Optimizing care for children with medical complexity

The team-based approach

Amie Jones, MD
Chair, Division of General Pediatrics and Adolescent Medicine
Assistant Professor of Pediatrics
Mayo Clinic Children's Center

MAYO CLINIC

Disclosures

- *I do not have any conflicts of interest to declare*

- *No off label use of medication will be discussed*

MAYO CLINIC

Learning objectives

- Understand the commonly used definitions for pediatric populations in healthcare
- Recognize the impacts of medical complexity at the person-level (child and family), system-level, and from an economic perspective
- Be able to compare and contrast some of the current care models serving children with medical complexity
- Be familiar with Mayo Clinic's complex care approach and experience
- List areas where technology solutions are evolving to improve complex care management

MAYO CLINIC

Defining pediatric populations in healthcare

1. Children described as "**healthy**"

- Limited healthcare utilization beyond age-appropriate immunizations, preventive care, and treatment for acute illness or injuries

MAYO CLINIC

Defining pediatric populations in healthcare

1. Children described as "**healthy**"

2. Children and youth with special health care needs (**CYSHCN**)

- Increased risk for chronic physical, developmental, behavioral or emotional conditions
- Require health related services of a type or amount beyond that required by children generally

MAYO CLINIC

Defining pediatric populations in healthcare

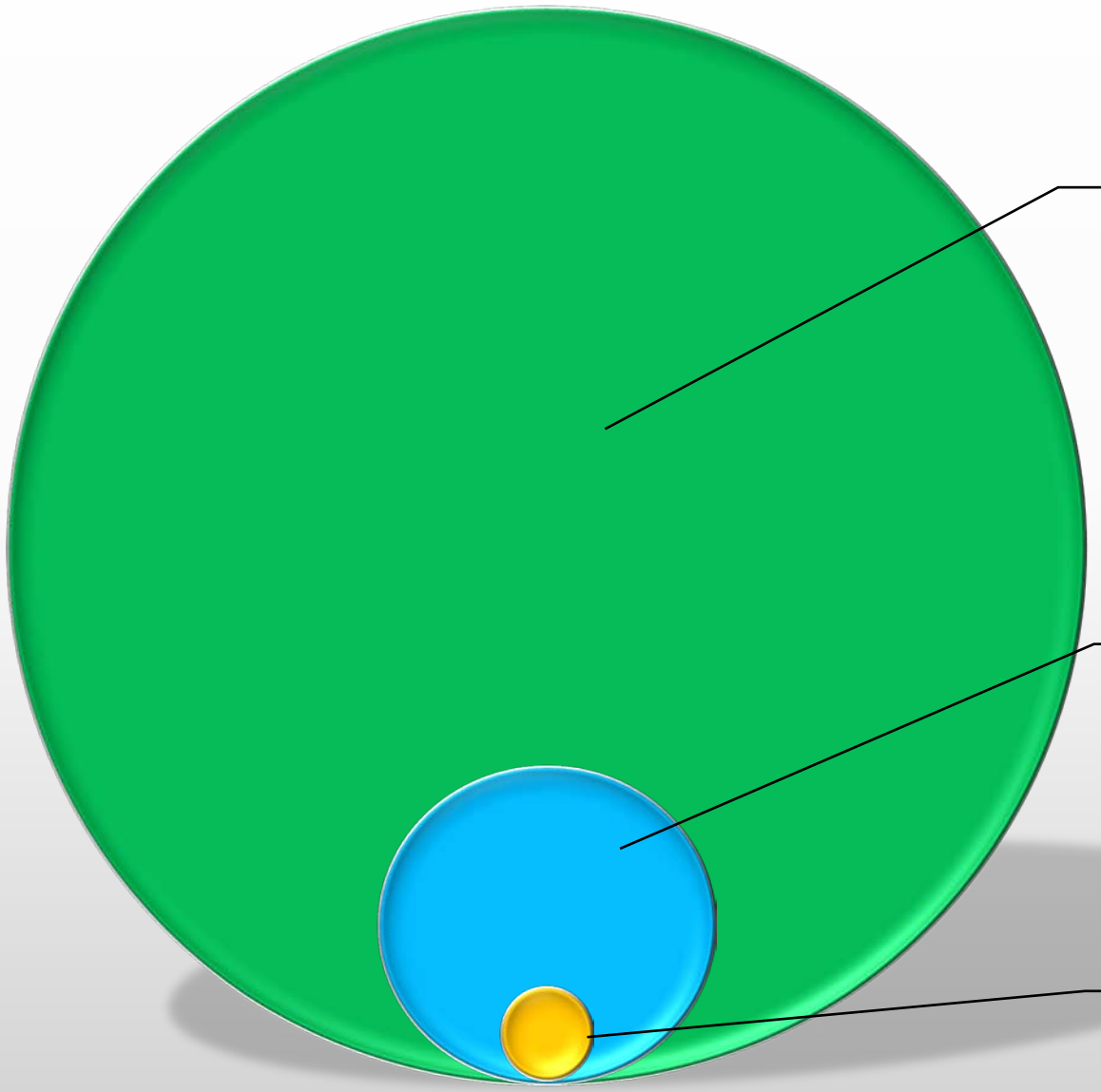
1. Children described as "**healthy**"

2. Children and youth with special health care needs (**CYSHCN**)

3. Children with medical complexity **(CMC)**
   - "complex chronic," "medically complex," and "medically fragile"

- Significant chronic conditions in 2+ body systems >1 yr
- Expected to be episodically or continuously debilitating
- Progressive condition, deteriorating health, decrease in life expectancy
- Technology dependent > 6 mon
- Cancer with no remission for 5 yr

MAYO CLINIC



US population
0-18 years old
"healthy"
(74 million)

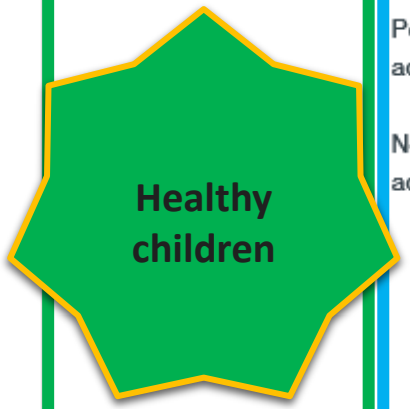
CYSHCN (20%)
(14.6 million)

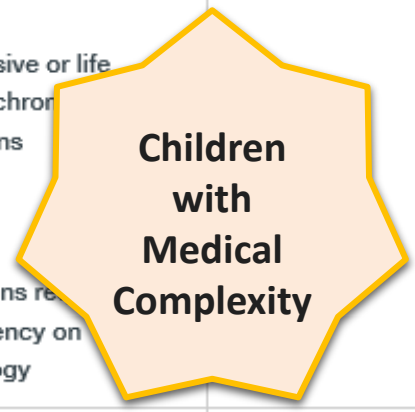
CMC (0.5%)
(400,000)

