MASSACHUSETTS CONSORTIUM
for Children with Special Health Care Needs
A Program of New England SERVE

Care Coordination in Massachusetts Findings & Recommendations of a Three-Year Study

Final Report:

Introduction & Executive Summary

Prepared by the Care Coordination Work Group
of the Massachusetts Consortium for Children
with Special Health Care Needs

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Introduction

Background

The Care Coordination Work Group of the Massachusetts Consortium for Children with Special Health Care Needs was created in February 2003. Its creation was driven by a Consortium analysis of the state of financing for care of children and youth with special health care needs in Massachusetts. Findings of the analysis were:

- Few Massachusetts children with special health care needs lack insurance entirely;
- Many, however, are "underinsured," lacking coverage for specialty care, medical equipment or therapies that are important to their health and development; and
- Most families of children and youth with special health care needs bear substantial burdens – in terms of time required, money spent, and family life foregone – in the struggle to assure adequate, much less optimal, care for their children.

One service emerged as particularly critical to helping families find resources to fill gaps in coverage *and* to helping families identify sources for and manage interactions with all of the players who may appear in their lives as they care for their children.

This report focuses on meeting, rather than documenting, the need for care coordination. It is, nonetheless, worth noting how overwhelming that need is for many families of children with special health care needs. Appendix 1, which identifies sources that document need for care coordination in Massachusetts, lists national surveys, state surveys and needs assessments, and reports from parent and provider organizations. It is also important to note that the need is not limited to children with any one kind of condition. Research findings indicate, and the work of the Consortium in this area confirms, that while resources are most sharply lacking for some groups of children, there is no group of children with special health care needs for whom high quality, family-centered, culturally competent care coordination is available on a widespread or consistent basis.

Organization of this Report

This report focuses on the future – on where we are going with care coordination. It starts, therefore, with a proposal for a care coordination system, and works backwards to explain the process by which the proposal was reached. An executive summary precedes the body of the report. Appendices provide a list of data sources related to care coordination, the instruments used for data collection in this project, key informants interviewed for this project, and a list of Work Group participants and Consortium staff who contributed to this project or this report.

The proposal itself covers: 1) care coordination at the service delivery level; 2) how access and quality assurance can be built into the system so that the promise of care coordination is fulfilled for children and their families; and 3) how it makes sense to finance this system. The methods section, which comes next, explains how the proposal was derived. The final section identifies specific findings and recommendations that underlie the proposal.

Executive Summary

The Massachusetts Consortium for Children with Special Health Care Needs proposes a system of care coordination housed in the medical home of children with special health care needs in the state. In this system, a care coordinator would work for the family but in close collaboration with the child's primary care provider. The care coordinator's role would include coordination of health services of all types (including specialty and mental health care), therapies, and health services received in the child's home and school. But it would go further, assessing child needs and family needs related to the child's care broadly, and working with the family to address those needs.

The model is housed within an existing service system. Rather than create a free-standing system, it builds on the family's relationship to their child's provider, simultaneously enhancing the capacity of clinicians to provide effective primary care for children with a range of conditions and the capacity of families to identify and articulate their needs, find and secure services, and negotiate the complex and often contradictory rules of different systems of care.

Definition of Care Coordination

The Consortium definition of care coordination reflects the breadth of that view:

> Care coordination is a central component of an effective system of care for children and youth with special health care needs and their families. Care coordination is an ongoing process which engages families in development of a care plan and links them to health and other services that address the full range of their needs and concerns. Principles of care coordination reflect the central role of families and the prioritization of child and family concerns, strengths and needs in effective care of children with special health care needs. Activities of care coordination may vary from family to family, but start with identification of individual child and family needs, strengths and concerns, and aim simultaneously at meeting family needs, building family capacity and improving systems of care.

The Care Coordinator's Job

The job of the care coordinator defined here does not necessarily require licensure or accreditation in a particular discipline. It does, however, draw on skills and knowledge from several disciplines. It requires knowledge of the full range of services relevant for children with developmental, physical, cognitive, behavioral and emotional conditions. It calls for familiarity with common conditions that affect children and ability to understand the health implications and familial impact of less common conditions that may affect children and their families. Key attributes of the care coordinator in this system are:

- Ability to listen to, learn from, and meet needs of families;
- Ability to listen to, understand, and address challenge facing providers;
- Detailed familiarity with systems of care;
- Ability to solve problems with creativity and tenacity;
- Capacity to master both technical aspects and functional implications of a range of conditions that may affect children and youth;

- Ability to see trees (the daily challenges of care giving that confront families and providers) and forests (the structural elements of systems that produce conflict);
- Professionalism: the ability to view clients and colleagues without judgment and to respond to conflict impartially and without personal entanglement.

