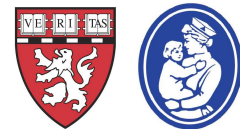


Addressing the Needs of Children with Complex Chronic Pathology

Jay G. Berry, M.D., M.P.H.

Division of General Pediatrics | Complex Care Service
Boston Children's Hospital | Harvard Medical School



Thank you!!!

I'm sorry!!!

Request!!!

Goals of This Discussion

Convey U.S. experiences of caring for children with medical complexity

- 1. Epidemiology and impact**
- 2. Quality of care**
- 3. Views on society and health**
- 4. Clinical innovations and policy**

Child with Medical Complexity

Clinical Case

14 year old with cerebral palsy

Child with Medical Complexity

Clinical Case

14 year old with cerebral palsy, shunted hydrocephalus, neurogenic bladder, scoliosis, hip dysplasia, asthma, GERD, epilepsy, intermittent diabetes insipidus, and osteopenia

Child with Medical Complexity

Clinical Case

14 year old with cerebral palsy, shunted hydrocephalus, neurogenic bladder, scoliosis, hip dysplasia, asthma, GERD, epilepsy, intermittent diabetes insipidus, and osteopenia; who relies on gastrostomy, orthotics, cathing supplies, and an augmentative communication device

Child with Medical Complexity

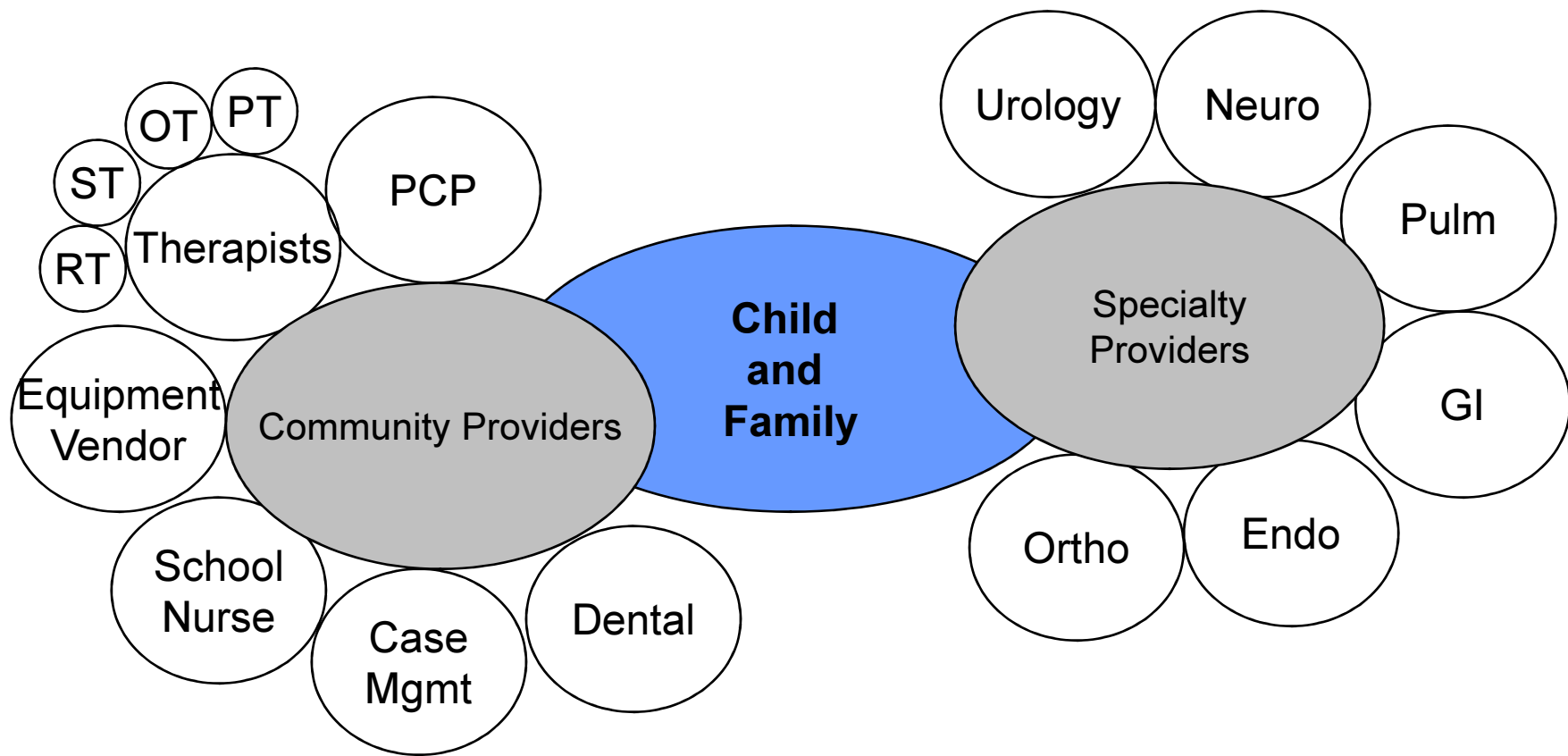
Clinical Case

14 year old with cerebral palsy, shunted hydrocephalus, neurogenic bladder, scoliosis, hip dysplasia, asthma, GERD, epilepsy, intermittent diabetes insipidus, and osteopenia; who relies on gastrostomy, orthotics, cathing supplies, and an augmentative communication device; with parents who have on-going financial and home caregiving struggles.

Child with Medical Complexity

Clinical Case

Health care team of the child with cerebral palsy:



Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
----------------	---

Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
Chronic medications	8

Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
