Previous research suggests access to health insurance and a primary care provider (PCP) in a medical home can reduce emergency department (ED) utilization and hospital days for children with medical complexity (CMC). However, other studies point out that access to health insurance and a medical home does not explain all unnecessary ED utilization. The CARE Award provided a unique opportunity to understand the reasons behind preventable ED utilization for a population that had access to health insurance and a medical home, and to test quality improvement (QI) interventions to decrease ED visits. Access to care is critical for CMC given the fragile nature of their conditions. The framework for improving access to care that ensured families have access to the right care, at the right time, with the right provider, was developed by understanding why families used the ED and how to help them manage their child when acute illness or an exacerbation occurs.
Access to Care: What We Learned from Families

Improving the care delivery system for children enrolled in the CARE Award required better knowledge of what happens when they became ill. Specifically, what did parents do when their child developed symptoms? CARE Award QI teams from the 10 participating sites interviewed more than 500 families after ED visits to uncover what led them to the ED and what could have been done to prevent the visit. Results showed that families took their child to the ED before calling their provider half the time, and over two-thirds of families felt they would have been comfortable going to their PCP instead of the ED. A sample of survey results is presented below.

SURVEY

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you call your PCP prior to taking your child to the ED?</td>
<td>50%</td>
<td>50% of families said yes</td>
</tr>
<tr>
<td>Did you have an access plan in place before the ED visit?</td>
<td>68.2%</td>
<td>68.2% of families said yes</td>
</tr>
<tr>
<td>Did you feel after the ED visit that your child’s medical issues could have been addressed in a visit to your PCP?</td>
<td>76.8%</td>
<td>76.8% of families said yes</td>
</tr>
</tbody>
</table>

CARE Award teams were then asked to interview five families each on why they used the ED instead of calling their PCP or making an appointment. Four key themes emerged from these interviews:

1. I took my child to the ED because he/she always ends up in the ED when he/she gets these symptoms
2. When I call my PCP, I get a nurse advice line and a nurse who is not familiar with my child, and does not have access to the medical record
3. It took too long for my PCP to call back
4. When I go to the ED, I get all my child’s tests, X-rays and consultations in one place, and I leave with a plan. It’s not efficient when I go to the PCP.

It became clear families needed a system for accessing care that:

- Told them which provider to call, when to call, and how best to reach them
- Specifically addressed the medical issues that made their child sick
- Told them how to prevent their child from becoming sick and what to do when he/she did become sick
- Provided timely phone access to a provider who knows their child and has access to his/her medical record
- Offered primary care services after-hours and on weekends
Designing Systems to Improve Access

Access to care was one of five closely related change concepts implemented (Appendix B) to transform the delivery system as part of the CARE Award.

Using these change concepts as a foundation for care transformation, each site worked with families to identify the Dynamic Care Team (DCT) that included their primary care and specialty providers, as well as other individuals important to the family, such as social workers, care coordinators, etc. Once the team members were identified, each family was given an access plan that listed their team members, and how to reach them for routine and urgent issues.

The following graphs show the time to reach our goal for high-quality adoption of two change concepts in participating complex care and primary care practices (PCP).

Measurement of high quality implementation of the change concepts included the number of enrolled children, as well as the average number of core elements of the change concept implemented.

On average, it took nine to 10 months to adopt these change concepts, with more rapid adoption taking place in the primary care practices. This lengthy implementation period was due to the considerable upfront time commitment required to identify the DCT, and review with families how to best access each team member.

To improve access to care over the course of the CARE Award, many of the sites increased education and self-management skills to better manage acute illness, enhanced access to after-hours care/consultation, and provided phone and telemedicine access to care.

Increased Skills for Managing Acute Care Illness

Post ED visit interviews showed that for a given clinical problem, families didn’t know what to do to treat the problems, who to call, or when to take their child to the ED. These insights led project leadership to enhance the access plan change concept by adding a contingency action plan and emergency care plan.

