Can We Do Better?
Children with Medical Complexity: Patients, Providers & Payers

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Disclosures

• I am a very general pediatrician
• I do take care of children with medical complexity
• I do work for a Children’s Hospital
• My presentation reflects my personal perspective in these roles- not official statements of my children’s hospital, children’s hospital organizations or the American Academy of Pediatrics
MEDICALLY COMPLEX CHILDREN

Children With Medical Complexity And Medicaid: Spending And Cost Savings

ABSTRACT A small but growing population of children with medical complexity, many of whom are covered by Medicaid, accounts for a high proportion of pediatric health care spending. We first describe the expenditures for children with medical complexity insured by Medicaid across the care continuum. We report the increasingly large amount of spending on hospital care for these children, relative to the small amount of primary care and home care spending. We then present a business case that estimates how cost savings might be achieved for children with medical complexity from potential reductions in hospital and emergency department use and shows how the savings could underwrite investments in outpatient and community care. We conclude by discussing the importance of these findings in the context of Medicaid’s quality of care and health care reform.
Children with Medical Complexity

- Children with medical complexity are a growing population with expensive, complex, and chronic medical conditions.
- These conditions often lead to:
  - functional limitations, which are often severe;
  - substantial needs for health services to maintain health,
    - including numerous clinicians, medications, medical equipment, therapies, and surgeries;
  - high health resource utilization.
- Previous studies showed that about 0.4–0.7 percent of all US children (roughly 320,000–560,000 children) have medical complexity at the highest levels.
- These children account for 15–33 percent of health care spending for all children (about $50–$110 billion annually).
Children with Medical Complexity

*Health Affairs 2014*

- In 2011 children with medical complexity accounted for 5.8 percent (n = 214,765) of all children covered by Medicaid in the Truven study database.
- The most prevalent chronic conditions endured by children with medical complexity were
  - neurologic or neuromuscular (24.5 percent),
  - congenital or genetic (22.1 percent),
  - cardiovascular (18.9 percent);
  - 45.8 percent of the children had three or more chronic conditions.
- One-fourth of the children were eligible for Medicaid because of a disability.
- **Children with medical complexity accounted for 34.0 percent ($1.6 billion) of all health care spending for children with Medicaid.**
  - Spending was highly concentrated within a subset of children with medical complexity: 5 percent of these children accounted for 50 percent of total spending on children with medical complexity.
## Exhibit 1

<table>
<thead>
<tr>
<th>Health service</th>
<th>Percent of children using the health service</th>
<th>Annual spending per child ($)</th>
<th>Percent of health care spending for children with medical complexity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital care</td>
<td>13.0</td>
<td>5,903</td>
<td>47.2</td>
</tr>
<tr>
<td>Outpatient specialty and other care</td>
<td>66.0</td>
<td>3,136</td>
<td>25.1</td>
</tr>
<tr>
<td>Medications</td>
<td>89.9</td>
<td>1,677</td>
<td>13.4</td>
</tr>
<tr>
<td>Outpatient therapy</td>
<td>22.4</td>
<td>593</td>
<td>4.7</td>
</tr>
<tr>
<td>Emergency care</td>
<td>32.3</td>
<td>383</td>
<td>3.1</td>
</tr>
<tr>
<td>Primary care</td>
<td>59.6</td>
<td>275</td>
<td>2.2</td>
</tr>
<tr>
<td>Laboratory and radiographic testing</td>
<td>54.9</td>
<td>230</td>
<td>1.8</td>
</tr>
<tr>
<td>Home health care</td>
<td>3.2</td>
<td>204</td>
<td>1.6</td>
</tr>
<tr>
<td>Medical equipment and supplies</td>
<td>16.7</td>
<td>98</td>
<td>0.8</td>
</tr>
</tbody>
</table>

*Source:* Authors’ analysis of 2011 data from the Truven Marketscan Medicaid Database.
No single CMC diagnosis: CRGs 5b-9

<table>
<thead>
<tr>
<th>MEDICAL COMPLEXITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>NON-CHRONIC (CRGs 1,2)</td>
</tr>
<tr>
<td>Brief Description</td>
</tr>
<tr>
<td>Example Conditions</td>
</tr>
</tbody>
</table>

*CRG (Clinical Risk Groups) category 5 is broken up into two subcategories by the Children’s Hospital Association – 5a and 5b. The definition of medical complexity includes 5b, “single dominant chronic disease,” such as patients with sickle cell disease or congenital heart disease.
Children with Medical Complexity
Multiple diagnoses & care providers
K’s medical care: how well coordinated?

