

Medical Home Care for the Child with Medical Complexity: Care Coordination and Shared Decision Making

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Children with Medical Complexity

- Multiple significant chronic health problems
- Multiple organ systems
- Result in:
 - Functional limitations
 - High health care needs or utilization
 - Often require need for, or use of, medical technology
- Approximately 1% of children account for up to one third of overall health care spending



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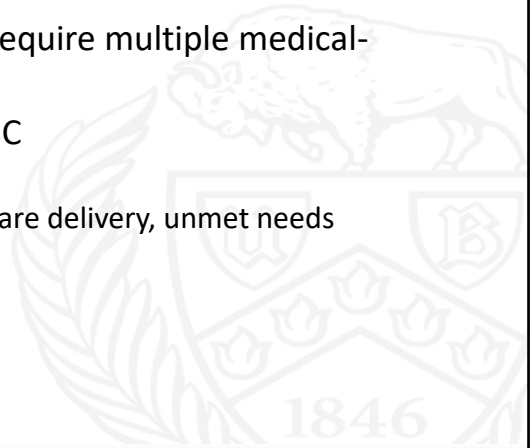


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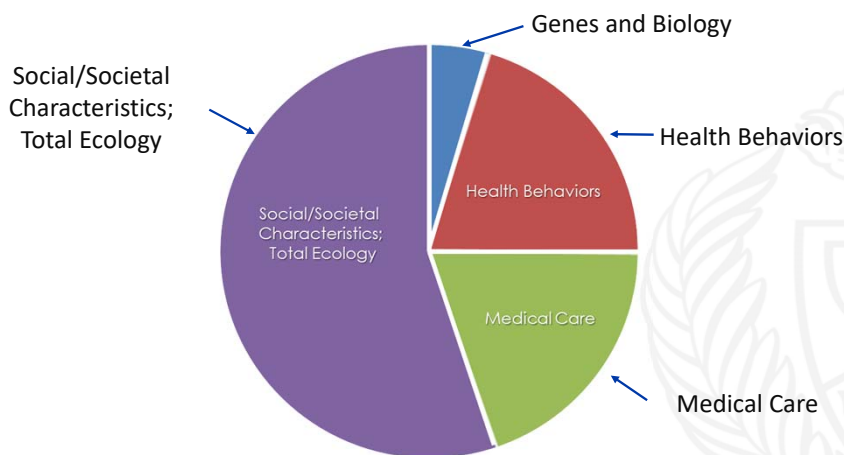
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The issue

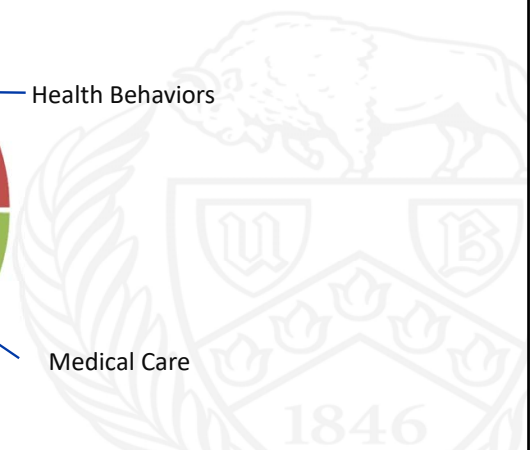
- Children with medical complexity (CMC) require multiple medical- and community-based support services
- “Care coordination” = logical need for CMC
 - High risk of fragmented care
 - Resulting risk of duplicated care, inefficient care delivery, unmet needs



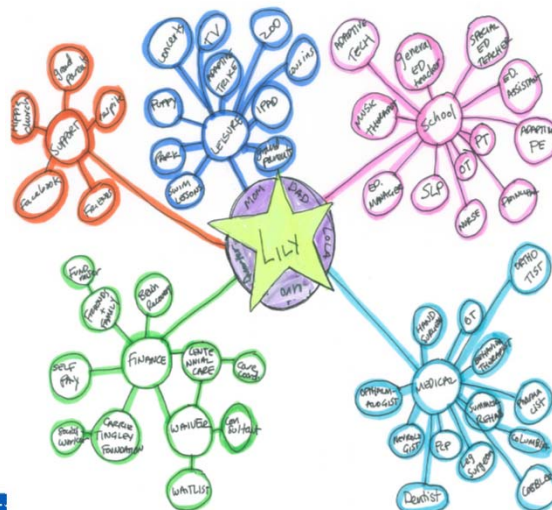
What determines health?



Centers for Disease Control and Prevention. Social determinants of health.
<http://www.cdc.gov/socialdeterminants/FAQ.html>.