MAYO CLINIC

3M Clinical Risk Group (CRG) Categories

	Non-Chronic (CRGs 1, 2)	Episodic Chronic (CRGs 3, 4)	Lifelong Chronic (CRG 5)	Complex Chronic (CRGs 6, 7, 9)	Malignancies (CRG 8)
Brief Description	Acute conditions that will not last one year	Chronic conditions that will last one year and are likely to be episodic in manifestation Potentially curable with adequate treatment Not likely to adulthood	More severe primary condition in one body system that is more likely to cause significant long-lasting health impairment	Significant chronic condition in two or more body systems or Progressive or life limiting chron conditions or Conditions re dependency on technology	Malignancies requiring active treatment
Example Conditions	Fracture, pneumonia, appendicitis, trauma	Asthma, depression, conduct disorders	Type 1 diabetes, congenital heart disease	A child with diabetes, encephalopathy and chronic pulmonary disease. Down syndrome, cerebral palsy, cystic fibrosis	Leukemia, bone tumors, brain tumors





MAYO CLINIC

PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Pediatrics. 2014 Jun; 133(6): e1647–e1654.
doi: 10.1542/peds.2013-3875

PMCID: PMC4035595
PMID: 24819580

Pediatric Medical Complexity Algorithm: A New Method to Stratify Children by Medical Complexity

- The algorithm is reliable for classifying children by complexity
  - Sensitivity was 89% for **C-CD**, 45% for **NC-CD**, and 80% for those **without CD**.
  - Specificity 85% to 91% in Medicaid claims data for all 3 groups.
- Subsequently has been updated to ICD-10 codes

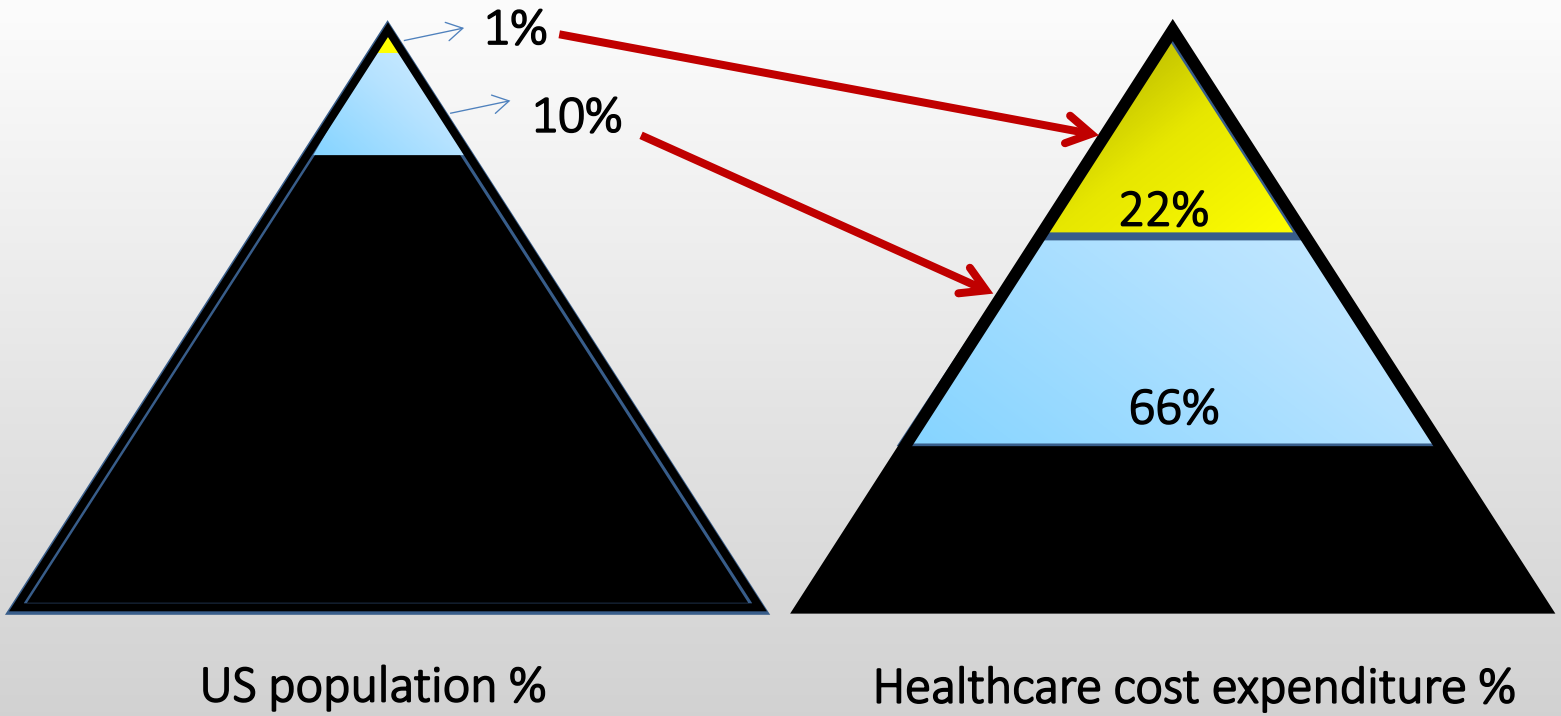
MAYO CLINIC

CMC population

- The population is growing
  - Expanding therapies and treatments extending lifespan
- The impact of caring for CMC is significant
  - Financial
  - Individual
  - System
- “Canaries in the coal mine”
- “Trickle-up” effect

