engage families in multiple levels of involvement, such as family advisory committees, parent mentors, family navigators, self-management facilitators, and direct participants on QI teams and in related QI activities.

**Access**
Provide 24/7 access to knowledgeable and trusted clinicians while building reliable relationships through a single point of contact for, and frequent touches with, families. This includes check-in and pre-visit calls and accompanying families to specialty visits.

**Activate**
Build and monitor a culture of family-centered care among all staff through ongoing activities such as family-led staff orientation and in-service education.

**Partner**
Create shared plans of care with active family involvement and family-derived goals that extend beyond medical treatment and short-term outcomes, and include action steps that guide family participation in goal attainment.

**Guide**
Develop access plans with individually relevant contingency guidance developed with, and understood by, families.

**Monitor**
Continuously monitor families’ experience of care through surveys, focus groups and individual interviews. Use this information to further improve care.

**Follow-up**
Use ED visit follow-up calls to ascertain how families make a decision to use the ED and how to improve alternative access options.

**Question**
Always question how families can become more engaged in service improvements and how care can become more family-centered.

**Support**
Provide tangible supports to families who are participating on QI teams such as stipends, child care and transportation.

**Encourage**
Provide staff support to families assuming QI and family advisory roles to foster their confidence and comfort as team members, and provide answers to questions and clarification about their roles.

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**Children's Hospital Association**
Families have underused expertise as health care system users. Providers and organizations can successfully use this knowledge by cultivating a culture of family-centered care. This invokes models of partnership with families in the care of children with medical complexity (CMC), as well as in the design and improvement of care delivery systems.

These concepts informed a guiding principle for the CARE Award (see Appendix A) and challenged participating teams. They found that aspiring to true family-centered care required a deep and pervasive cultural change among all care delivery team members and across all systems in which they work. As one CARE QI team member related, “We thought we were practicing family-centered care until we were asked to partner with families differently in the CARE Award.”

The Institute for Patient and Family-centered Care is defined as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families. Patient- and family-centered care provides the framework and strategies for improving quality, safety and the experience of care.” This definition aligns with those adopted by the U.S. Maternal and Child Health Bureau and the American Academy of Pediatrics, which consider family-centered care to be a standard of practice for high-quality care. While family-centered care characterizes an overriding care delivery principle, the engagement of families in mutually beneficial partnerships translates that principle into active practice. Family partnerships affirm families as full members of their children’s clinical care teams and engages them in the planning, testing, and implementation of care delivery improvements. Based on evidence that family-centered practices and partnerships improve outcomes for patients and families, the CARE Award called for the direct participation of families on quality improvement (QI) teams, and in the design and evaluation of clinical methods and tools grounded in shared decision-making with families and members of their health care team.

The CARE Award Model
With funding from the Center for Medicare and Medicaid Innovation, the CARE Award convened teams from 10 children’s...
hospitals and 41 primary care practice sites to improve outcomes and reduce costs of care for children with the most complex health care needs. QI teams were expected to include clinical team members and at least one parent of a child with medical complexity. These parent partners played an active role in the development and testing of change ideas, not simply a post-hoc advisory role.

Four change concepts created the framework for a QI collaborative anchored by the development of population registries, and the design and implementation of care processes that target better planning of, and access to, the right care at the right time. The model targeted care delivered in hospital-based complex care clinics and in hospital and community-based primary care practices, aiming for improved care coordination among providers and the same quality of care in all settings. Monthly measures of concept implementation, and emergency department (ED) and hospital utilization were combined with baseline and periodic measures of medical home functionalities and the family experience of care to assess the impact of the QI effort on CMC.

The change concepts (Appendix B) included: a registry to track patient status, a dynamic care team (DCT) with family and clinical care providers designated by the family, an access plan to facilitate timely access to the best care, a care plan developed with the family and shared by the DCT.

All participating sites had electronic health records that, once geared to track CMC, provided registry functions. In addition, process improvement efforts focused on the development of DCTs, access plans and care plans. The work was informed by the goal of uniform quality across sites and the importance to good outcomes for behavioral health and social determinants of health.

During the final year, the change concepts were enhanced in several ways to advance the level and quality of family engagement. First, care plans included short and long-term goals explicitly derived from the families and not solely from the clinical team members, with action steps to guide family participation in

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**Tips for Choosing Family Partners**

The best family partners may be ones that are:

- More experienced with navigating the local health care system and managing their child’s health care needs
- More experienced contributing as members of a QI team, or have support from other parents on the team
- Not in crisis, transition, or dealing with active health issues in their child
- Able to advocate for all families and provide constructive input, rather than focusing only on their own child
- Given a choice of roles including membership on a family advisory group or participation in a QI project
- Well-connected with family advocacy organizations and/or graduates of family leadership training programs

All participants saw a significant decline in reported hospital days for enrolled patients.
reaching the identified goals. Second, access plans were expanded to include contingency planning to better inform family decision-making about how, when and where to seek care, and emergency care plans that provide first responders and ED personnel with vital patient information to effectively begin treatment.

Finally, teams conducted follow-up interviews with families that had recently used the ED to better understand what determined their decision to seek emergency care.

**Experience with Family Partnerships**

Participating sites and their associated complex and primary care settings interpreted the expectation of family engagement in a variety of ways that evolved over the collaborative. A QI process that required direct family participation was a challenge to many of the teams, particularly some of the primary care settings. Challenges ranged from a lack of prior experience with this type of family engagement to a perception that most families had too many demands in caring for a CMC. Aligning real-time participation in meetings or calls with the availability of families created logistical challenges.