Care map: why we perform care coordination (and what needs coordinating)



Kuo, D. Z., et al. (2018). "Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?" *Pediatrics* **141**(Suppl 3): S224-S232.

Care coordination characteristics

- "...a patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes."
- Four defining characteristics of care coordination:
 - family-centeredness
 - planned, proactive and comprehensive focus
 - promotion of self-care skills and independence
 - emphasis on cross-organizational relationships

COCWD, AAP (2014). "Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems." *Pediatrics* **133**(5): e1451-1460.

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

American Academy of Pediatrics (2014). "Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems." *Pediatrics* 133(5): e1451-1460.



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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



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Whose care is it anyway?

Common shortcomings of “care coordination” delivery

- Case management, not care coordination
 - Narrow scope or focus, often biomedical
 - May have 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, instead of across sectors and organizations
 - As a result, may be missing team members



Additional thoughts

- Coordinating the coordinators
 - Each coordinator has a narrow focus
 - Families often describe themselves as coordinators
- Fragmented care = unpredictable pathway to get to health
 - Families travel across service sectors that don't often speak with each other
 - However, coordinated care can be predictable and “designed”
 - Think of other examples of experiences that are “designed”
 - A supermarket is “designed”
 - Traveling to work is “designed”
 - What about caring for a child with medical complexity?



Care coordination experience isn't consistently designed

- Variation in how care coordination is **operationalized**
 - Training, staffing levels, and location of staffing
 - Scope of duties, ranging from case management of a specific condition to collaboration with community-based services
 - Evidence thus far is limited - intensive care management services may have some impact on preventable hospitalizations for specific children
- How do you make all of this work properly?
- **"Whose care is it anyway?"**

"Every part of a VW Golf"



Kuo, D. Z., et al. (2018). "Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?" *Pediatrics* 141(Suppl 3): S224-S232.
<https://katrinadstevens.com/2017/12/19/sandy-hook-lets-respond-thoughtfully-and-compassionately-not-simply-react/car-parts/> but unattributed



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Reviewing health care delivery terms that should apply to ALL children

- Starting with the definition of primary care
- "level of a health service system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and co-ordinates or integrates care provided elsewhere by others." – *B. Starfield (1998)*
- Applies equally to children with medical complexity



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The “medical home”

- Originally used as a term describing a centralized place to keep medical records
- AAP’s definition in 2002
 - “accessible, family-centered, continuous, comprehensive, coordinated, compassionate, culturally effective...”
 - “...delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care.”
- Again, think about how this applies to medical complexity...



Children’s Health

- “The extent to which individual children or groups of children are able or enabled to <a> develop and realize their potential, satisfy their needs, and <c> develop the capacities that allow them to interact successfully with their biological, physical and social environment.”
- What influences health for CMC?

Bright Futures 4th edition



Social Determinants of Health

- “Health starts in our homes, schools, workplaces, neighborhoods, and communities...Our health is also determined in part by access to social and economic opportunities; the resources and supports available in our homes, neighborhoods, and communities; the quality of our schooling; the safety of our workplaces; the cleanliness of our water, food, and air; and the nature of our social interactions and relationships.”
- CMC are more likely to be affected by SDH



“Advanced Primary Care”?

- Other terms include:
 - Medical Home
 - Patient-Centered Medical Home
 - Comprehensive Primary Care
 - Chronic Care Model
- The term’s not as important as understanding that promoting health and wellness in childhood, *given today’s understanding of the drivers of health*, entails a life-course approach to health

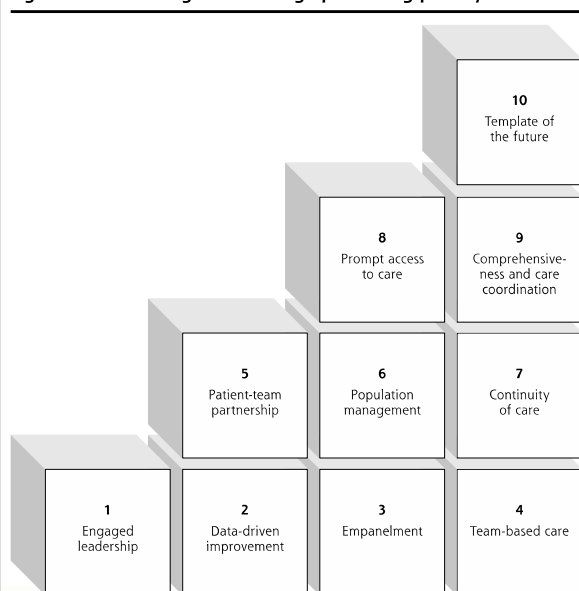


And just what IS the Life Course Model?

