



A Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?

July 26, 2018



Today's Moderator:

Christopher Stille MD, MPH

Professor of Pediatrics and Section Head, General Academic Pediatrics, University of Colorado School of Medicine, Children's Hospital Colorado

PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

MARCH 2018 • VOLUME 141 • SUPPLEMENT 3

A SUPPLEMENT TO PEDIATRICS

Building Systems That Work for Children With Complex Health
Care Needs

Rishi Agrawal, MD, MPH, Christopher Stille, MD, MPH, Editors

Sponsored by the Lucile Packard Foundation for Children's Health.

*Based on follow-up from a symposium held December 7–8, 2015, Washington,
District of Columbia.*



Visit lpfch.org/aapsupplement to access all the articles in this series

Ask Questions!

We look forward to a lively discussion with our audience.
Enter questions in the GoToWebinar question box.

Meet Our Speakers



Dennis Z. Kuo
MD, MHS

Associate Professor, University at Buffalo
Chief, Division of General Pediatrics, UBMD



Ann S. O'Malley
MD, MPH

Senior Fellow,
Mathematica Policy Research



Michele Juda

Executive Director,
Parent to Parent of New York State

The background features a series of concentric circles in light gray and dashed lines, creating a ripple effect. A large blue speech bubble shape is centered on the page, containing the main text.

Care Coordination: Whose Care Is It Anyway?

Dennis Z. Kuo, MD, MHS

July 26, 2018

The Issue

- Children with medical complexity have multiple chronic conditions
- CMC require multiple medical- and community-based support services
- “Care coordination” = logical need for CMC
 - High risk of fragmented care
 - Resulting risk of duplicated care, inefficient care delivery, unmet needs

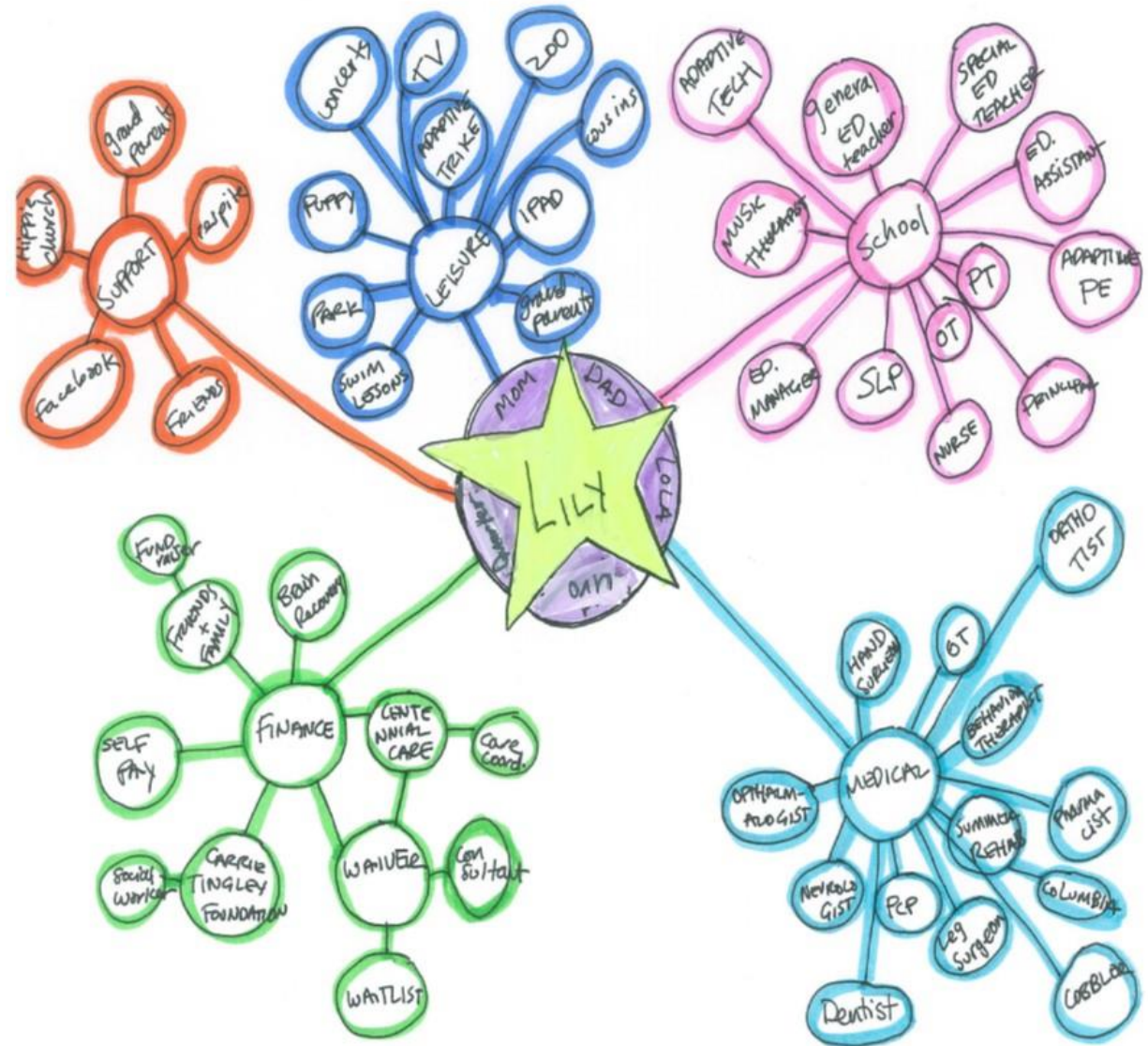
American Academy of Pediatrics: Definition of Care Coordination

