Problem Statement: Approximately two-thirds of all children with medical complexity (CMC) are covered by Medicaid. Although these children represent only 6% of the total pediatric Medicaid population, they incur 40% of Medicaid spending on children and constitute 10% percent of admissions to children’s hospitals. These children are also more likely to utilize emergency departments, an additional cost to Medicaid.

So, our question became: “How do we support families who have medically complex children to increase their resources and decrease their stress/anxiety so that they do not utilize the emergency department so frequently?”

What did we do to attempt to answer this question?
We utilized the CARE Award model of care coordination (illustrated below) to inform our approach: CARE Award-enrolled parents (i.e., those with children with medical complexity) were asked to join a parent advisory group. They were then asked to diagram their resources (the “dynamic care team”) in a care map format. Then, parents were asked in what situations they would contact each resource and especially, who they would utilize when an emergency arose. Parents were also asked how their anxiety could be decreased in an emergency and as a result, the emergency care plan, below, was produced.

The CARE Award Model of Care Coordination

- Dynamic Care Team
- EMR-made DCT
- Parent-made DCT
- Increased Parental Resources
- Decreased Parental Stress/Anxiety

EMR Access Plan
- Provider, therapists and other caretakers identified by family and providers
- A list of the medically complex children at a practice.
- A plan of how to ensure that information is not lost when a child transitions in/out of hospital.
- Goals for the care of the child, determined by providers and family.
- EPIC’s LPOC module constructs this for providers and families.
- Emergency Care Plan (Made with Parent Input)
- This also includes specific action plans such as those for allergies, etc.
- Who to contact depending upon level of need and urgency.

Here, the parent indicated the resources they can contact in emergencies and for Joey’s general health and safety.

What were our findings?
Parents who’ve recently received a diagnosis or problem statement for their child would benefit from being connected to more, diverse resources and a contingency plan to utilize when an emergency arises. If this could be offered to parents sooner after an initial diagnosis, ED utilization could be reduced for this population.

What will we do next?
The tools and lessons learned from the CARE Award are being applied to more families earlier after a first diagnosis of a medically-complex condition. We are currently considering strategies to connect these parents with one another and more resources to utilize before the ED.

Parents of these children are incredibly stressed and sometimes worried and anxious. Often, one parent must devote the majority of their time to caretaking and may not work, adding even more stress to the family.

Also important:

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