Care Mapping: An Innovative Tool and Process to Support Family-Centered, Comprehensive Care Coordination

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Introduction

Gabe is a 10-year-old boy with multiple medical issues including:

- mitral stenosis
- intellectual disability
- short stature/failure to thrive
- ADD
- hypotonia
- kyphoscoliosis, and
- stimulus-induced drop episodes.

But what about his need for assistance with activities of daily living and his barriers to recreation and participation in his community? How are his medical needs addressed at school? What community resources might benefit his well-being? Who is trained to coordinate all these issues?

To communicate this complexity, Gabe's family created a care map depicting his care needs. The process and product enabled unexpected and significant beneficial consequences. Could the creation and use of this tool benefit other families and providers as well?

Statement of the problem

Care coordination has been defined as "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services" (AHRQ Care Coordination Atlas, 2011). A framework for care coordination of child health needs has been proposed by Antonelli, McAllister, and Popp (2009) and includes recommendations for key functions, activities, and measures. Care planning is a critical component of care coordination, yet there is a dearth of information available to drive evolution of this competency for patients, families, and primary care team members. Care planning is often done unilaterally by families, if at all, or by providers in a prescriptive fashion.

Caregivers act as the primary care coordinators for themselves and their family members, and develop strategies to cope with the stressful demands of care coordination. Care coordination adds considerable stress to care giving; caregivers have expressed a need and desire for more information sharing and quality communication and help navigating the system of care (Golden, Nageswaren 2012).

Graphic tools such as *genograms* and *ecomaps* are used in individual and family counseling in disciplines such as social work and nursing (Hartman 1995). However, the intervention typically is focused on documenting social relationships, is driven by a professional, and is used outside the primary care setting. Moreover, it is generally used as a family assessment tool, not as a tool for care coordination.

Objectives of the intervention

- Begin to assess families' perceptions of a tool to guide care coordination for children with special health care needs
- Begin to assess professionals' perception of a tool to guide care coordination for children with special health care needs
- Support the evolution of family-professional partnership by raising awareness of the capacity, strengths, and needs of each stakeholder

Methodology

Utilizing semi-structured interviews, conducted in person and electronically, de-identified information was collected from five families of children with care coordination needs, from five care providers and one systems change advocate.

This project was granted an exemption by the Boston Children's Hospital IRB.

Description of the intervention and organizational context

This is a family-initiated project. We present an innovative tool, the care map, to support a strategic approach to the provision of comprehensive, patient- and family-centered care coordination in primary care.

We will present perceptions of families and providers of how the tool can be utilized to encourage family-professional partnership and to support families in care planning and self-management.

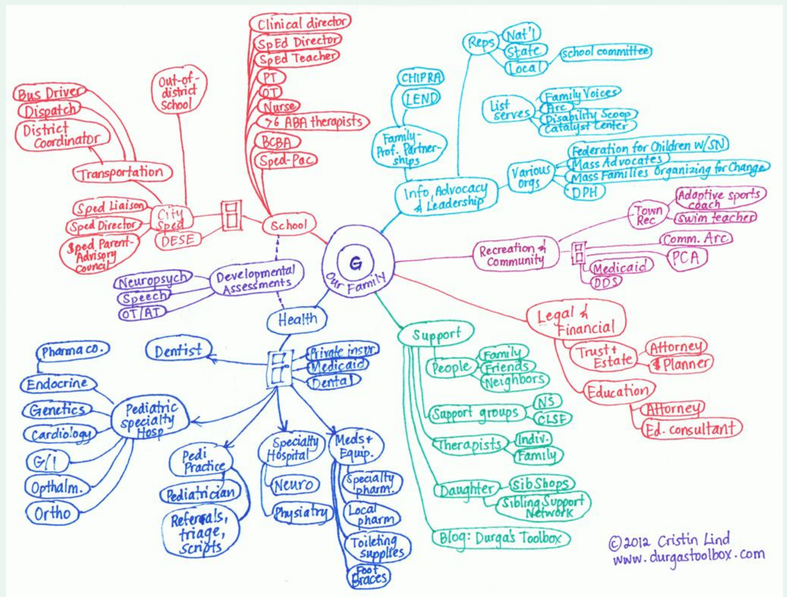

Figure 1. Care Map created by Gabe's family, depicting his care needs and supports.