- Activities that lead to integrated care
- Fundamentals
 - Patient- and family-centered
 - Assessment driven
 - Team-based activity
- Outcomes
 - Meets the needs of children and youth
 - Enhances caregiving abilities of families
 - Achieves optimal health and wellness

Important Terms

Care Coordination	Team-driven activity in between direct services
Care Integration	The result of effective care coordination
Case Management	Narrower activity, often focuses on specific condition within scope of a specific agency or organization
Care Management	Broader scope of activities, closer to care coordination

Care Map: Why We Perform Care Coordination (and what needs coordinating)



Needed Infrastructure for Care Coordination

- Staffing is just the start...
 - Number of staff
 - Roles of staff
 - Prior experience and training needs
- Tools for care coordination
 - Patient assessments
 - Workflow design and information flow
- Practice resources
 - Patient registry
 - Measurement tools
 - Team meetings

Implementation

- Patients and families are partners at all levels of implementation
- Staffing considerations
 - Internal or external (community partners)
 - Experience and training
- Care team dynamics
 - Team-based care principles
 - Team lead / designated contact

Duties of Designated Care Coordinators

- Develop a longitudinal partnership with assigned patients/families
- Administers and reviews structured assessments
- Partners with family to develop and maintain shared plan of care
- Follow-up duties in between service visits
 - Follows up on assigned tasks
 - Manages information flow between service providers
 - Responds to feedback based on information received and sent out

Whose Care Is It Anyway?

Common Shortcomings of Care Coordination Delivery

- Case management, not care coordination
 - Narrow scope or focus, often biomedical
 - Inadequate training for non-biomedical areas, e.g. transportation, housing, education, cultural competency
- Insufficient infrastructure
 - Tools and scope may be limited to organization or agency
 - Missing team members
- Coordinating the coordinators
 - Narrow focuses
 - Families often describe themselves as coordinators

Conclusions

Effective care coordination entails planning across the care spectrum, particularly social determinants of health

Care coordination is a team-based activity

Effective care coordination requires planning and infrastructure, including tools, training, and leadership across multiple sectors

Care **integration** is the goal

Additional Thoughts

- Fragmented care = unpredictable pathway to get to health
 - Coordinated care can be predictable and “designed”
 - Families travel across service sectors that don’t often speak with each other
- Care integration for CMC requires a series of feedback loops across the multiple service sectors
 - The sectors individually may do a good job
 - The in-between communication is often missing
 - Service needs in a different sector may be missing unless we ask about it
- A care coordinator’s task is to identify needs across sectors and actively manage the information flow

Where Do We Go from Here?

- Culture change – embrace the full spectrum of care
 - Medical care and direct medical services
 - Social determinants of health
- Relational coordination
 - It's about the relationships
 - Processes across sectors
- Evaluation of care coordination – understanding its value, both waste reduction AND more effective care delivery
- Adequate payment for care coordination services, particularly under value-based payment models

Ann S. O'Malley

Senior Fellow, Mathematica Policy Research



Key Thoughts

- Improved data exchange between different providers, including better capture of data on CMCs' social and behavioral health needs, is a key to improving coordination and the quality of care.
- As part of the team coordinating care, care coordinators are more effective when embedded in the patient's usual provider's practice, when they have some in-person interactions with the patient/family as well as personal introductions of child/family by the primary care physician to the care coordinator.

(Stewart, Bradley, Zickafoose et al 2018)

- Clearly define the desired short and long-term outcomes of coordination programs.

Michele Juda

Executive Director, Parent to Parent of New York State



Key Thoughts

- Caregiver well-being is critical and must be assessed and supported to improve outcomes. Parents often cite being connected to another parent as one of the most helpful interventions they experienced.
- Better coordination of care is dependent on the interactions that occur in each patient encounter.
- Insurers and regulators are essential partners in attempts to transform the system of care. Care coordination levels the playing field and creates another locus of knowledge about siloed systems, the challenges of multi-system navigation, financing of care and regulatory burden to strengthen the advocacy efforts necessary to better integrate care.

Submit your questions in the question box



Dennis Z. Kuo
MD, MHS

Associate Professor, University at Buffalo
Chief, Division of General Pediatrics, UBMD



Ann S. O'Malley
MD, MPH

Senior Fellow,
Mathematica Policy Research



Michele Juda

Executive Director,
Parent to Parent of New York State



Upcoming Conversations

Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions

August 22

Visit: lpfch.org/aapsupplement