US healthcare expenditures

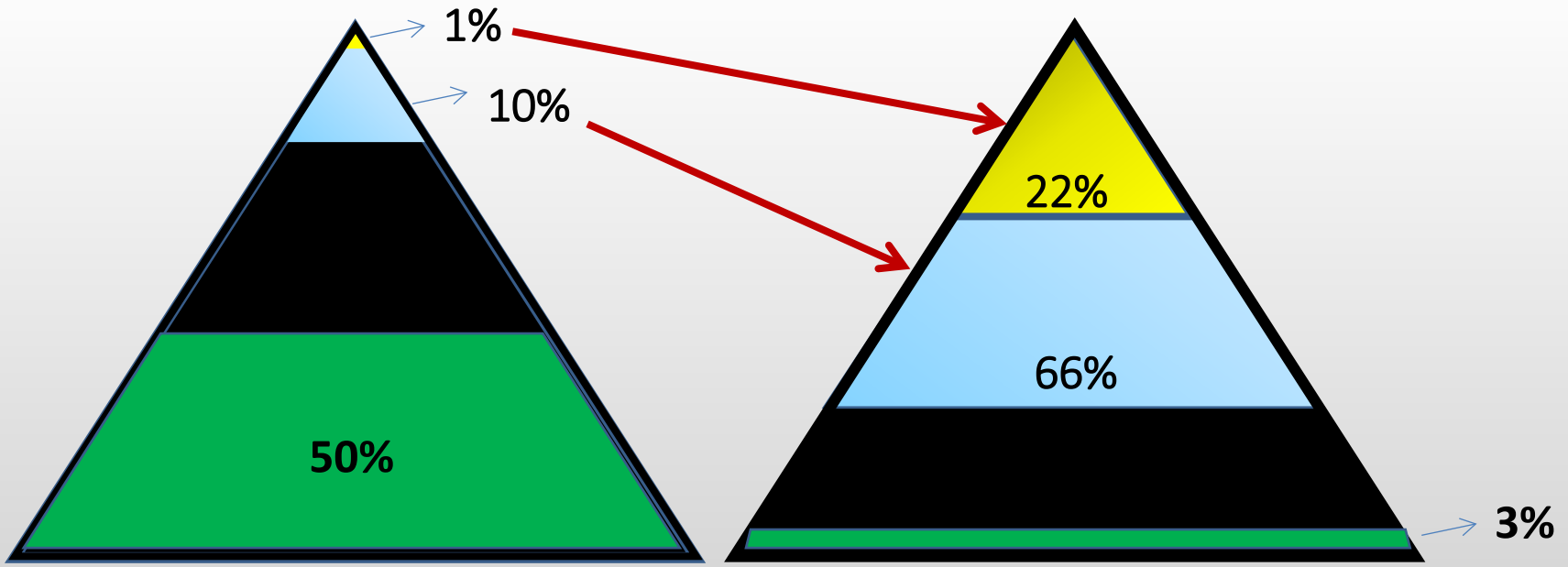
- $3.5 trillion annually (2017)
- 17.9% gross domestic product
- Utilization to cost ratios



MAYO CLINIC

US healthcare expenditures

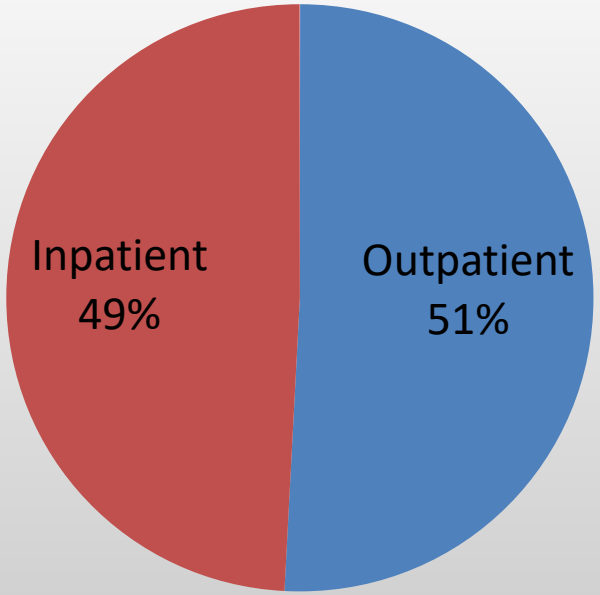
- $3.5 trillion annually (2017)
- 17.9% gross domestic product
- Utilization to cost ratios



MAYO CLINIC

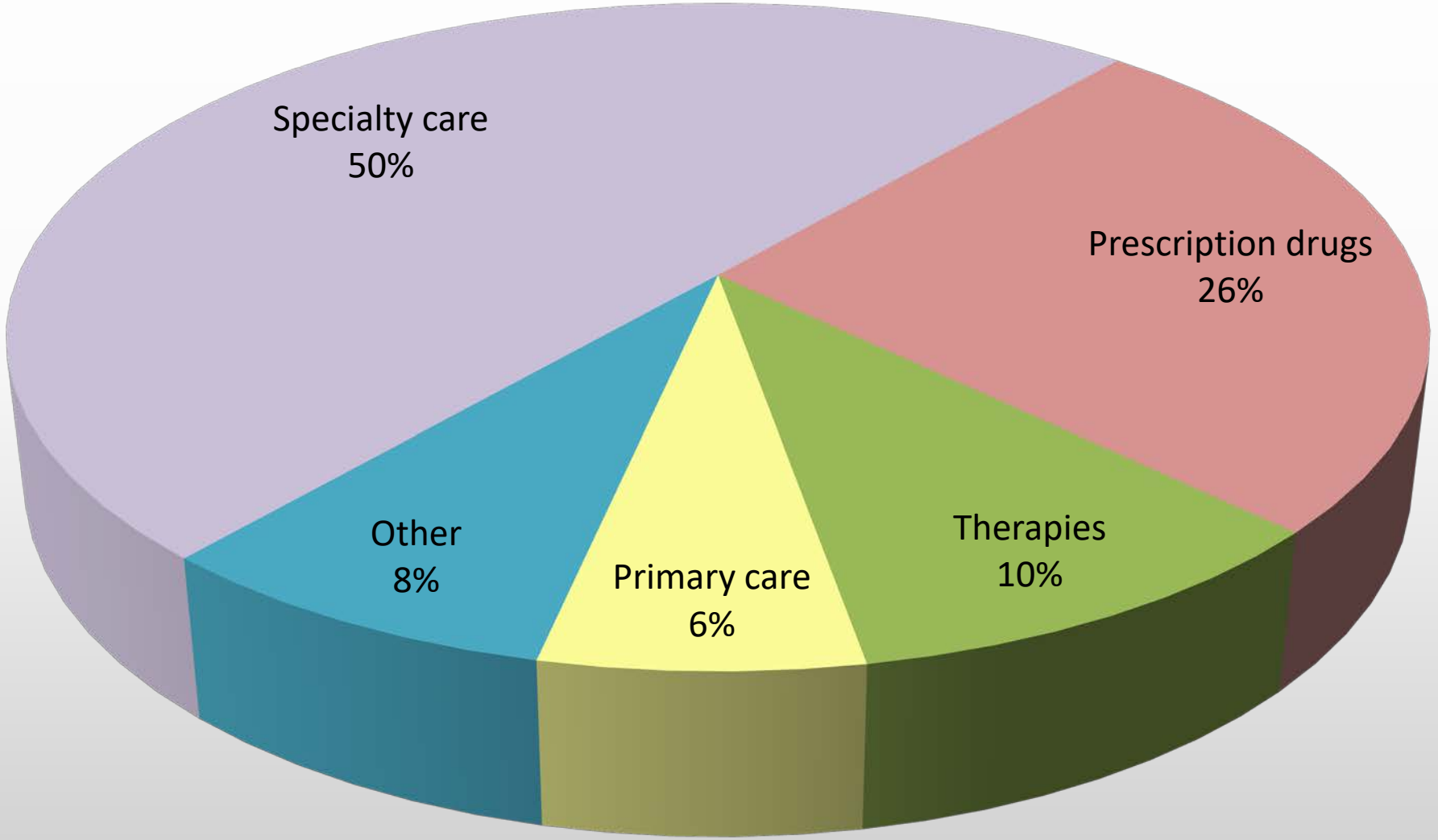
Financial impact of pediatric healthcare