Chronic medications	8
Surgeries	10

Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
Chronic medications	8
Surgeries	10
Acute hospitalizations	15

Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
Chronic medications	8
Surgeries	10
Acute hospitalizations	15
Emergency department visits	45

Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
Chronic medications	8
Surgeries	10
Acute hospitalizations	15
Emergency department visits	45
Outpatient clinic visits	150

Child with Medical Complexity

Clinical Case

Health services use of the child with cerebral palsy:

Health Service	N
Chronic medications	8
Surgeries	10
Acute hospitalizations	15
Emergency department visits	45
Outpatient clinic visits	150
Telephone calls to the clinics	600

Children with Medical Complexity

Clinical Attributes

- Chronic health problems
 - Lifelong, incurable
 - Affect multiple systems
 - Impair functioning
- Intense healthcare needs
 - Multiple medications
 - Indwelling medical devices
 - Recurrent health services



Chronic Conditions

Children with Medical Complexity

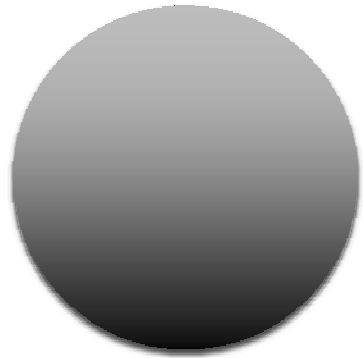
- Cerebral palsy spastic quadriplegia
- Complex congenital heart disease
- Cystic fibrosis
- Diabetes mellitus
- Glutaric acidemia
- Inflammatory bowel disease
- Multiple congenital anomalies
- Nephrotic syndrome
- Schizophrenia
- Sickle cell anemia
- Spina bifida...

Epidemiology and Health Services Impact

Children with Medical Complexity

Epidemiology and Health Services Impact

Children with Medical Complexity

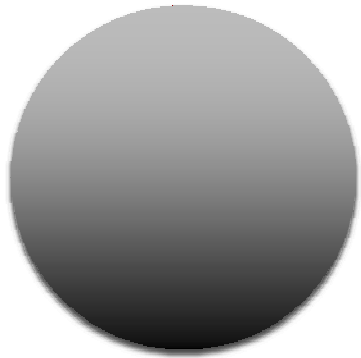


<1%
of all
children¹

¹Kuo *Arch Ped Adol Med* (2011)

Epidemiology and Health Services Impact

Children with Medical Complexity

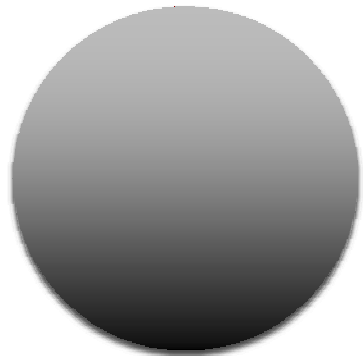


<1% —————> **~500,000 US children**
of all
children¹

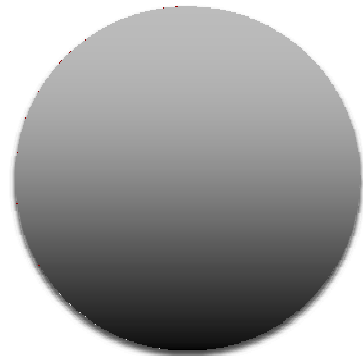
¹Kuo *Arch Ped Adol Med* (2011)