An effective care coordinator might be a nurse, a social worker, an educator, a therapist, or an experienced parent advocate who has these attributes. Ideally, in fact, since the model involves a statewide network, care coordinators would come from multiple disciplines and bring different kinds of knowledge and skill to the system.

Day-to-day, care coordinators will assist families in the practice setting, helping them identify needs and find resources based on a care plan drawn up in response to family needs. But they will also engage with providers in the practice and in the broader community, building connections and finding ways to link services that are typically fragmented and misaligned. They will come together at a state level to identify systemic problems and promote systemic solutions.

Beyond the Practice Level

This model envisions care coordinators housed in primary pediatric practices, working closely with physicians and other practice staff to coordinate all kinds of health care and other relevant services for CYSHCN. But the care coordinators do not work for doctors; rather, in this model, they work for community organizations that contract with the state to serve families. Care coordinators partner with but are not employed by practices. This is a critical feature of the model.

The state Department of Public Health has a critical role in this model. It oversees the system, with responsibility for certification of vendor organizations, for training and certification of individual care coordinators, and for engaging practices in the system and assuring that they are committed to a medical home approach to care of children and youth with special health care needs. Monitoring and evaluation of the system are also state functions in this plan, with the health department convening an interagency group to guide continuing quality improvement efforts.

Funding the System

This model is designed to meet the baseline coordination needs of children with all types of special health care needs. It is not designed to substitute for specialized therapies or clinical interventions of any sort. It is aimed at creating a system that can identify needs of families early – ideally on an anticipatory basis – and assure effective and timely referrals, relieving family isolation and alleviating stress in the process.

A patchwork of care coordination is out there already. Many payers, some clinical facilities, some diagnosis-specific organizations, several state agencies and a number of practices already provide some degree of coordination to some children and their families. The question is how to weave that patchwork into a single coordinated system. Years of experience teaches us that fragmented funding produces fragmented services. This model draws on pooled funding from some of the entities that already support limited care coordination, supplementing their support with public and private resources to create a single, comprehensive, community-based system statewide.

While definitive data are not yet available, evidence suggests that investment in care coordination is cost effective. It shifts how money is spent, however, paying upfront to avert downstream costs of hospitalizations, emergency room visits, and prolonged care to resolve problems that could have been prevented. It also shifts the burden of cost, alleviating the substantial share born by families who pay financially as well as emotionally for uncoordinated care.

The model is designed to maximize the efficiency of care coordination. Placement of care coordinators in medical practices will permit coordinators to encounter families on an as-needed basis, allocating time to cases depending on complexity rather than a rigid appointment system. The potential for care coordinators to share information with practice staff and design systematized procedures to address common resource and referral problems will also reduce time burdens across the system. This expands system capacity to serve large numbers of children and families at reasonable cost.

How will money flow through the system? While the details of the system will require substantial discussion among stakeholders, a broad strategy grows out of the design of the system. We envision a formula-based allocation of costs to private payers for care of children who meet system eligibility criteria. State funds will make up the rest, some through the mechanism of Medicaid reimbursement and some through direct state allocation. Funds will be pooled to support contracts with vendor agencies; vendors will hire and pay care coordinators, assigning to participant practices based on caseload. The Department of Public Health will manage the state payer of last resort function.

Next Steps

Building the system described here will require commitment of parents, providers, payers advocates, agencies and policymakers. Only if all stakeholder groups are engaged will medical home care coordination become a reality. Steps to that end include:

- Outreach to and intensive conversation with parent organizations, provider groups, diagnosis-specific groups and payers about this model;
- Resolution of key questions related to funding of the system, notably the basis for allocating responsibility to different payers;
- Design, at least at a broad level, of a system linking medical home care coordination to specialized supports in specialty clinics and managed care organizations; and
- Development of a legislative proposal funding a pilot project based on the model.