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Q&A Summary
Medical Home Care for the Child with Medical Complexity:
Care Coordination and Shared Decision-Making

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Available On Demand:
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1. What do you see as the insurance provider's role for the child with medical complexity?

   The insurance provider creates an appropriate payment structure, including payment for care coordination services under fee-for-service or global payment with expectations for care coordination. The insurance provider in some cases may also provide the care coordination.

2. How would you define or describe (or give examples for) patient-team partnership (building block 5) and continuity of care (building block 7)?

   Specific aspects of medical home care include assignment of a continuous primary care provider, use of patient panels with risk stratification and assignment of resources, and tools and resources to promote and measure continuity of care.

3. How can we best coordinate team feedback among the multiple specialists, vendors and community providers?

   Team feedback can be coordinated through communication protocols and expectations, with a point person whose job it is to specifically be that point person to coordinate messages. Often that person is called a care coordinator. For a primary care practice, I think nurse training is important for a child with medical complexity.

4. Are there guidelines for an appropriate "caseload" for a pediatric nurse care coordinator?

   Complex care services have assigned caseloads of around 125-150 patients. Care for patients with higher acuity results in lower caseloads; medical technology and at least five specialists may result in caseloads of less than 100, while services for patients with lower acuity may result in caseloads of more than 200.

5. What are the measurement tools used to show time/value gained for care coordination?

   See https://medicalhomeinfo.aap.org/tools-resources/Pages/Care-Coordination.aspx.

6. How do you prepare for transition to adult care, including adult topics such as sexual health and health decisions and independence?

   The American Academy of Pediatrics has published guidelines on the timing of these discussions. Got Transition has a framework and tools: https://www.gottransition.org/. Some children with medical complexity will also need discussion on guardianship.

7. Given the emphasis on value-added for care coordination, how do you justify the cost of hiring care coordinators, especially for social determinants like housing, transportation, etc.?

   Under value-based payment, payers may add care coordination payments for this purpose; this may be part of a certification process for the Patient-Centered Medical Home (PCMH), for example. It is important that these funds are tracked and designated for the purpose of care coordination.

8. How do we connect clinical staff members who need to be a part of the care coordination with data-based technology solutions?

   Work with your electronic medical records vendor for potential solutions such as data registry or care planning tools, which can sometimes be found under the "population management" suite of tools that emphasize registry and risk stratification. You may find that there is no "out-of-the-box" tool tailored to a child with medical complexity and it will require some development. Consider networking with a children's hospital if there is a complex care service that may have already worked on templates and tools.

9. How can the nurse case managers who work telephonically with the parents do better with these complex children? The practices do not often take the lead with these children.

   I find that a nurse within the practice is essential to caring for a child with medical complexity. If there is a nurse case manager who works telephonically, that case manager can assume a number of the tasks and it is important for the practice-based nurse coordinator to communicate with the case manager regularly; otherwise the family ends up coordinating the coordinators. On the other hand, if done properly, the caseload for the practice-based care coordinator can go up if there is a community-based case manager.

10. Language barriers can be an issue too. What care coordination approaches can help to expand utilization of care support and address complex issues for families with these barriers?

    Cultural competency is fundamental to successful care coordination. There are best practices when addressing language barriers and cultural diversity, including self-assessment, language services, cultural brokers and hiring families from the community. More information can be found at https://nccc.georgetown.edu/.

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