



# The National Landscape for Children with Medical Complexity

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**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)

Children with Medical Complexity and Medicaid: Spending and Cost Savings. (2014). Berry, J, Hall, M, Neff, J, Goodman, D, Cohen, E, Agrawal, R, Kuo, D & Feudtner, C. *Health Affairs*



# 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



# 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



# 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

*What children with medical complexity, their families and providers deserve from an ideal healthcare system.* (2015) Jay Berry, MD, MPH, Briefing Paper: Lucile Packard Foundation for Children's Health.



# 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 CoIIN – current QI network with ten states testing care delivery improvements and APMs



# Questions and Discussion



# Thank you!

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