The Care Coordination Conundrum and Children and Youth with Special Health Care Needs

What Is Care Coordination?
Who Should Receive It?
Who Should Provide It?
How Should It Be Financed?

Sara S. Bachman, Ph.D., Meg Comeau, MHA and Katharyn M. Jankovsky, MSW

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Children and youth with special health care needs (CYSHCN) generally require services from a broad range of providers and systems. As a result, they and their families have a greater-than-average need for high-quality care coordination. While the definition of care coordination is much debated, it generally involves an interdisciplinary approach to ensuring access to health care and social support services, in which a care coordinator manages and monitors an individual’s needs, goals, and preferences based on a comprehensive plan.

Support is nearly unanimous for care coordination as an essential benefit for CYSHCN.

However, current care coordination payment methods have resulted in:
- Poorly structured payment mechanisms
- Low reimbursement rates
- Insufficient incentives to pay for care coordination
- Lack of clarity about who is responsible for financing, providing and reimbursing for care coordination
- Overall limits on funding for services for CYSHCN, among others

Consequently, CYSHCN and their families experience gaps in services, inefficient patterns of care, and additional caregiving burden, all of which have a negative impact on child and family health and well being. In this paper we provide a comprehensive analysis of these issues as well as recommendations for moving the field forward.

Through a literature review, stakeholder interviews and policy analysis we examined various definitions and models of care coordination—including eligibility criteria and types of providers—and identified persistent barriers to adequate financing and reimbursement.

We concluded that broad financing and payment reform to support care coordination is imperative to ensure that all CYSHCN who need care coordination get it at the right time, in the right amount, by the right providers, and at the right cost.

Care coordination models must move away from narrowly focused programs and FFS financing and reimbursement in order to achieve long-term financial stability. Ultimately, payment for care coordination in the context of a risk-adjusted global budget is optimal. Pooling resources and sharing savings should help reduce financial risk and incentivize practice change. Linking care coordination to improved outcomes, increased quality, and greater accountability through the establishment of standardized process and outcome measures will assist in evaluating return on investment (ROI). Maximizing these strategies will help move the field closer to an adequate payment structure that benefits all stakeholders.

We recommend that stakeholders work in partnership to:

1. Develop a new care coordination paradigm grounded in pooled resources and broad population-based financing and reimbursement models that include CYSHCN as well as other population groups such as adults with chronic illnesses and frail elders.

2. Establish the evidence base for care coordination for children, and develop specific metrics and outcomes for the service, including return on investment (ROI) from multiple stakeholder perspectives, including payers, providers and families.

3. Develop risk-adjustment models for CYSHCN to level the playing field and encourage health plans and providers to enroll and serve high-need groups.

4. Identify the care coordination services that should be part of a bundled/capitated payment.

5. Link bundled or capitated payments to improved quality indicators and health outcomes.

6. Provide care coordination in teams that include licensed and non-licensed staff with shared responsibility for clinical and non-clinical coordination tasks. Include peer parents on these teams to increase appropriate family involvement, promote communication with family members and aid in quality improvement efforts.