Care Coordination for Children and Youth with Special Healthcare Needs (CYSHCN): Key Functions and Strategies

Oregon Pediatric Improvement Partnership (OPIP)

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Background

Children and youth with special healthcare needs (CYSHCN) represent roughly 15-20% of the childhood population and account for almost 80% of healthcare expenditures. There is also an unquantifiable cost to families of CYSHCN. In the absence of a high functioning medical home, families are required to become care coordinators in addition to their role as the caretaker of the child. Families of CYSHCN articulate frustration at being unable to "parent" their children due to the overwhelming demands of navigating the complex systems of care – and often at least one family member is not able to work.

Objectives

The work summarized in this poster spans across projects, though a shared objective for each was to implement, test and measure functions of care coordination for CYSHCN.

Care Coordination Functions

For the purposes of our projects, we utilized the functions of care coordination:

1. Provide separate visits and care coordination interactions
2. Manage continuous communications
3. Complete/analyze assessments
4. Develop care plans with families
5. Manage track tests, referrals, outcomes
6. Coach patients and families
7. Integrate critical care information
8. Support care transitions
9. Facilitate team meetings
10. Use health information technology

Outcomes

Office Report of Systems and Processes have included: 1) Medical Home Index: Revised Short Form© (MHI-RSFO), a tool specific to Children & Youth with Special Health Care Needs; 2) National Committee for Quality Assurance Patient-Centered Medical Home (NCQA PCMH™); and 3) Oregon Patient Centered Primary Care Home (OCHP) attestation data. The following data describe improvements to care coordination observed in the Enhancing Child Health in Oregon (ECHO) project:

Practice Transformation in ECHO

- Practices transformed their level of medical homes services. Practices improved on NCQA PCMH™ 2011 (>35%) and care specific to CYSHCN as assessed by the MHI-RSFO (>19%).
- Across the practices, they improved the most on standards related to population health and care management (NCQA Standard of Pan & Manage Care -42%) and access to care and continuity with personal doctor or nurse (NCQA Domain Enhance Access & Continuity -50%).
- For CYSHCN, practices improved on care coordination (>25%), outreach to community based providers (>25%), and their organizational capacity to care for CYSHCN including their mission and models of team based care (>25%).
- All eight of the practices have achieved Tier 3 status on the Oregon PCMH standards. The ECHO practices are in the top 25% of all practices that have attested.

Key Lessons Learned

- Identifying care coordination functions and testing different ways to implement across the practice was the most effective approach. Practices that hired care coordinators before going through this process were less successful.
- Practices were successful in implementing care coordination in variety of ways, not always through hiring a care coordinator.
- Effective implementation of shared care plans requires role clarification, is time intensive, and is transformative.
- Partnership with and input from patients in designing care coordination programs is essential.

Ways to Support Coordination

Systems can support this work in practices in a variety of ways. The following are of highest priority:

- Recognize the importance of child-specific models
- Provide data that support population management and provide information about services received outside primary care
- Consider bundled payments that support care coordination services

References