Organizational and Policy Options for Implementing and Sustaining High Quality Comprehensive Care Coordination for Children with Medical Complexity

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Designing Systems that Work for Children with Complex Health Care Needs
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Background

- Children with medical complexity (CMC) require particularly specialized and intense medical and community services.

- Although only about 0.4 to 2.3% of all children are medically complex, they consume more healthcare resources than their counterparts.

- Primary care providers may feel uncomfortable caring for CMC for the following reasons:
  - Lack of specialized knowledge and familiarity with various community, governmental, and educational resources
  - Lack of time and assistance to become familiar with above and develop and maintain relationships with organizations
  - Risk that CMC patients would consume a large amount of a practice’s resources for chronic condition management and care coordination
Care coordination for CMC requires greater skills and resources

- Care coordination skills for CMC differ from children with more common conditions (e.g. asthma and obesity).

- Caring for CMC requires:
  - Greater communication with medical specialties, schools, and specialized education services and community agencies.

  - Transitioning children into adulthood may involve:
    - Legal complexities of guardianship
    - Alternative living arrangements
    - Finding adult physicians comfortable with caring for these childhood diseases in adults
Medical and community support services

<table>
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<tr>
<th>Medical Services</th>
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<tr>
<td>• Hospital-based specialty care</td>
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<tr>
<td>• Pharmacy supplies</td>
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<td>• Home healthcare supply companies</td>
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<tr>
<td>• Outpatient and rehab programs (speech, physical, occupational)</td>
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<tr>
<td>• Mental health providers</td>
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<td>• Palliative care services</td>
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<tr>
<td>• Home nursing programs/patient care attended programs</td>
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<td>• School nurse/school-based medicine</td>
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<tr>
<th>Community Support Services</th>
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<tr>
<td>• Respite care</td>
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<tr>
<td>• Medical child care services</td>
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<tr>
<td>• Special education programs/out placement schools</td>
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<tr>
<td>• Childcare options</td>
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<tr>
<td>• Supplemental security income program</td>
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<td>• Title V programs</td>
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<td>• Palliative care programs</td>
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<tr>
<td>• Community and foundation supported activities/services</td>
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<td>• Sibling and parent support groups</td>
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<td>• Specialized play groups/adaptive physical activity programs</td>
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Challenges:
- Complex network of state and local government agencies
- Differing enrollment criteria, cost, service delivery capacities, etc.
- Availability of resources changes over time
- Difficulty gaining enough knowledge about each service and keeping up with changes
Current models of care coordination

1. Hospital or specialty-based program for CMC

2. State-level case management

3. Care coordinator employed by a single primary care practice

4. Care coordinator provided by integrated healthcare delivery system via contract with insurer
## Current models: Strengths and challenges

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<tr>
<th>Model</th>
<th>Service strengths</th>
<th>Service challenges</th>
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| 1. Hospital- or specialty-based program for children with medical complexity | • Providers have inside knowledge of services within the hospital  
• Ease of communication between program and specialists  
• Option to provide inpatient services  
• Staff have expertise in medical complexity | • Lack of natural connection to primary care  
• Lack of connection with local community resources, since programs likely draw from a large geographical area  
• Some patients likely travel long distances to hospital for appointments  
• Perverse incentives for hospital to fund such a program if it results in decreased utilization of hospital services |
| 2. State-level case management | • Case managers specialize in medical complexity  
• Knowledgeable about public programs/resources  
• Can provide care across payer spectrum  
• Potentially more oversight by public/patient groups | • Lack of natural connection with primary care and specialty providers  
• Potentially inflexible enrollment criteria that is set by the agency  
• Less knowledgeable about private community resources  
• No business case for privately insured patients  
• Little ability for electronic record sharing with primary care  
• May have limited knowledge of medical complexity |
| 3. Care coordinator employed by a single primary care practice | • Strong connection with primary care practice  
• Care coordinator can serve other family members if also seen in the practice  
• Familiarity with local community and able to develop personal relationships with agencies to facilitate referrals  
• Primary managed by practice so can change depending on practices' needs | • Less familiarity with state and hospital-level programs targeted toward children with medical complexity  
• Unless practice is large, may not have the volume to maintain expertise and relationships with programs/entities that serve children with medical complexity |
| 4. Care coordinator provided by integrated healthcare delivery system via contract with insurer | • Strong specialization in issues related to complex care  
• Ability to see all claims/utilization and track over time | • Less connection with primary care, especially of practice has only a few patients with certain insurer  
• Less connection with tertiary care, community programs and agencies  
• Little oversight/influence by patient |
Current models: Financial drivers

- **Hospital-or specialty based program for CMC (funder = hospital)**
  - If utilization decreases, perverse incentives for institutions reimbursed by service
  - Potential way to attract patients/donors to hospital
  - Possibly increase workplace satisfaction and reduce turnover

- **State-level case management (funder = MCHB Title V or Medicaid)**
  - Service level sensitive to revenue streams/budget cuts
  - Incentive to reduce utilization but only for patients with public insurance