Epidemiology and Health Services Impact

Children with Medical Complexity



<1%
of all
children¹

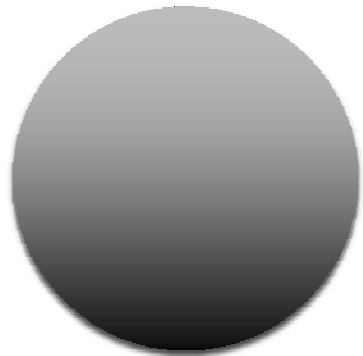


30%
of all
pediatric
healthcare
costs²

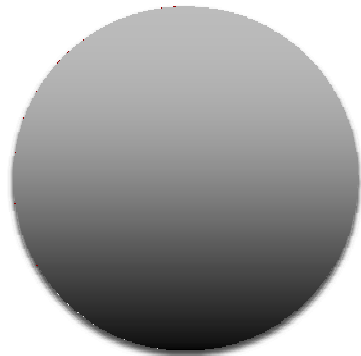
¹Kuo *Arch Ped Adol Med* (2011), ²Cohen *Pediatrics* (2012)

Epidemiology and Health Services Impact

Children with Medical Complexity



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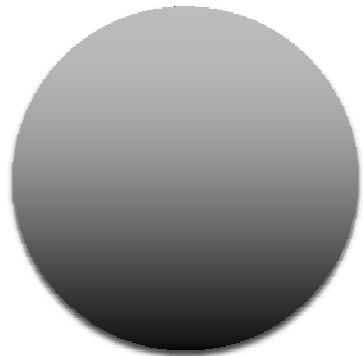
~\$100 billion (annually)*

¹Kuo *Arch Ped Adol Med* (2011), ²Cohen *Pediatrics* (2012)

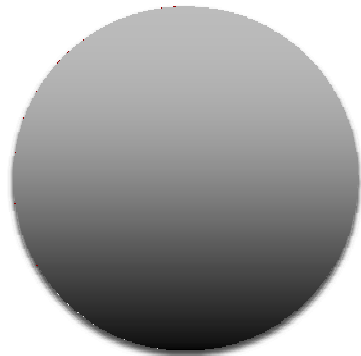
*Berry *Health Affairs* (2014)

Epidemiology and Health Services Impact

Children with Medical Complexity



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children¹



30% —————>
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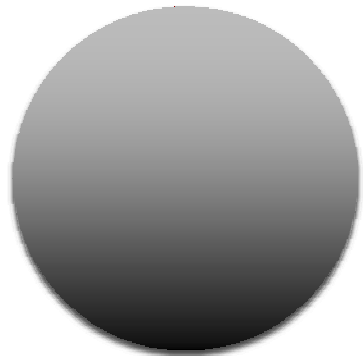
~\$100 billion (annually)*
1% home care

¹Kuo *Arch Ped Adol Med* (2011), ²Cohen *Pediatrics* (2012)

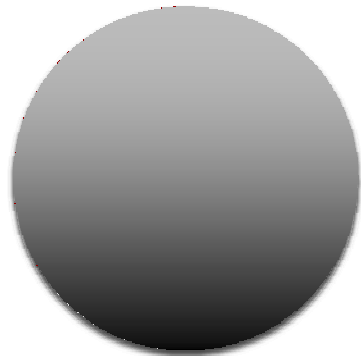
*Berry *Health Affairs* (2014)