- Depts: 15
- Specialists: 30+
- Diagnoses: 22
- Therapies: 3
Children with Medical Complexity
Care Coordination: Who Really Manages?

http://www.childrenshospital.org/care-coordination-curriculum/care-mapping
Gaps in Care Coordination: Challenges & opportunities

• Too few or too many case managers or care coordinators
  • Health Plan
  • Primary Care Practice team
  • Complex Care Program (for Children with Medical Complexity)
  • Specialty care team(s)
  • Hospital discharge planning
  • Subacute care setting
  • School/special education setting
  • Home care/nursing/DME/transportation
  • Pharmacy/formulary
• Poor communication and coordination among the coordinators
Care teams & plans: Dynamic, coordinated, family-centered & shared

- Put patient & family at center?
- Who is on your child’s care team?
  - Primary care, complex care program, specialist, care coordinator(s), case manager, social worker, plan case manager/coordinator...
- Who is important? Who is secondary?
- What are shared goals for child/family & providers/plan?
  - Shared goals vs wishes
  - Dynamic care team (shifting locus of care)
  - Action & emergency plans
- One shared care plan vs multiple care plans
“Complex Care” Programs

- Most children’s hospitals establishing “complex care” clinics or programs to better address clinical and care coordination needs of children with medical complexity (and families)
  - Outpatient (primary care medical home vs consultative based on location/needs of family)
  - In-patient coordination & discharge planning
  - Multidisciplinary care team
    - Generalist/primary care pediatrician, nurse practitioners, nurses, care coordinators, social workers, parent navigator/peer support, support services
  - Early research in care/payment pilots suggest improvement in care outcomes, cost reduction & family satisfaction:
    - Reduction in hospital days
    - Admissions for ACS conditions
    - 30-day unplanned readmissions
    - ED visits not associated with admission
  - CMS supporting six CMMI awards to demonstrate & evaluate care & payment models for children with medical complexity
Complex Care Published Results

**Texas Medical Center***
- Enhanced medical home for high-risk children with chronic illness
- Medicaid payments decreased $6243 (95%CI, $1302-$11 678) per child-year.*

**Massachusetts**
- Primary care practice care coordination intervention
- Decrease in hospitalization rate (58% to 43%)

**UCLA**
- Tiered medical home for complex patients
- Decrease in average # ED visits from 1.1 (SD 1.7) to 0.5 (SD 0.9)

**U. of North Carolina**
- Center for complex and chronic conditions covering 29 counties
- 55% reduction in re-hospitalizations; 3 year savings $6m.

**Children’s Hospital of Wisconsin**
- Medical home for children with medical complexity
- Over 50% reduction in inpatient care

**Cook Children’s Health Care System**
- Coordinated care program for children with medical complexity
- CMMI CARE award participant

*JAMA. 2014; 312(24) 2640-2648. doi: 10.1001/jama.2014.16419*
Payers, providers, patients: Opportunities for better care coordination, outcomes & lower cost

• These are the most medically fragile children - many with progressive illness trajectories
  • Not all expenses can be prevented or reduced
• Early evidence that improved care coordination, communication, rapid response can improve care & reduce expense for CMC
  • CMS funding six CMMI initiatives for children with medical complexity
• Payer/health plan resources vs care team resources
  • Plan resources vs embedded in clinical care team (primary care, complex care, specialty care)
  • Emerging Medicare payment models - chronic complex care coordination, transitional care management
Questions & discussion

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