



A Conversation on the Emergence of Pediatric Complex Care

April 10, 2018



Today's Moderator:

Rishi K. Agrawal MD, MPH

Associate Professor of Pediatrics, Northwestern
University Feinberg School of Medicine

Pediatric Specialist, Lurie and La Rabida Children's
Hospital in Chicago



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



Eyal Cohen
MD, MSc, FRCP (C)

Staff Physician, Paediatrics
The Hospital for Sick Children



Jeffrey P. Brosco
MD, PhD

Professor, Clinical Pediatrics, University of
Miami, Miller School of Medicine

Deputy Secretary, Children's Medical Services,
Florida Department of Health



James Perrin
MD

Professor of Pediatrics
Harvard Medical School

PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Status Complexicus? The Emergence of Pediatric Complex Care

Eyal Cohen, Jay G. Berry, Lee Sanders, Edward L. Schor and Paul H. Wise

Pediatrics 2018;141;S202

DOI: 10.1542/peds.2017-1284E

**Lucille Packard Foundation for Children's Health
Webinar**

April 10th, 2018

Disclosure

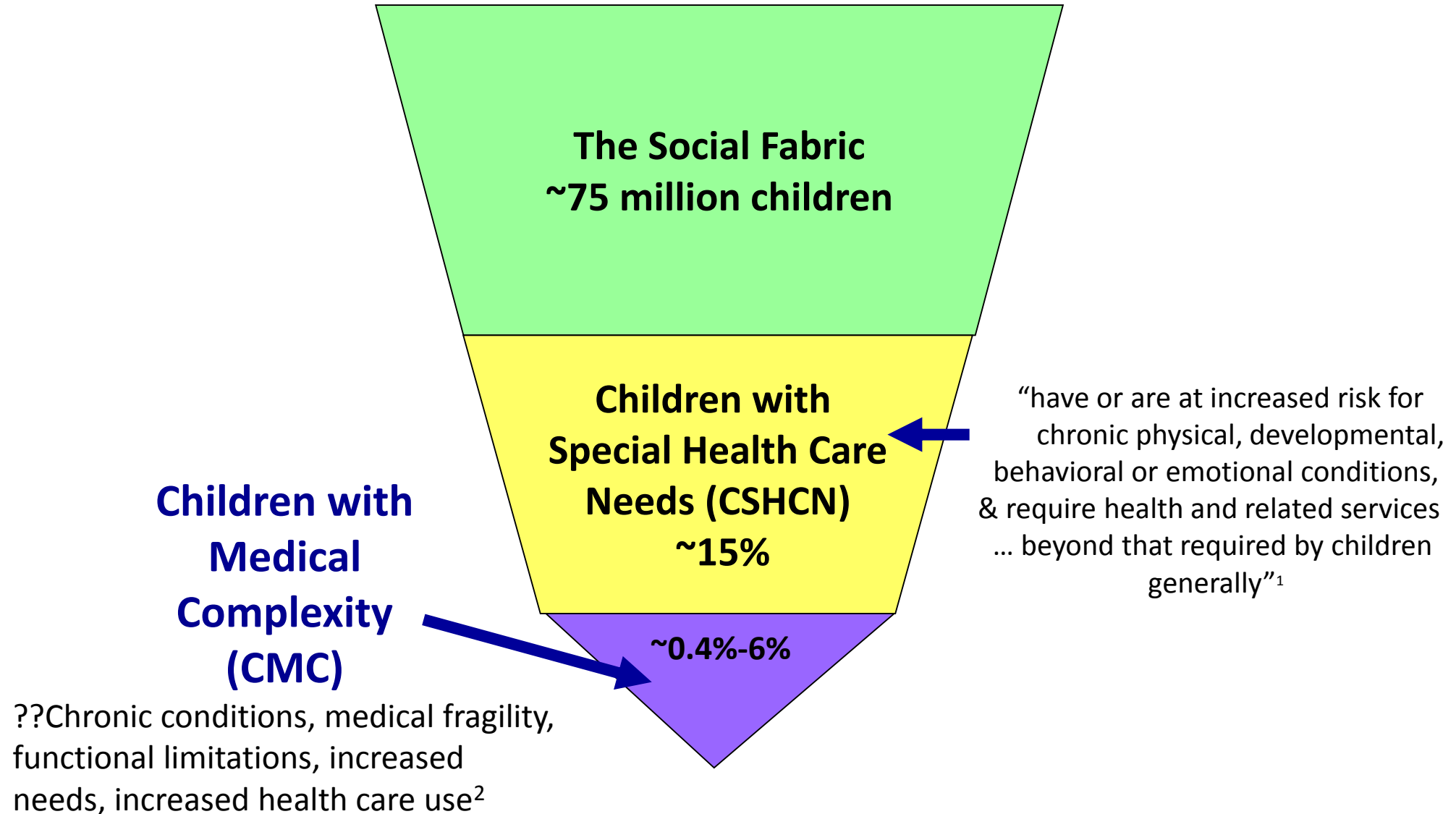
- Eyal Cohen was supported by the Canadian Foundation for Healthcare Improvement, the Canadian Institutes of Health Research and the Commonwealth Fund, a private independent foundation based in New York City.
- Jay Berry was supported by the Agency for Healthcare Research and Quality (R21HS23092).
- 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 1960s¹

¹Health Aff 2014;33(2):2099-2105.