Epidemiology and Health Services Impact

Children with Medical Complexity



<1%
of all
children¹



30% —————>
of all
pediatric
healthcare
costs²

~\$100 billion (annually)*

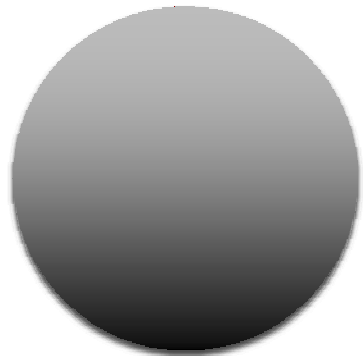
1% home care
2% primary care

¹Kuo Arch Ped Adol Med (2011), ²Cohen Pediatrics (2012)

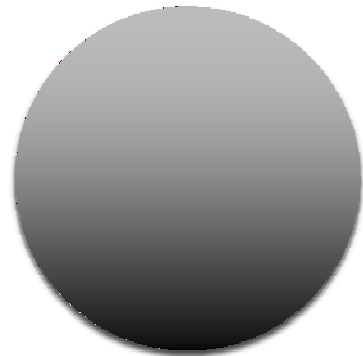
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30% —————>
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costs²

~\$100 billion (annually)*

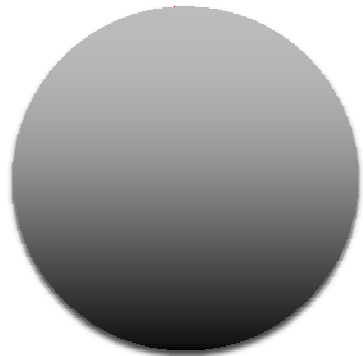
1% home care
2% primary care
3% emergency care

¹Kuo Arch Ped Adol Med (2011), ²Cohen Pediatrics (2012)

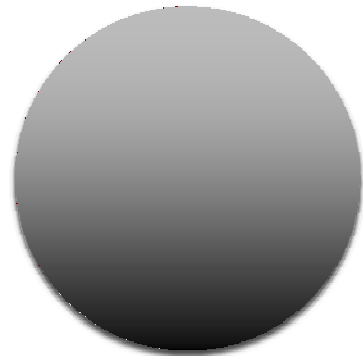
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Epidemiology and Health Services Impact

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~\$100 billion (annually)*

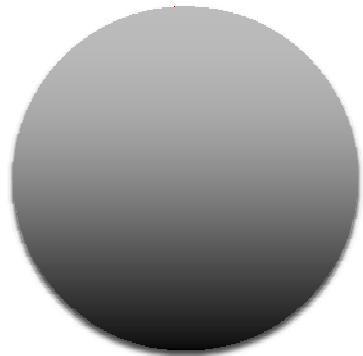
1% home care
2% primary care
3% emergency care
13% pharmacy care

¹Kuo *Arch Ped Adol Med* (2011), ²Cohen *Pediatrics* (2012)

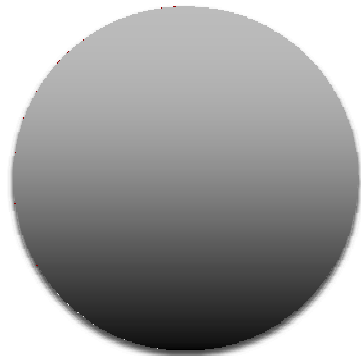
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Epidemiology and Health Services Impact

Children with Medical Complexity



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~\$100 billion (annually)*

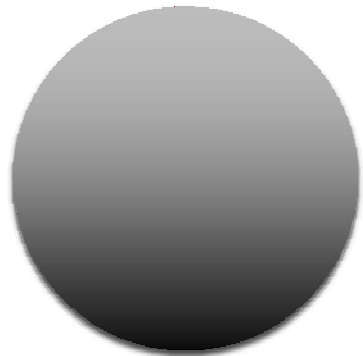
1% home care
2% primary care
3% emergency care
13% pharmacy care
25% specialty care

¹Kuo Arch Ped Adol Med (2011), ²Cohen Pediatrics (2012)

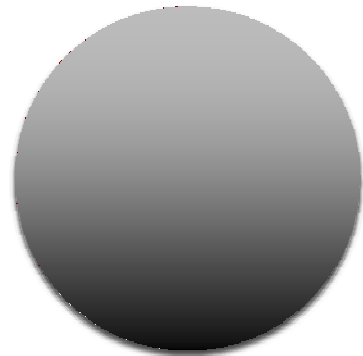
*Berry Health Affairs (2014)

