The National Landscape for Children with Medical Complexity

Children with Medical Complexity in New Jersey
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Children with medical complexity – setting the stage with some numbers

- How many US children are medically complex?
  - 0.4-0.7% (approx. 320,000 – 560,000)

- How much does their care cost?
  - 15-33% of total pediatric spending (approx. $50-110 billion annually)

Who are children with medical complexity?

- No national consensus definition as yet
- Other forms of complexity:
  - Social complexity
  - Gaps/barriers in the system of care
Who are children with medical complexity?

- Today’s definition:
  - Children and youth between ages 1-21 with:
    - Multiple, significant chronic health problems that affect multiple organ systems;
  - Resulting in:
    - a) functional limitations and b) high health care need or utilization; and,
    - Often the need for or use of medical technology

Kuo, D. & Houtrow, A. Recognition and Management of Medical Complexity. (2016). Pediatrics
Medicaid highlights for children with medical complexity

- EPSDT and cost-sharing protections specific to children
- State plan amendments like TEFRA/Katie Beckett and home- and community-based service (HCBS) waivers – enhanced services and supports
- Supplemental coverage which “wraps” private (often inadequate) insurance
Medicaid highlights for families of children with medical complexity

- Link between poverty and presence of complex needs
- Link between presence of complex needs and poverty
- Pathways to financial hardship:
  - High out-of-pocket costs for care
  - Higher expenses for routine household needs
  - Lower parental income

*Breaking the Link Between Special Health Care Needs and Financial Hardship.* (2017.). The Catalyst Center, Boston University.
System of care highlights for providers and states

- High levels of unmet need
- Lack of evidence-based practice guidelines
- Home- and community-based services underfunded/understaffed
- Reimbursement rates - access
- Result:
  - Siloed, fragmented, inefficient care that negatively impacts child quality of life, family well-being, physician satisfaction, cost-effectiveness and value

Promising practices (examples)

- Policy level
  - Promoting wrap coverage through SPAs, waivers and buy-in programs
    - Access to EPSDT and parental disregard specifically
  - ACE Kids Act
  - Alternative payment methods to increase value and cost-effectiveness
Promising practices (examples)

- **Practice level**
  - Discharge planning processes with meaningful family education
  - **Shared** plan of care
  - Emergency plan
  - Emerging: CMC CoILN – current QI network with ten states testing care delivery improvements and APMs
Questions and Discussion
Thank you!

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