- Children accounted for 8.4% of total US healthcare spending which was approximately $300 billion dollars (2016)
- Children with medical complexity (CMC)
  - Account for 15–33 % of all pediatric healthcare costs ($50–$110 billion/year)
  - Comprise 0.4 to 0.7 % of all US children (320,000–560,000 children)
  - Breakdown of cost based on delivery location:



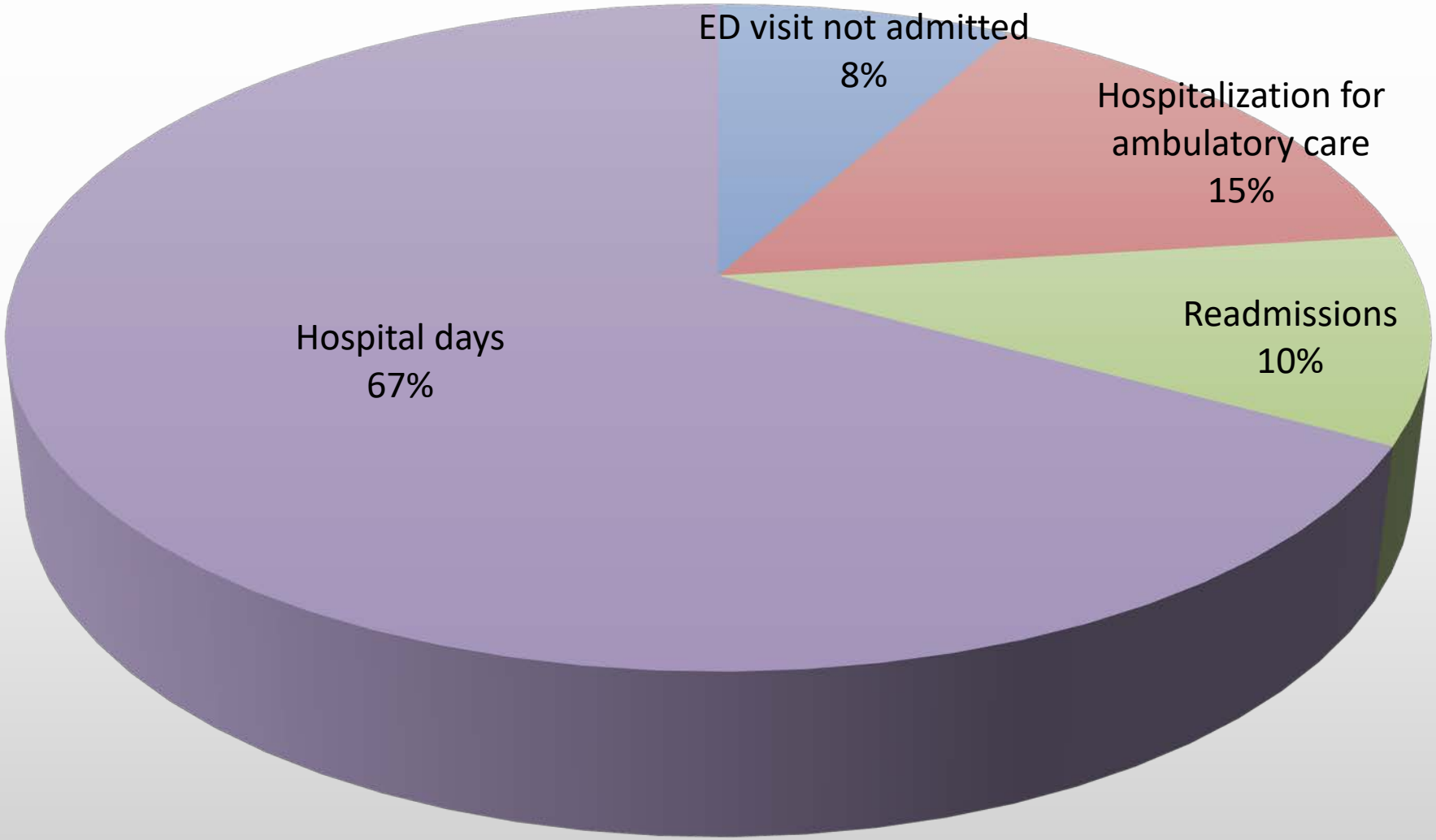
MAYO CLINIC

Pediatric CMC: Out-of-hospital expenditure



MAYO CLINIC

Pediatric CMC: Hospital based expenditure



MAYO CLINIC

Complex Care: Payment models

- Fee for service
  - Lack of transparency
  - Not structured to incentivize medical neighborhood approach
  - Limited (but evolving) reimbursement for care coordination activities
- Incentive based models
  - Accountable Care Organizations (ACO)
    - Population health management
    - Varied payment strategies (shared savings)
  - Pay for performance (P4P)
    - Financial risk-sharing
    - Supports care coordination with primary care
  - Bundled payments
    - Clinical episodes of care