Mattel Children’s Hospital UCLA had prior experience developing a program that worked with families to identify two to three clinical scenarios most likely to lead to an ED visit or hospitalization. For each scenario, team members working with the family developed a contingency plan using the Asthma Action Plan as a template. A child with chronic lung disease may have a set of interventions that enhance airway clearance. For a child with epilepsy, it could be an emergency plan for a seizure lasting more than five minutes. Separately from CARE, Mattel completed a randomized
controlled trial of an intervention using action plans and a transition to home for hospitalized patients in 144 CMC. This best practice was shared with all CARE QI teams to expand the access plan functionality.

Enhanced Access to After-Hours Care
Sites were surveyed on access to care midway through the CARE Award. The survey showed all CARE practice sites provided phone access after hours. However, less than 10 percent of these sites provided triage with an M.D. or RN who was known to the family. Fifty-three percent of sites provided triage with a nurse answering service, and only 40 percent of families had access to a clinician medical record access.

Most CARE sites offered same day care, with approximately 60 percent offering extended hours and 58 percent offering extended weekend hours.

In general, primary care practices were less able to provide after-hours phone triage by an RN with access to the child’s medical record. This was particularly true for independent practices.

A significant percentage of the complex care programs and PCP sites were not able to provide after-hours access from a provider who was knowledgeable about the child. This gap in care was difficult to close because of costs and necessary structural changes.

In spite of the known effectiveness of providing primary care access after-hours and on weekends, only one practice increased their access to after-hours care during the CARE Award.

Phone and Telemedicine Care Access
Interview results showed that it was important for families to speak to someone who knows their child and can access the EMR before going to the ED. Cincinnati Children’s Hospital Medical Center linked the PCP care coordinator with the triage nurse in primary care so advice would come from a trusted provider. Another strategy used by Children’s Mercy Kansas City was a telemedicine link to the home for illness episodes. Providers examine, diagnose, and make recommendations for care over the telemedicine link. While these routine visits were designed as part of a more comprehensive assessment, providers identified issues with adherence to the treatment regimen that, when remedied, could decrease the likelihood of an ED visit. Children’s National Medical Center is using telemedicine for virtual home visits and follow-up visits. Several site care coordinators initiate phone contact with high-risk families at regular intervals to identify potential problems and ensure preventive therapies are in place.
Parent Empowerment
Outside the CARE Award, Lucile Packard Children’s Hospital Stanford developed a self-management program to help families interact more effectively with the health care system. These programs address important issues relating to access to care such as, “What to do if your child is sick in the middle of the night,” and “How to best communicate with your medical team.” Learning is self-selected by families and intended to complement parental knowledge of how to best care for their child.

During phone contact with families after an ED visit, families were often offered follow-up education about care that can be provided at home, and tips for when to call their provider or go to the ED. Some sites used simple behavioral reminders, such as refrigerator magnets, to identify who parents should call before going to the ED.

Family Engagement in Improving Access to Care
Methods to develop action plans jointly with families and providers varied across the CARE Award sites. Several sites allocated time during the visit to identify with the family conditions that were likely to lead to an ED visit or hospitalization, and to develop an action plan that addressed preventive care and acute care. One site involved a parent advisory group in the development of a templated plan and workflow design. Other CARE Award sites found it more efficient to develop action plans and review them with families during a patient encounter. One site utilized their care coordination team to review and refine the access/action plans developed. In ED follow-up phone calls, some families said they were aware of the access/contingency action plans but did not understand how to use them. Participants believe this lack of understanding may stem from varied levels of family involvement in the plan development.