Many of the hospital-based teams felt their preexisting family-advisory committees could provide the necessary family engagement, albeit in a more reactive capacity. Among the successful efforts to more fully partner with families, Lucile Packard Children’s Hospital Stanford developed parents as paid mentors for other parents, and St. Joseph Children’s Hospital incorporated direct parent participation on QI teams.

During learning sessions, family voices were clearly heard and their input increasingly appreciated by participating teams, many of which revised and expanded their family partnership methods.

From the standpoint of family engagement in individual care relationships, even teams that professed adherence to the principles of family-centered care realized a higher level of family partnership was necessary. Barriers were care and access plan development, setting goals that were purely clinical in nature, and access procedures that made more sense to providers than families. In these cases, teams focused on educating families so they would follow the care and access plans created by providers, rather than work with families toward a better understanding of, and response to, their needs.

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**Tips for Engaging Family Partners**

Family partners may engage most productively when:

- Roles and expectations are clarified for all team members
- Pay and other incentives are provided for their time
- Innovative approaches and options for real-time participation and communication are offered
- Training in QI science and methods is provided
- Their suggestions and ideas are valued and acted upon when possible
- They are asked to review and suggest changes in care; help customize care plans for the range of family needs and situations

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I appreciate hearing the voices of families—it is very important. Every member of the family panel brought enlightening thoughts to the table.

—CARE QI team member
Learning sessions and huddle calls focused on examples of collaborative family engagement with supportive testimony from parents. Teams were asked to explain how family input was shaping the content of care and access plans. These efforts were successful when teams recruited senior leadership support to reshape their work culture, and gather and respond to family input. In some instances, this work was left to practice transformation facilitators with limited leverage to make systemic changes in culture or workflow with respect to family input.

Enhancements made to the change concepts during the CARE Award’s final year generated a higher degree of partnership with families in the development of care and access plans. Care plans included more goals related to quality of life and everyday functioning, and access plan contingencies permitted families a greater ability to make access decisions based on circumstances and their child’s unique characteristics. Teams interviewed over 500 families following ED visits, providing insights on the nuanced realities they face when their child’s health status changes unexpectedly, and the need for prompt assistance from someone they know and trust.

Family Partnership Innovations
Most CARE Award teams found innovative and measurable ways to better partner with, and learn from, families. Examples of family engagement innovations include:

- **Four sites** developed paid roles for parents on QI teams, mentors to other parents, parent navigators or advisors. This simplified parent participation in QI team activities enhanced the parent’s sense of being a valued team member, and created a shared stake in the outcomes of system changes.

- **Children’s Hospital Colorado** worked with families to design an emergency plan format so they could have individualized emergency action plans. This would guide them in access of care decisions and provide information for first responders and ED personnel on the child’s health history, DCT members, and care planning goals.

- **Wolfson Children’s Hospital** collected feedback from families indicating they were confused by the inconsistent terminology clinical team members used for the new tools (e.g. care plans, access plans, emergency care plans). As a result, terminology, labeling and tool formatting was standardized to make their purpose more clear.

- **Children’s Hospital of Philadelphia** organized evening educational events for families. One event demonstrated the concept of care mapping to visually portray each child’s array of supports, services and resources, and the relationships among them. Participating family completed a care map for their child, an activity that helped providers see the complexities that families of CMC face. Another evening was organized as a resource fair with community services and agency booths to explain their services and how to access them.

- **Lucile Packard Children’s Hospital Stanford** convened a family advisory team that met monthly and actively participated in the redesign and implementation of change concepts.

CARE Award Outcomes
All participants saw a significant decline in self-reported hospital days for enrolled patients, and this decline was highly correlated with the penetration of patient-centered care plans and access plans over the course of the project. Care and access plans were vetted and tested against family feedback so that the engagement of families may have contributed to this core outcome. Family feedback and family involvement indicators on the Medical Home Index (MHI) saw 23 percent and 16 percent improvement respectively between baseline and final administrations of the MHI, and some practices reached the highest possible scores for these indicators. While high increases related to having low
scores at baseline for some clinics and practices, earlier solicitation of direct family input could have resulted in even better performance on the MHI indicators during the project.

Several family survey tools were used at repeated intervals during the CARE Award to elicit direct input from families about their experience of care. Survey results were adjusted to account for patient age, gender, duration of case management prior to enrollment, site of care, and hospital system. After adjustment, statistically significant improvements were seen in the Family Centered Care Assessment survey overall, its decision making interaction domain, the PEDSQL-FIM survey overall, and its daily activity domain.

**Conclusion**

Families need to be essential partners, not only in the care of their own children, but also in the QI practices so necessary for true system change and transformation, particularly systems of care for CMC. To be successful, family partnerships should be embedded as a core value in the culture of the health care organization, with senior leadership support for provider and system change.

Family partnerships can lead to increased family confidence and ability to manage health care interventions for their child, more effective shared decision-making and care planning among the dynamic care team, increased satisfaction with the health care experience, and decreased utilization of emergency and in-hospital services. Families must be supported in this role via education, mentorship, clear definition of roles, demonstrated value and application of their suggestions, and compensation for their efforts.

Ongoing efforts to seek input from families via surveys, focus groups and interviews strengthen care improvements and support sustainability of family-focused changes to the care delivery system.

Photo: Allyn DiVito, Johns Hopkins All Children’s Hospital, St. Petersburg, Florida
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.
REFERENCES


3American Academy of Pediatrics Committee on Hospital Care and Institute for Patient and Family-Centered Care; Patient and Family-Centered Care and the Pediatricians Role: Policy Statement; Pediatrics, 2012, 129(3), 594-604.


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