Key findings

The care mapping process and the tool have the potential to support an approach to family-centered care coordination.

The process of creating and sharing the information conveyed by the tool supports the notion of family-professional partnership.

Both families and providers feel that it provides an effective, comprehensive snapshot of a child's care team and has the potential to reveal unmet needs across both a continuum of care and a wide range of domains.

Families feel that it will improve their ability to communicate the complexity of the care they are coordinating while staying focused on their strengths and accomplishments.

Providers feel that it will improve communications with families, enable a systematic assessment of the care coordination needs of patients, and provide a framework for measurement of outcomes related to care coordination.

Next steps

Future efforts include refinement of the tool as well as development of guidelines for its implementation, including the following:

- Work with families who have children with behavioral health and medical needs to develop the skills to create their own care maps
- Work with primary care providers, subspecialty providers and community care providers (eg, schools, child development) to learn how to effectively engage families in a discussion of care coordination utilizing this tool as a focal point
- Measure outcomes resulting from utilization of the care mapping tool:
  - Clinical
  - Patient experience
  - Provider experience
  - Resource utilization

Results

Domains	Parent/Family	Professional
Family-Professional Communication	*"I would share it with any new person coming into our lives. It would give them a bigger picture."* *"If anything happened to me, this would help someone figure out how things fit together."*	*"This tool is great in providing both a 'big picture' macroscopic overview … but also a microscopic detailed view of the complexity of Gabe's care."* *"It shows the complex world of the child with a special need(s) and their family."*
Patient , Family, and Provider Experience	*"This would give me an extraordinary psychological boost, to see what we've got covered and feel like we've got it under control."* *"I'd give this to our pediatrician to prompt them to think about ways to help; give it to other doctors to give them an idea of what we're doing; to therapists who look at us funny when we say we can't do something; … anywhere I want to give a perspective on our everyday lives."* *"[Some professionals we work with] have no idea what our life looks like. This could communicate that and help prioritize [together]."* *"This would [give me] the ability to see the whole picture and … gaps, create goals and next steps."*	*"This supports explicit conversation about care coordination needs and family/ health system assets, elevating family-professional partnership to a level of strength-based approach, rather than deficit-based."* *"It elevates the role of family from simply recipient of care to one of partner—even driver—of their care."* *"Effective implementation of this tool will require development of family skills and provider sensibilities with respect to shared accountability for outcomes."* *"This has the ability to support the family-centered road map across a community of service providers, enabling integration of care."*
Resource Utilization	*"[The people who work with us] can … help us avoid duplication or consolidate services, and … help identify needs and fill them."* *"This tool could identify a family that is fragile or needs more help."*	*"I find it incredibly valuable as … an index…; the categories that it provides can serve as a checklist to make sure that each of the dimensions are addressed."*
Advocacy for Systems Change		*"This Care Map has been used to drive [CHIPRA grant-funded MA Child Health Quality] Coalition task force discussions around the importance of family capacity building."* *" [A]t a healthcare reform summit, I was talking about how powerful a tool it was to understand the need for care coordination and how best to present that need to lobbyist[s]."*
Measurement and Accountability		*"In conjunction with care tracking mechanisms in the Patient- and Family-Centered Medical Home such as the use of registries, this tool will support the implementation of mechanisms of accountability in this era of health care reform."* *"It sets a framework for measurement of outcomes related to prescribing and receiving services across the continuum of care. It is not simply the care received in one location, given by a single provider."*

References

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