Major barriers to family engagement were time and resources. Successful sites noted it required a two to three hour time commitment to develop plans with each patient. Care coordinators, or unlicensed care coordination staff, had the responsibility to work with families to complete the plan. At some CARE Award sites, this resolved the problem of clinical providers having insufficient time to work with families to develop and maintain access/contingency action plans. PCP sites had more difficulty than hospital-based complex care services engaging families in the design of access plan templates and participation in QI activities.
Access and Health Care Utilization
CARE Award access and contingency plans were designed to impact ED utilization, and to a lesser extent, outpatient visits. The team hypothesized if parents knew how to treat their children when an acute situation arose, and when to call their provider before going to the ED, unnecessary ED and office visits could be avoided. As seen in the utilization chart above, change concept implementation appears related to reductions in ED visits, but further research will be needed to prove a causal relationship.

Future Opportunities to Improve Access
All CARE Award participants felt there was an opportunity for more effective family involvement in the design and implementation of care. Lucile Packard used a framework for family involvement. In this context, Human Centered Design is defined as a design and management framework that develops solutions to problems by involving the human perspective in all steps of the problem-solving process. Human Centered Design typically takes place in the context of observing the problem within context, brainstorming, conceptualizing, developing and implementing the solution.

Better use of technology is another opportunity for improvement. Most sites indicated their EHR could better integrate care coordination information and communication across the care team. Greater engagement of parents through patient portals was seen as an important way to more effectively involve families in health care team decision making. Wider use of telemedicine as an alternative encounter would facilitate access without the barriers of time and travel. Greater interoperability between EHRs would allow families to access providers after hours who had knowledge of their child’s medical history.

More widespread use of contingency action plans would allow possible prevention of acute exacerbations, and provide families with the knowledge and skills to manage their child’s condition at home.

Conclusion
Learning from parent surveys and interviews enabled CARE Award teams to understand gaps in the care delivery system from the patient perspective, strengthen tools that improve access to care and CARE Award sites reported reductions in unnecessary ED utilization.

Preliminary results from claims data shows ED and inpatient utilization reductions were achieved during full implementation of the project.
Best Practices for Improving Access to Care

1. Engage families in the design of the access plan and its implementation.
   —Lucile Packard Children’s Hospital Stanford

2. Involve families in the negotiation of contingency action plans.
   —Mattel Children’s Hospital UCLA

3. Provide continuous improvement of access plan with refinement of contingency action plans.
   —All CARE Award sites

4. Develop a rapid response from a provider who knows the patient and has access to the EHR when families call.
   —Children’s Mercy Kansas City, Lucile Packard Children’s Hospital Stanford, St. Joseph’s Children’s Hospital, Children’s Hospital of Philadelphia, Wolfson Children’s Hospital

5. Talk with families after ED visits, whether at their next scheduled appointment or in a follow-up phone call.
   —Lucile Packard Children’s Hospital Stanford, St. Joseph’s Children’s Hospital, Children’s Mercy Kansas City

6. Offer same day appointments, plus after-hours and weekend care.
   —Cincinnati Children’s Hospital Medical Center, Lucile Packard Children’s Hospital Stanford, Cook Children’s Health Care System, PCMH (Tampa) and Suncoast Health Clinic (Tampa)

7. Consider telemedicine encounters for families who live far from the clinic site and have difficulty with travel.
   —Children’s Mercy Hospital, Children’s National Health Center
CARE Award Defined

The CARE Award, Coordinating All Resources Effectively, is a landmark national collaborative project aimed at improving quality outcomes and reducing the cost of care for children with complex medical conditions (CMC) 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, over 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 Hospital Medical Center (Fort Worth, TX)
Lucile Packard Children’s Hospital Stanford (Palo Alto, CA)
Mattel Children’s Hospital UCLA (Los Angeles, CA)
St. Joseph’s Children’s Hospital (Tampa, FL)
The 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.

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.

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, community and educational providers. DCT members recognize each other by name and role, and have effective systems for timely communication among team members.

Every family will have an access plan containing three components:
1. 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.

2. A contingency plan with 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.

3. An emergency care plan that provides essential information to 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 be avoided, important family preferences, list of child’s physicians/contact information, and the presence of an advanced directive form.

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 child/family have the same understanding of roles, acknowledge 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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