Epidemiology and Health Services Impact

Children with Medical Complexity



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30% —————>
of all
pediatric
healthcare
costs²

~\$100 billion (annually)*

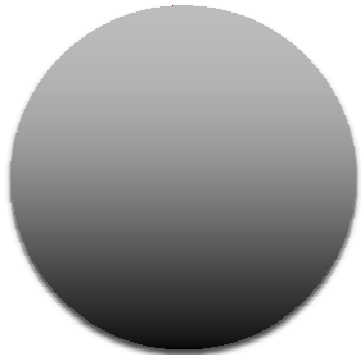
1% home care
2% primary care
3% emergency care
13% pharmacy care
25% specialty care
47% hospital care

¹Kuo Arch Ped Adol Med (2011), ²Cohen Pediatrics (2012)

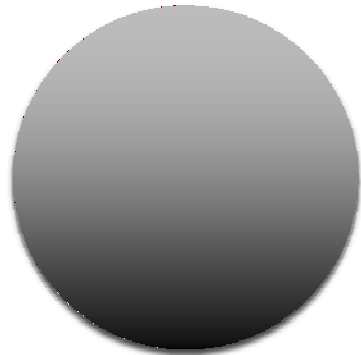
*Berry Health Affairs (2014)

Epidemiology and Health Services Impact

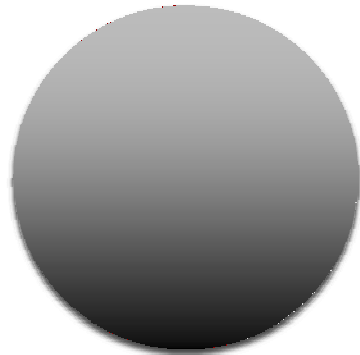
Children with Medical Complexity



<1%
of all
children¹



30%
of all
pediatric
healthcare
costs²



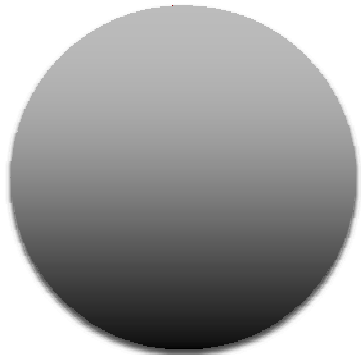
55%
of all
pediatric
inpatient
costs*³

*in children's hospitals

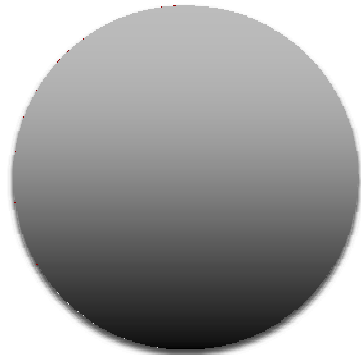
¹Kuo *Arch Ped Adol Med* (2011), ²Cohen *Pediatrics* (2012), ³Berry *JAMA Pediatrics* (2013)

