A Conversation on the Emergence of Pediatric Complex Care

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Lucile Packard Foundation for Children's Health
Today’s Moderator:

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The **Lucile Packard Foundation for Children’s Health** works to ensure that children and youth with special needs will be served by a family-centered system that provides ready access to a comprehensive array of high-quality, coordinated services designed and delivered to efficiently and effectively meet their unique physical, emotional, social and developmental needs.
Ask Questions!

We look forward to a lively discussion with our audience. Enter questions in the GoToWebinar chat box.
Meet our Speakers

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Jeffrey P. Brosco
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Professor, Clinical Pediatrics, University of Miami, Miller School of Medicine
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– The views are those of the authors and not those of the funders, their directors, officers, or staff.
Mismatch between child health care system and childhood need

• Growing numbers of children with chronic needs
  – >400% increase in prevalence of children with chronic conditions since 1960s

¹Health Aff 2014;33(2):2099-2105.
The Cone of Care*

The Social Fabric
~75 million children

Children with Special Health Care Needs (CSHCN)
~15%

Children with Medical Complexity (CMC)
~0.4%-6%

“have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions, & require health and related services ... beyond that required by children generally”¹

¹ Adapted from Robert Armstrong. The Challenge of Caring for Canada’s Children and Youth.
³ Pediatrics 2011;127(3):529-538

*Adapted from Robert Armstrong. The Challenge of Caring for Canada’s Children and Youth.
PubMed-indexed publications over time

![Graph showing the number of publications indexed by PubMed over time, categorized into Pediatric complex care, CSHCN, and CMC.]
Why?

(A) CSHCN definition is too broad for some purposes
Why?

(A) CSHCN definition is too broad for some purposes

(B) Dramatic impacts of CMC
- Health System
  - Expenditures
  - Hospitalizations
  - Adverse Events
  - Mortality
- Families
  - Stress
  - Expenses
  - Parental health

Pediatrics 2010;126(4):647-655; Jama 2016;316(23):2515-24, and others
Why else?

(C) Complements current trends in health care
    – Complex care
    – Patient safety
    – Control of health care spending
    – Payment reform
Challenges

(A) Knowledge gaps

– Incomplete and/or vague definitions
  • Different definitions for different purposes

– Ascertainment
  • Over-reliance on readily available data vs. patient- and family-reported data
  • Not dynamic
Challenges

(B) Lack of Evidence-Based Approaches

Rapid proliferation of structured complex care programs focused largely on care coordination

- Lack of standardization
- Lack of high quality evaluations
- RCTs with divergent findings
Challenges

(C) Mental/Behavioral health
  – Relatively little focus in most complex care programs
  – Highly prevalent
  – May need different system response, much more community-focused
Practice and Policy Implications

• Scoping – Who is in and who is out?
  – May need multiple definitions for different purposes
Practice and Policy Implications

• Where does this leave CSHCN?
  – Much larger residual group on non-CMC CSHCN
  – Common conditions (asthma, ADHD, obesity)
  – May need different approaches
Practice and Policy Implications

- Over-weighting of hospital-based care?
  - Legislative
  - Logistic
  - Congruent with many system metrics
Practice and Policy Implications

• Over-weighting of hospital-based care?
  • Legislative
  • Logistic
  • Congruent with many system metrics

– Limitations
  • Improvement opportunities (and cost savings) may be limited
  • Under-emphasis of other components of care
  • Geographic realities
Practice and Policy Implications

• Broadening of outcome measures
  – Beyond cost and hospital-system metrics
    • E.g., access, child/caregiver/family well-being, school attendance, financial health, independence, societal integration, etc.
  – An opportunity for child health services research
Conclusions

• Rapid shift in discourse from CSHCN → CMC without time to confront implications for health system change

• Will this lead to meaningful changes or is the child health system simply echoing terminology with resonance in adult-oriented health systems?
Opportunities

• Reconciliation of definitional issues
• Orienting interventions to appropriate targets
• Careful consideration of all components of care
• Reframing:
  – Even if health care costs are not consistently modifiable, outcome frameworks can address many modifiable outcomes with impacts on children, their families and the health care system
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Submit your questions in the chat box

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