MAYO CLINIC

CMC: Child impacts

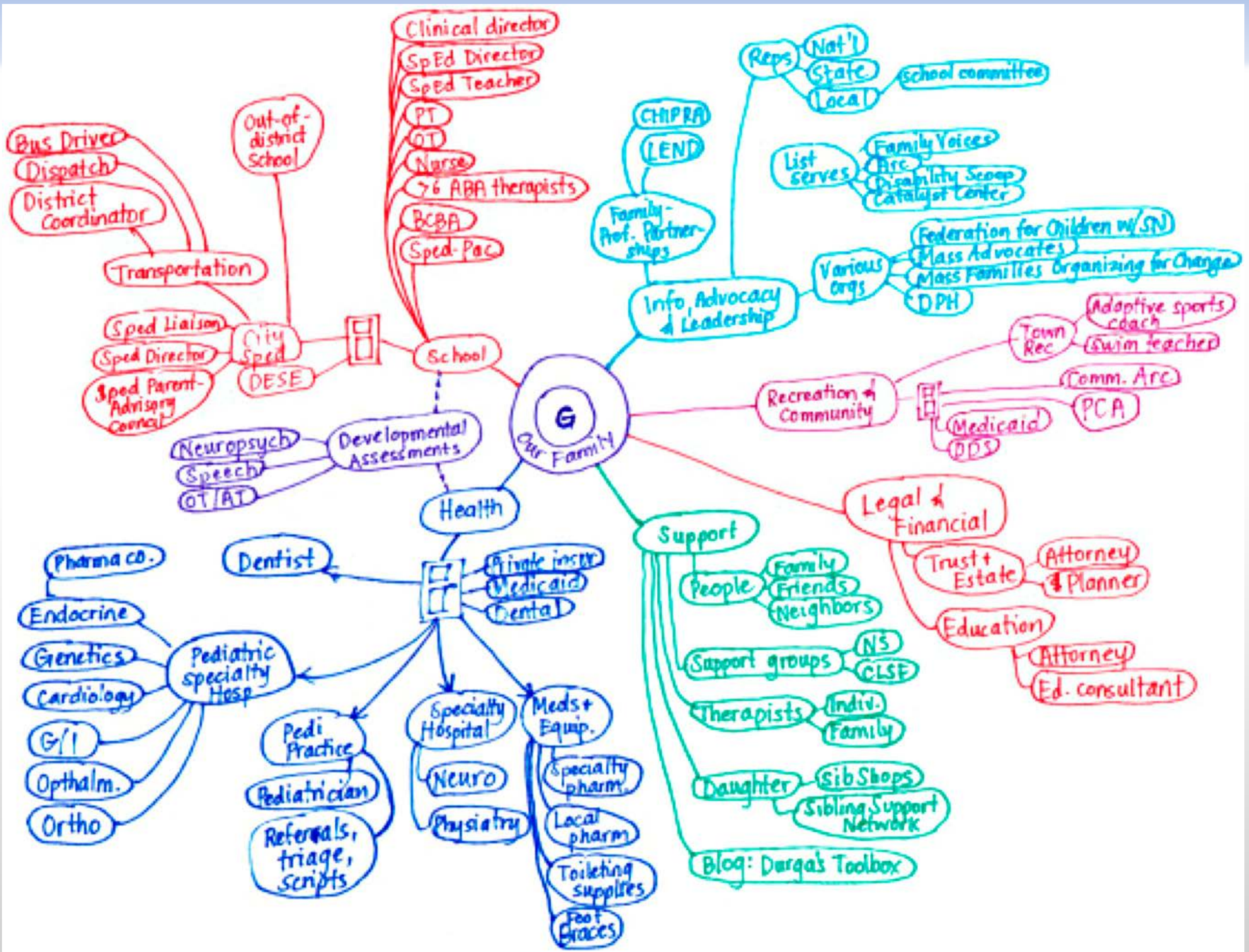
- Estimated that >50% have at least one unmet need
- Functional limitations
- Technology dependent or assisted
- Psychological stress
- Behavioral problems

MAYO CLINIC

CMC: Caregiver and family impacts

- Burden of serving as medical manager and health systems navigator
  - Act as care coordinator
  - Provide direct patient care
- Impact on work and financial health
  - 54% of CMC families report quitting work because of their child's issues
  - 57% report financial problems
- Increased risk of caregiver physical and mental health issues
  - Anxiety, depression, fatigue, headaches

MAYO CLINIC



Care map created by the mother of a child with medical complexity

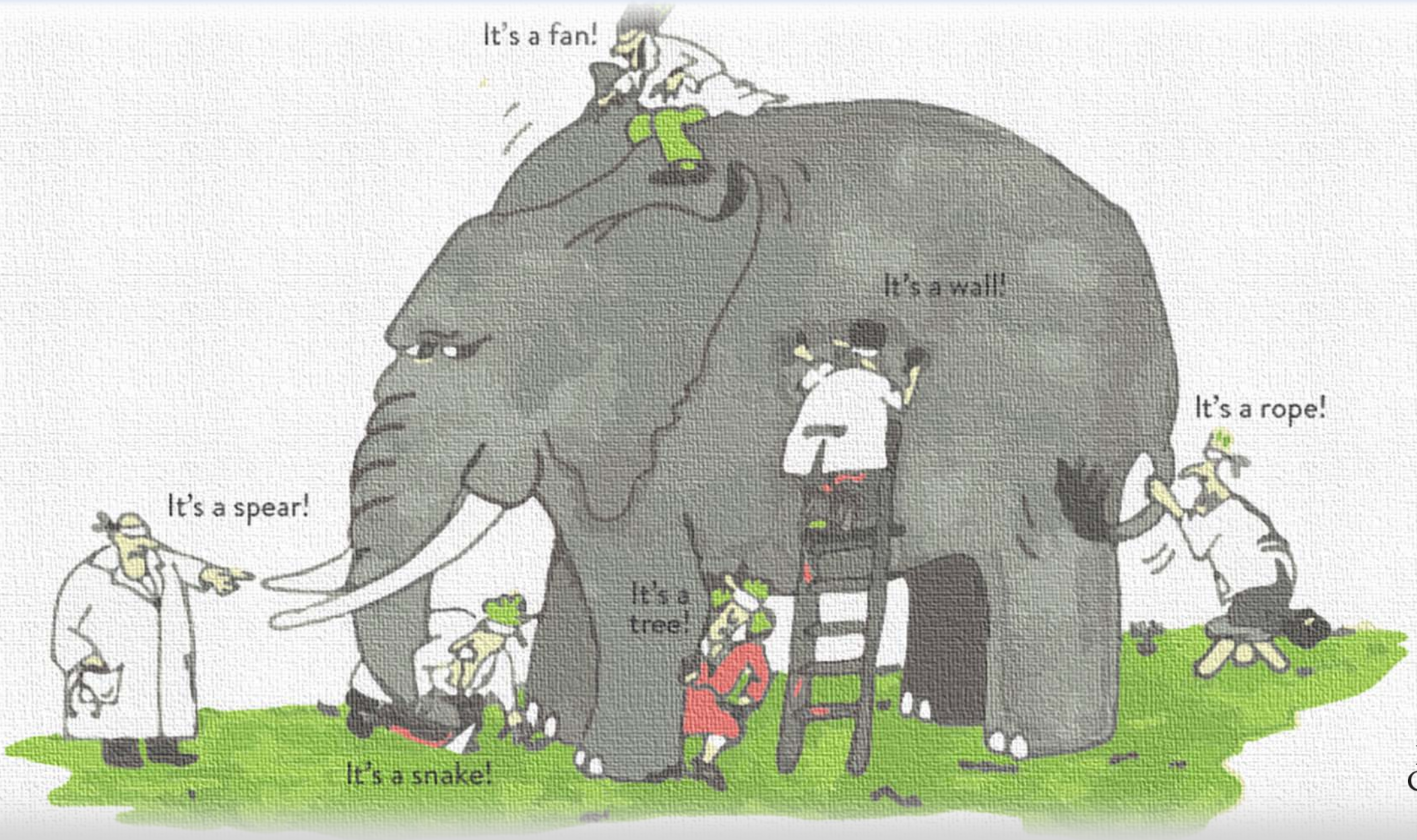
Kuo DZ, Houtrow AJ, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Recognition and Management of Medical Complexity. *Pediatrics.* 2016;138(6):e20163021

MAYO CLINIC

Complex Care: System impacts

- Primary care providers (PCP)
  - Maintaining expertise in “rare” conditions difficult
  - Often limited support staff such as RN care coordinators (RNCC) or ancillary staff to assist with care coordination
  - High non-visit care burden (less reimbursement)
  - Patients often miss routine visits
- Specialty providers
  - Shortages (particularly in pediatrics)
  - Often geographically distant from patient
  - High “burnout”
  - Can lack “whole person” view