- **Care coordinator employed by a single primary care practice (funder = practice revenue)**
  - Little to no financial incentive under FFS model to coordinate
  - May be sacrificing other resources to target larger populations (e.g. obesity, immunization) to benefit a small number of patients

- **Care coordinator provided by integrated healthcare delivery system via contract with insurer (funder = insurer via contract with network)**
  - Incentivized to reduce utilization
  - Disincentivized to provide services unlikely to affect utilization, or to patients with non-modifiable utilization patterns
Although the current models work well for many clinical situations, smaller primary care practices and family medicine practices would benefit from an additional model:

- **Shared care coordinator over several practices**

The care coordinator serves several functions:

- **Provides a working and extensive knowledge of the services available** for CMC with a certain patient catchment area

- **Facilitates and organizes communication** between providers, families, and services

- **Screens and links families to appropriate resources** and offers advice on how to best advocate for their child and navigate the system

- **Facilitates written care plans**, connects families with support groups

- **Conducts pre-visit planning sessions** to help establish thoughtful agendas prior to health maintenance exams
Program capacity and structure

- Reasonably manage 200-300 active patients with moderate to severe medical complexity at a time:
  - Prevalence of medical complexity ~1.5% and panel size for full time pediatrician 1,500-2,000 (22 to 38 CMC)
  - A single care coordinator could cover medically complex patients for about 8-10 FTEs
  - Number of cases would vary inversely with the number of practices a care manager is affiliated with
  - Maximum # of practices: 10-12 for one care manager
Important considerations for implementation

- Care coordinator should be well-connected, well-integrated, and at least partially co-located, in the primary care practice to foster teamwork.

- Responsibilities of practices, care coordinators, and community partners should be well-delineated.

- Threshold for referral should be flexible and family-centered such that pediatricians and families can decide whether care coordination services are needed.

- The care coordinator would have his or her time protected for coordination activities and be free from responsibilities elsewhere in practices.

- The care coordinator would be managed primarily by the practices themselves so that job responsibilities can be flexible and consistent with practices’ overall mission and other competing or complementary initiatives.
Barriers to implementation

- Building the case for prioritizing funding for this position
- Creating a funding mechanism by which multiple practices can share a resource
# Partners pediatric high risk care program

| Staffing       | 1 clinical manager and 5 RN care managers  
|                | 2 social workers  
|                | Medical director and pedi psychiatrist  
|                | Pharmacist and CRS support available for consult  
| Patient Panel  | 3,260 total patients reviewed (as of Nov 2015)  
|                | 52 pediatric practices have care manager assigned and patients validated  
|                | 280 patients enrolled in the program  
| Care Model     | Initial Care Manager Assessment  
|                | Patient and Family focused Care Plan  
|                | Social Worker Assessment Tool  
|                | Payer blind opt-in for select practices rolled out in October 2015  
| IT             | Assessments and care plans available in the care management system  
|                | An icon in the EMR alerts pediatrician of high risk patient  
|                | Email notifications sent to care managers and pediatricians  
|                | Live on Epic for initial launch, on-going roll-outs anticipated  
| Innovations    | Transition to adult care innovations pilot in progress  
|                | Patient TRAQ survey used to identify gaps in transitions knowledge  
|                | Short videos (vidscrips) used for patient education about transitions  

## Launch Date
November 2013
Making the business case

- Improved clinical and patient-centered outcomes and health utilization savings with care coordination services for those with chronic conditions

- Savings in the healthcare system:
  - Decreasing preventable morbidity
  - Decreasing ED and hospital utilization
  - Savings from reducing duplicative care and gains in efficiency by primary care providers

- Savings outside the healthcare system:
  - Patient may achieve more in school
  - Parents more fully employed, more productive at work, and spend more time caring for their other children

- Measure patient experience to assure satisfaction and quality
Stakeholders

- **Pediatricians and pediatric practices**
  - Saved time in care coordination
  - Help in preventing recurrence of flares of chronic symptoms
  - Decreased frustration
  - Greater career satisfaction

- **Insurers**
  - Improved communication and quality of care may decrease duplicative care, ED and hospital utilization
  - Although increase in ambulatory care, pharmacy and medical supplies – will make costs more predictable

- **Community agencies**
  - Increase referrals, and ensure appropriate
  - Help facilitate communication
Measurement and accountability

- Incorporate incentive payments to practices
- Use patient experience (e.g. PCMH and CAHPS) to benchmark practices and reward practices
- Risk adjust hospitalizations and emergency room use
- Develop patient- and family-centered quality of care measures
- Clearly define expectations for shared care coordinators and align with payment and evaluation sources
Conclusion

- The shared care coordinator model will provide a substantially tighter connection among families with CMC, their medical homes, and their medical neighborhoods.

- The model is feasible and sustainable under several different funding mechanisms.

- Achieve greater quality of care, decreased utilization, and improved clinical and psychosocial outcomes, with minimized burden to vulnerable families.