Epidemiology and Health Services Impact

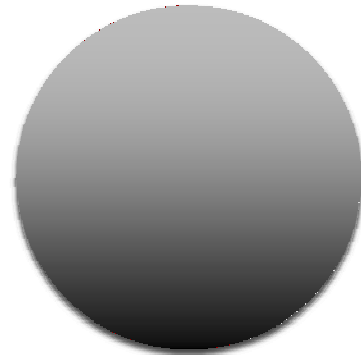
Children with Medical Complexity



<1%
of all
children¹

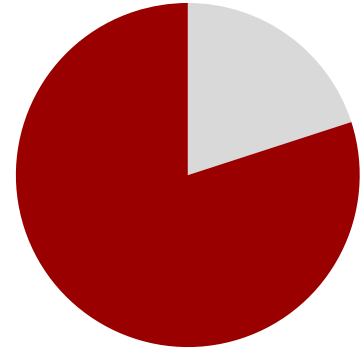


30%
of all
pediatric
healthcare
costs²



55%
of all
pediatric
inpatient
costs*³

*in children's hospitals



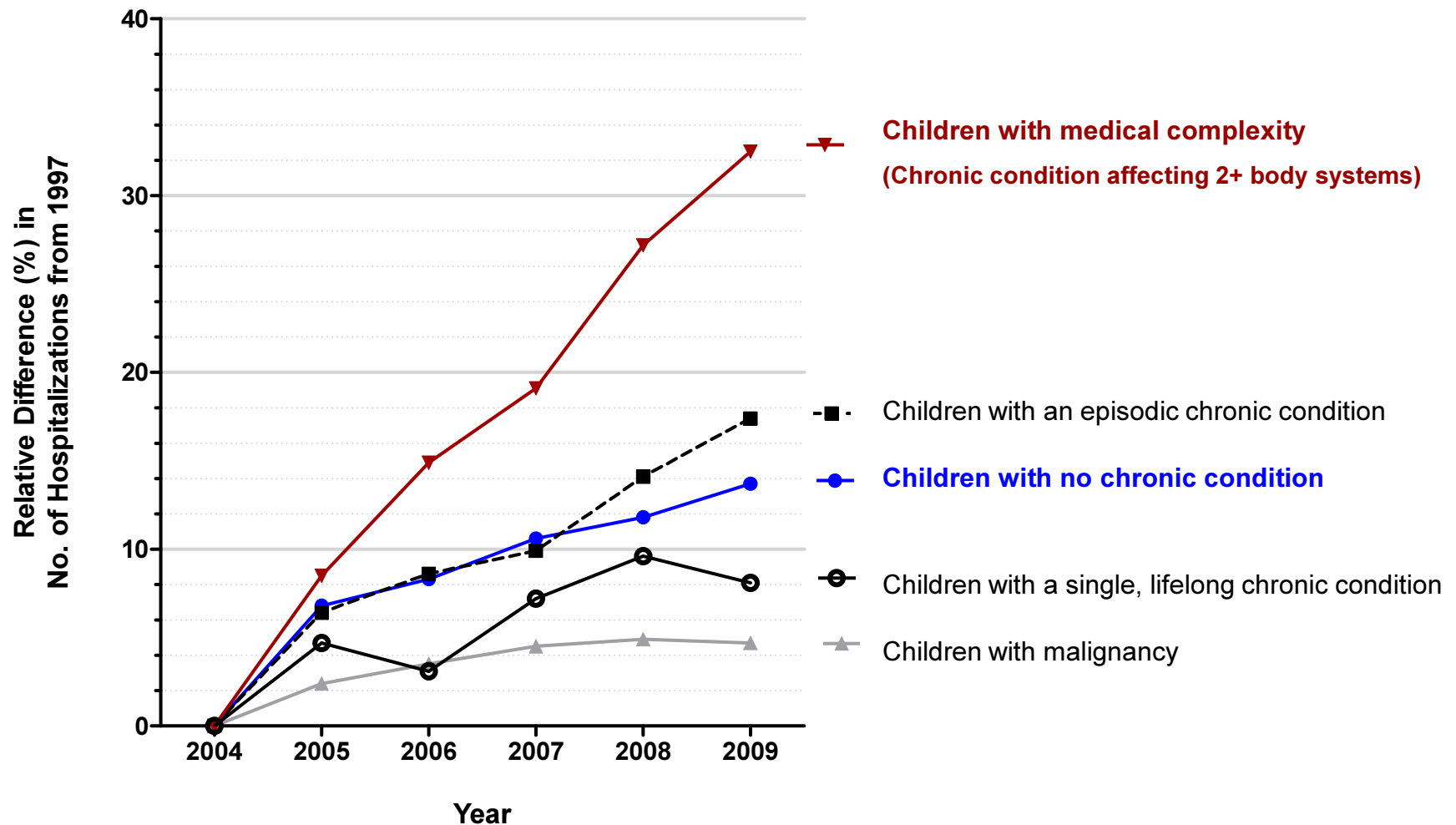
85%
of all
pediatric
30-day
readmission
costs*⁴

*in children's hospitals

¹Kuo *Arch Ped Adol Med* (2011), ²Cohen *Pediatrics* (2012), ³Berry *JAMA Pediatrics* (2013), ⁴Bogetz *Pediatric Clinics North Amer* (2014)