MAYO CLINIC



MAYO CLINIC

Complex care: Management goals

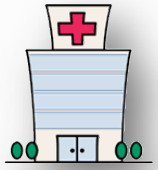
- Effective
  - Accurate diagnoses
  - Optimal medical management
  - Improved quality of life
- Coordinated
  - Appointments, procedures, and surgeries
  - Seamless communication between care providers and with child/family
  - Unified care plans
- Efficient
  - Reduce delays and travel needs
  - Avoid duplicative or unnecessary services

MAYO CLINIC

MAYO CLINIC

CMC: Management models

1. Community based medical home



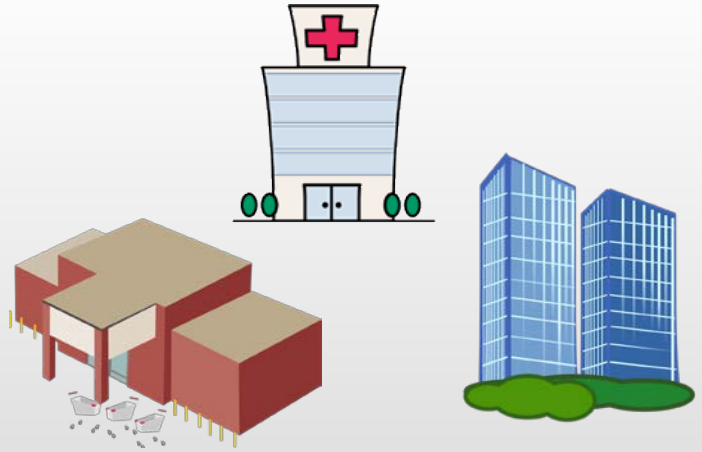
2. Hospital based complex care medical home (“enhanced primary care”)

3. Coordinated specialty care with primary care co-management

MAYO CLINIC

CMC: Management models

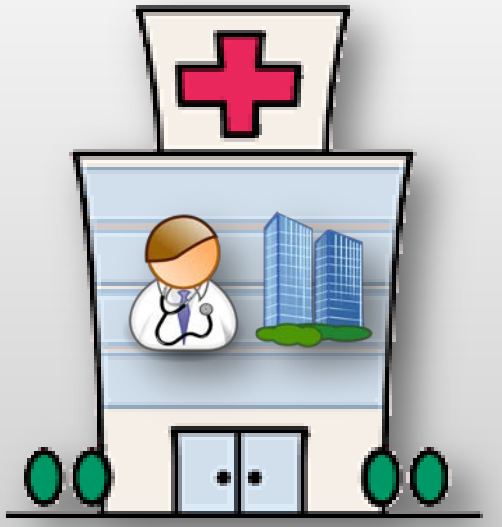
1. Community based medical home
   - Pros: Location, sibling/family care, community services connections, whole person view
   - Cons: PCP-specialist-hospital silos, infrastructure gaps



MAYO CLINIC

CMC: Management models

2. Hospital based complex care medical home ("enhanced primary care")
   - Pros: single site, experience, shared infrastructure
   - Cons: geography, may lack access for sibling/family care, high physician burnout and turnover, reimbursement disadvantage



MAYO CLINIC

CMC: Management models

3. Coordinated specialty care with primary care co-management
   - Pros: local connection, expertise of both primary care and specialty care, cohesive specialty view
   - Cons: infrastructure gaps, relies on active rather than passive team communication, navigating who does what

MAYO CLINIC

Effect of Hospital-Based Comprehensive Care Clinic on Health Costs for Medicaid-Insured Medically Complex Children

Arch Pediatr Adolesc Med. 2011;165(5):392-398.

Patrick H. Casey, MD; Robert E. Lyle, MD; Tommy M. Bird, MS; James M. Robbins, PhD; Dennis Z. Kuo, MD, MHS; Carrie Brown, MD; Arti Lal, MD; Aline Tanios, MD; Katherine Burns, MD

- Decreased chance of hospitalization: 7.4% vs 9.7%
- Decreased mean length of stay: 10.0 vs 14.5 days
- Decreased total costs to system
  - Mean annual cost decreased by $1766 for inpatient care
  - Claims and prescriptions increased, but overall costs for outpatient decreased by $1179.

MAYO CLINIC

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Effectiveness of a Comprehensive Case Management Service for Children With Medical Complexity

Tamara D. Simon, Kathryn B. Whitlock, Wren Haaland, Davene R. Wright, Chuan Zhou, John Neff, Waylon Howard, Brian Cartin, Rita Mangione-Smith

December 2017, VOLUME 140 / ISSUE 6
Article

- Randomized controlled trial access to a **hospital-based comprehensive** service
- No significant difference in hospital based utilization, including ED visits, hospital admissions, total hospital days, average LOS, and ICU admissions
- Some cost driven up due to increased access to care

MAYO CLINIC

Variable outcomes with CMC models

Communit

- Decreas
  work da
- Decreas
  baselin

Palfrey J, Sofi
Ganz, M. The
care: Evaluat
Pediatrics. 20

Communit

- Fewer E
  in PCM
- Costs fo
  were lo
  PCMH p
  adjuste

DeVries A, Li C
Barron J. Impa
healthcare ut
Journal of Ma

Coordinated s
medical home

- Increase in
  due to rec
  Mean PMP
  $1,429 to
- ER costs w

Cohen E, Lacomb
Integrated compl
with medical com
evaluation of tert
collaboration. BM
2012;12

Coordinated specialty care with PCP medical home

- Decreased total hospital and clinic costs ($16, 523 vs $26,781 per child per year).
- Reduced ED visits, hospitalizations, LOS and ICU admission

Mosquera R, Avritscher E, Samuels S, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: A randomized clinical trial. JAMA. 2014;312(4): 2640-2648.

MAYO CLINIC

$$Value = \frac{Quality}{Cost}$$

MAYO CLINIC

CMC: Quality measures

- Structural measures
- Process measures
- Outcome measures
- Patient experience measures

CMC: Quality measures

- Difficult to apply to heterogeneous population
- Lack of clinical practice guidelines specific to complex care
- Twenty developed by Pediatric Quality Measures Program COE
  - Eight have been endorsed by the National Quality Forum
    - Patient/family experience measures (survey)

MAYO CLINIC

Mayo Clinic Children's Center

- Children's Hospital
  - 148 pediatric beds
  - General and intensive care, psychiatry, nursery/neonatal, cardiovascular intervention, infusion therapy, surgical, rehabilitation and epilepsy monitoring areas
- Primary care
  - Rochester 37,000 paneled patients
- Pediatric Outpatient Specialty Clinics
  - 200+ medical providers
  - Over 40 specialties and multi-specialty clinics co-located
  - 50,000+ visits annually

Mayo model: Fundamentals

- Mission statement
  - Inspire hope and contribute to health and well-being by providing the best care to every patient through integrated clinical practice, education and research.
- Primary value
  - The needs of the patient comes first

    "The best interest of the patient is the only interest to be considered."