- Children and families are affected by biological and ecological exposures that either promote health or increase risk
- Health care professionals should identify family, neighborhood, and community determinants that influence lifelong health of patients
- Tailor the scope of practice to include:
 - Screening, **care coordination**, treatment plans, and health promotion
 - Collaborate with community partners and families
 - **Promote strengths** and **mitigate risk factors**
- **Again...**applies to CMC just as much as any other child



Figure 1. Ten Building blocks of high-performing primary care.



Bodenheimer, T., et al. (2014). "The 10 building blocks of high-performing primary care." *Ann Fam Med* 12(2): 166-171.



The premise of designed care coordination

- Coordinated care **can** be a predictable “designed” pathway of care across multiple sectors of care, including medical, education, financial, and community services
- Building effective care coordination pathways and processes with a cross-sector collaborative approach results in care integration
 - Care integration for CMC requires a series of feedback loops across the multiple sectors
 - Each feedback loop impacts the previous and subsequent steps
 - A coordinator’s task is to actively manage the processes of the feedback loops

Kuo, Ruud, Tahara, “Achieving Care Integration for Children with Medical Complexity,” https://www.lpfch.org/sites/default/files/field/publications/human_centered_design_11.29.18.pdf



Required elements to coordinate care

- Playbook: predictable care pathways **within and across systems**
 - Warm handoffs and information transfer
 - Clinical care pathways from the time of diagnosis
- Platform: data repository, templates, and Shared Plan of Care
- **Designated care team / care coordinator who can “curate” the entire process**
 - Think of a set of signs that tell you where to go
 - Examples: a traffic cop that directs traffic; a museum guide, etc.
 - **Coordinated care is designed and predictable**



Getting started for CMC

- Consider a single, designated central care coordination staff member acting as the “single point of contact”
- Standardize the training on the range of services that CMC utilize
 - Medical
 - Psychosocial (don’t forget behavioral)
- Centralized electronic communication tools, assessment tools, and a “care coordination dashboard” can be helpful to care coordinators

Experience from the Children’s Hospital Association *Coordinating All Resources Effectively* award



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Duties of designated care coordinators

- Develop a longitudinal partnership with assigned patients/families
- Administers and reviews structured assessments
 - Medical
 - Psychosocial
- 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



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Locus of care coordination

- Primary care practice
 - Hire your own
 - Train your own
- Other places
 - Complex care service
 - Accountable care organization
 - Community-based case manager
- Beware of having to “coordinating the coordinators”
 - Care coordination activities aren’t performed solely by one person
 - Care coordination is a team-based partnership with the family
 - Additional persons serving various care coordination roles where need is identified



Needed infrastructure for care coordination

- Staffing is just the start
- Consider:
 - Number of care coordinators
 - Roles of care coordinators
 - Prior experience and training needs
 - Clinical training
 - Hospital and/or ambulatory experience
- Ratio of CMC per coordinator: 50-200?



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
- Culture change
 - Practice transformation
 - Culture competency



Shared Decision Making

- Essential to care of CMC
- Elements
 - information is exchanged in both directions
 - all parties are aware of treatment options and what they are, and
 - all bring their knowledge and values-related priorities equally into the decision-making process
- Implementation
 - Demonstrate and model SDM
 - Utilize SDM tools in EMR/templates

Adams, R. C., et al. (2017). "Shared Decision-Making and Children With Disabilities: Pathways to Consensus." *Pediatrics* **139**(6).



Additional considerations for CMC

- Intellectual and developmental disabilities might lend itself to more interventions that might be considered alternative, complementary or unproven
- Quality of life issues (and may change over time)
- Future planning goals



Paying for care coordination

- Evaluation of care coordination
 - Understanding its value, both waste reduction AND more effective care delivery
 - Use of measurement tools of time/value gained
- Fee-for-service: care coordination codes (e.g. 99487–99489)
- Value-based payment models
 - Understand the landscape of PCMH, care coordination, and national organization and certification/standards
 - Remote collaborative services
- Collaboration with existing services



Where do we go from here?

- Culture change
 - Embrace the full spectrum of care
 - Medical care and direct services
 - Social determinants of health
- Relational coordination
 - It's about the relationships across services
 - Manage the processes across sectors
- Designing a predictable pathway of services to optimize health and wellness for CMC



Conclusions

- Care coordination is a team-based activity, although for CMC, designation of a dedicated care coordinator helps significantly
- Effective care coordination entails planning across the care spectrum, particularly social determinants of health
- Effective care coordination requires planning and infrastructure, including tools, training, and leadership across multiple sectors
- Care **integration** is the goal for CMC



Thank You!

Questions?



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