The Cone of Care*

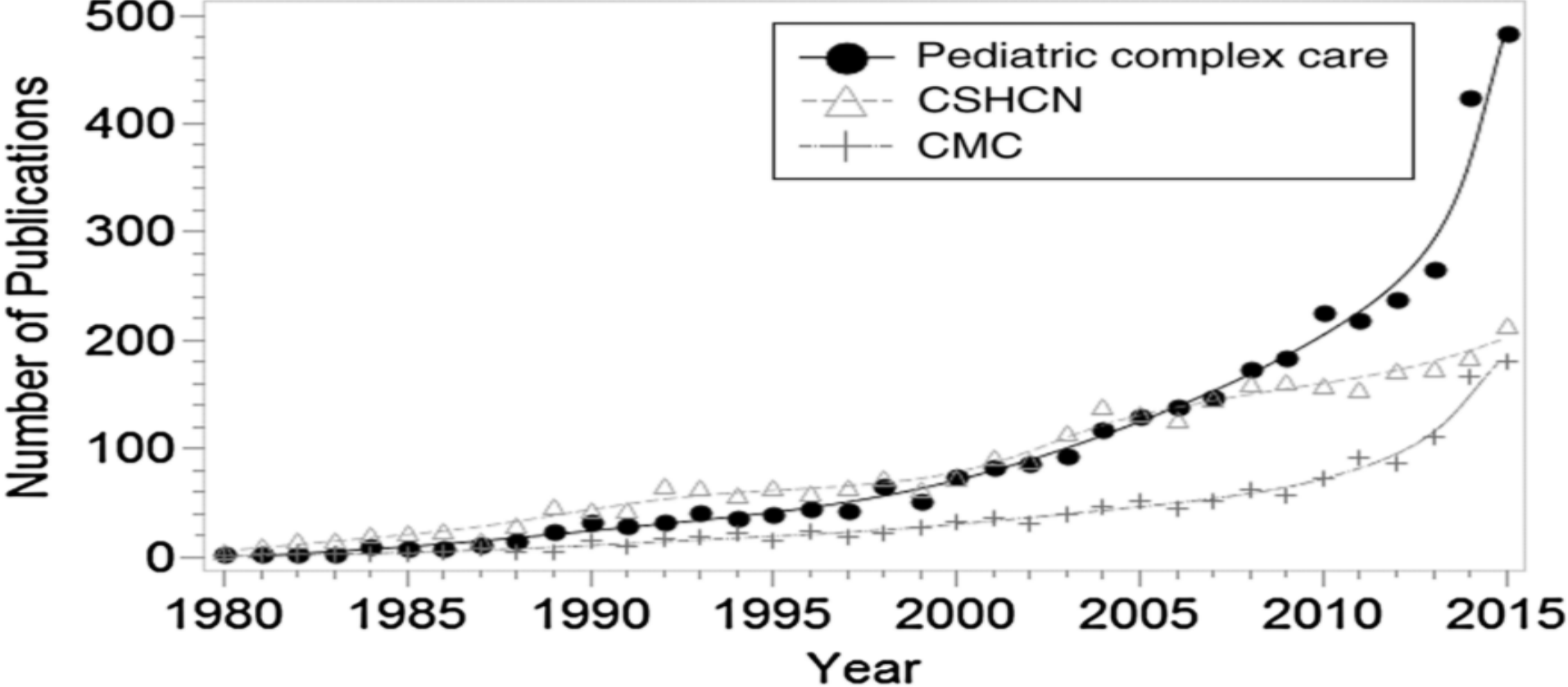


*Adapted from Robert Armstrong. The Challenge of Caring for Canada's Children and Youth.

¹ Pediatrics 1998;102(1):137-40

² Pediatrics 2011;127(3):529-538

PubMed-indexed publications over time



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

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



Contact:

eyal.cohen@sickkids.ca

Submit your questions in the chat box



Eyal Cohen
MD, MSc, FRCP (C)

Staff Physician, Paediatrics
The Hospital for Sick Children



Jeffrey P. Brosco
MD, PhD

Professor, Clinical Pediatrics, University of
Miami, Miller School of Medicine

Deputy Secretary, Children's Medical Services,
Florida Department of Health



James Perrin
MD

Professor of Pediatrics
Harvard Medical School



Upcoming Conversations

Meaningful Family Engagement, from Clinical Care to Health Policy

June 6

Models of Care Delivery for Children with Medical Complexity

June 28

Visit: lpfch.org/aapsupplement