    William Mayo, MD
- Culture of collaboration
  - "Grew up in middle of a corn field"
  - Non-profit organization

MAYO CLINIC

Mayo model: How does it work for CMCs?

- Core elements
  - Centralization of care
    - General pediatric provider "Quarterback" model
  - Breadth and depth of expertise
    - "Deep bench"
  - Child and family centric
    - Creating the experience

MAYO CLINIC

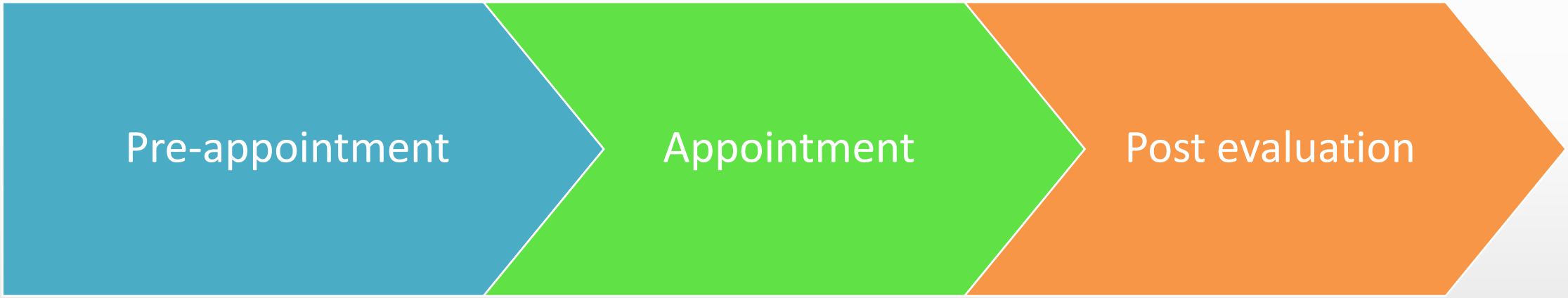
Mayo model: CMC patient care

- Local and regional CMC patients
  - **Primary care medical home model**
  - Paneled in complex care continuity clinic
  - Provider-RN care coordinator dyad
  - Carry a panel of around 110-120 established patients

- Destination CMC patients (1200 new patients annually)
  - Majority will evaluated through Pediatric Diagnostic and Referral clinic
  - Self referred (54%)
  - Provider referral (46%)
  - Children seen from all 50 states and 61 countries
  - Small percent become established continuity patients (275 patients paneled)
    - **Coordinated specialty with PCP co-management model**

MAYO CLINIC

Mayo model: Passport for destination CMC



MAYO CLINIC

Mayo model: Pre-appointment process team

- Scheduling team completes pre-visit questionnaires
  - Family defined goals of the evaluation
- Provider reviews request
  - Determines if more information is needed from
    - Records review
      - Leverage capabilities of the EMR
      - Try to reduce burden to families to get records when possible
    - Nursing phone call intakes
  - Calls to referring provider when needed
  - Places consult and testing requests to generate a tentative schedule
- Pediatric specific scheduler
  - Works directly with family to understand scheduling needs
  - Aware of sequencing of appointments
  - Coordination of anesthesia

MAYO CLINIC

Mayo model: Pre-appointment process team

- Scheduling team completes pre… …naires
  - Family defined goals of …
- Provider reviews reque…
  - Determines if more info…
    - Records review
      - Leverage capabiliti…
      - Try to reduce bur…
    - Nursing phone call …
  - Calls to referring pr…
  - Places consult and test… …schedule
- Pediatric specific schedule…
  - Works directly with family to… …eeds
  - Aware of sequencing of appoi…
  - Coordination of anesthesia

Targeted goals
Improved communication
Shared decision making
Efficiency
Decreased duplication

MAYO CLINIC

Mayo model: Appointment process team

- Initial patient visit with the diagnostic pediatrician
  - Generalist team as the “quarterbacks “
  - Child and family goals
  - Comprehensive history and physical
  - Assessments and shared decision making on finalization of plan
  - Facilitates getting any other info needed before consults
  - Timely documentation in shared records so patient doesn’t have to repeat over-over
- Desk schedulers finalize schedule and coordinate any additional orders
  - System supports to complete itineraries
- Provider connects with consulting specialists throughout the patient's journey

MAYO CLINIC

Mayo model: Appointment process team

- Initial patient visit with the di… …ician
  - Generalist team as the …
  - Child and family goals
  - Comprehensive history …
  - Assessments and share… …plan
  - Facilitates getting any…
  - Timely documentati… …ve to repeat over-over
- Desk schedulers finalize… …y additional orders
  - System supports to complet…
- Provider connects with cons… …oughout the patient's journey

Targeted goals
Improved communication
Shared decision making
Efficiency
Simplification
Decreased duplication
Coordination

MAYO CLINIC

Mayo model: Post evaluation process team

- Wrap up care
  - Last appointment is with the generalist “quarterback”
  - Jointly review to make sure goals were met
  - Re-cap individual specialty recommendations
  - Provide copies of testing to date and review the results
  - Discuss recommendations and use shared decision making between child/family and provider to finalize a unified “next step” care plan
  - Determine who needs to receive the records and updated care plan
    - Primary care provider (PCP)
    - Local specialty team
    - School or other care facility
  - If substantial care plan change “quarterback” will contact the PCP/referrer directly

MAYO CLINIC

Mayo model: Post evaluation process team

- Wrap up care
  - Last appointment is wit
  - Jointly review to make s
  - Re-cap individual specia
  - Provide copies of testi
  - Discuss recommenda etween child/family and provider to finalize a
  - Determine who needs are plan
    - Primary care provider (P
    - Local specialty team
    - School or other care facility
  - If substantial care plan change quarterback" wi ontact the PCP/referrer directly

Targeted goals
Improved communication
Shared decision making
Coordination
Closed loop
Decreased duplication
Shared mental model

MAYO CLINIC

Mayo model: Outcomes for complex patients

- Van Such M, Lohr R, Beckman T, Naessens JM. Extent of diagnostic agreement among medical referrals. J Eval Clin Pract. 2017 Aug;23(4):870-874.
  - 88% of those seen went home with new or refined diagnosis
    - 21% diagnosis completely changed
    - 66% received a refined or redefined diagnosis
  - Only 12% received confirmation that the original diagnosis was correct
- Mayo data (not yet published)
  - 55% referred for cancer care had change to treatment plan
  - 53% of patients referred for spine surgery were found not to need surgery
  - Pediatric complex referrals
    - Over 65% had diagnosis change or modification
    - Only 9% did not have any change to their care plan recommendations

MAYO CLINIC

The team “matrix”

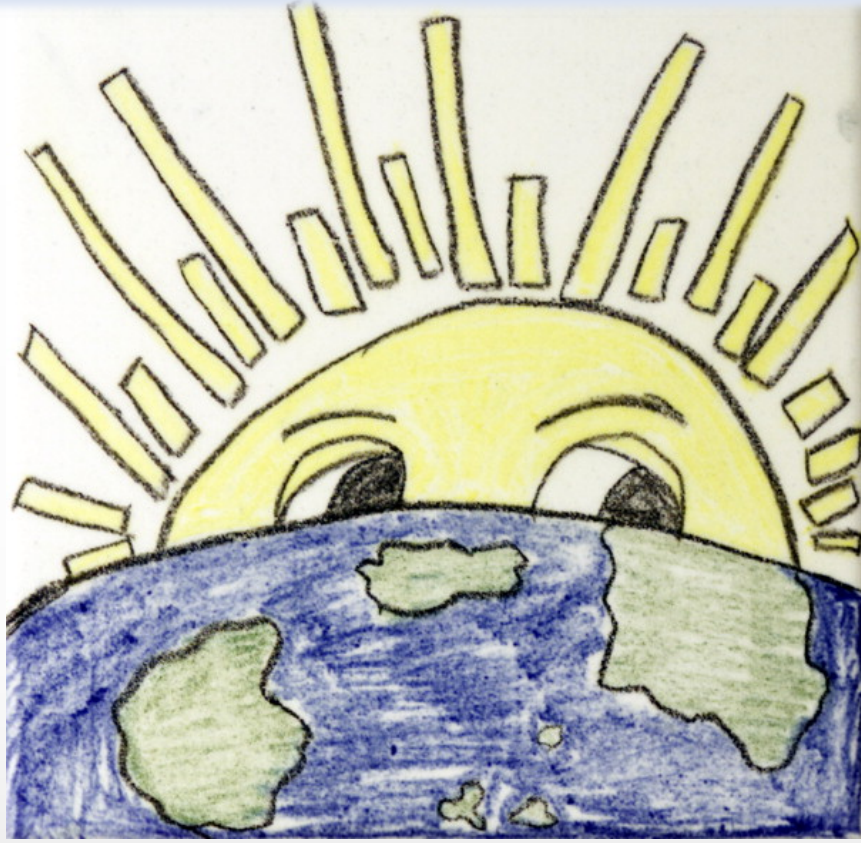
- Facilities
- Laboratory
- Radiology
- Anesthesia
- Child life
- Therapeutic services
- Nutrition
- Pharmacy
- Palliative care
- Child advocacy/abuse team
- Social work

Medical neighborhood model

Institute for healthcare improvement

What does the future hold

- Seamless electronic health records across all sites of care
- Integrated data systems (cloud based/blockchain technology)
  - To allow cross over medical databases with other predictors of health
    - Parent missed work days
    - Parental health status
    - Child missed school
- Artificial intelligence to survey/mine data
- Technology to support access to care
  - Simplicity in scheduling
  - Push outs for reminders of care needs
  - Telehealth
  - Improved social determinants responsiveness (language/health literacy)
- Self assessment
- Move from population to precision medicine
- Advancement of diagnostic and therapeutic interventions



MAYO CLINIC

References

1. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. Pediatrics. 1998 Jul;102(1 Pt 1):137-40.

2. Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. An epidemiologic profile of children with special health care needs. Pediatrics. 1998 Jul;102(1 Pt 1):117-23.

3. Stein RE, Silver EJ. Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. Arch Pediatr Adolesc Med. 1999 Jan;153(1):68-74

4. Carolyn Allshouse, Meg Comeau, Rylin Rodgers and Nora Wells Families of Children with Medical Complexity: A vie From the Front Lines; Pediatrics 2018; 141; S195

5. Berry JG, Hall M. Neff J. et al. Children with medical complexity and Medicaid: spending and cost savings. Health Aff (Miliwood). 2014; 33 (12): 2199-2206.

6. Mayer ML, Skinner AC, Slifkin RT: National Survey of Children With Special Health Care Needs. Unmet need for routine and specialty care: Data from the National Survey of Children with Special Health Care Needs. Pediatrics: 2004; 113(2).

7. America's Children: Health Insurance and Access to Care.National Research Council (US) and Institute of Medicine (US) Committee on Children, Health Insurance, and Access to Care; Edmunds M, Coye MJ, editors. Washington (DC): National Academies Press (US); 1998.

8. Thyen U, Kuhlthau K, Perrin JM. Employment, child care, and mental health of mothers carng for children assisted by technology. Pediatrics, 199 Jun; 103 (6 Pt 1): 1235-42.

9. Kuo DZ, Cohen E. Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. Arch Pediatr Adolesc Med.

10. Kuo DZ, Houtrow AJ, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Recognition and Management of Medical Complexity. Pediatrics. 2016;138(6):e20163021

11. National Quality Forum. Pediatric Measures. Final report, June 15, 2016. Washington, DC: National Quality Forum; 2016.

12. Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambulatory Pediatr. 2003; 3 (6): 329-341

MAYO CLINIC

References

12. Stein REK, Jessop DJ. Functional status II(R). A measure of child health status. Med Care. 1990; 28 (11): 1041-1055.

13. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. Arch Pediatr Adolesc Med. 2007;161(10):937–944

14. Hochman M, Asch SM. Disruptive models in primary care: caring for high-needs, high-cost populations. J Gen Intern Med. 2017;32(4):392-397.

15. Sia C, Tonniges TF, Osterhus E., Taba S. History of the medical home concept Pediatrics: 2004; 113 (suppl 5): 1473-1478

16. Mosquera R, Avritscher E, Samuels S, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: A randomized clinical trial. JAMA. 2014;312(4): 2640-2648.

17. DeVries A, Li C, Sridhar G, Hummel J, Bredbart S, Barron J. Impact of medical homes On quality, healthcare utilization, and costs. The American Journal of Managed Care. 2012;18(9):534-544.

18. Cohen E, Lacombe-Duncan A, Spalding K, et al. Integrated complex care coordination for children with medical complexity: A mixed-methods evaluation of tertiary care-community collaboration. BMC Health Services Research. 2012;12:366

19. Palfrey J, Sofis L, Davidson E, Liu J, Freeman L, Ganz, M. The pediatric alliance for coordinated care: Evaluation of a medical home model. Pediatrics. 2004;113(5 Suppl): 1507-1516

20. Van Such M, Lohr R, Beckman T, Naessens JM. Extent of diagnostic agreement among medical referrals. J Eval Clin Pract. 2017 Aug;23(4):870-874

21. Taylor EF, Lake T, Nysenbaum J, Peterson G, Meyers D. Coordinating care in the medical neighborhood: critical components and available mechanisms. White Paper (Prepared by Mathematica Policy Research under Contract No. HHSA290200900019I TO2). AHRQ Publication No. 11-0064. Rockville, MD: Agency for Healthcare Research and Quality. June 2011

MAYO CLINIC

Thank you

MAYO CLINIC