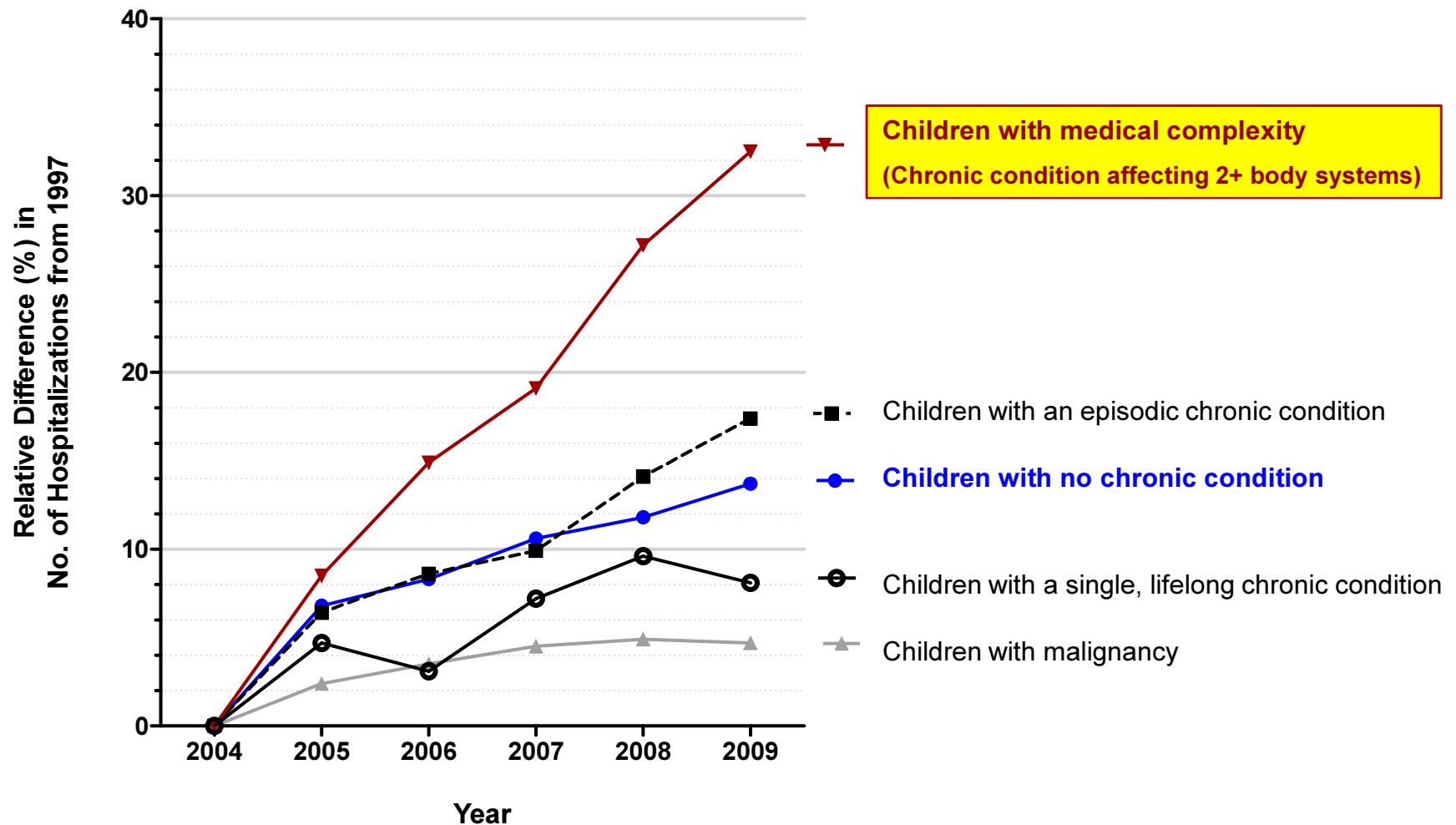
Increasing Number of Hospitalizations

Children with Medical Complexity in Children's Hospitals



Increasing Number of Hospitalizations

Children with Medical Complexity in Children's Hospitals



Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

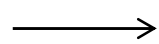
**Recurrent
Hospitalizations**

**Substandard
Outpatient Care**

Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival



Advances in neonatal and surgical care

- VLBW and extremely premature infants
- Infants born with severe, congenital anomalies

More Operations

Many infants who survive go on to develop multiple chronic conditions that increase their likelihood of hospitalization.

**Recurrent
Hospitalizations**

**Substandard
Outpatient Care**

Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

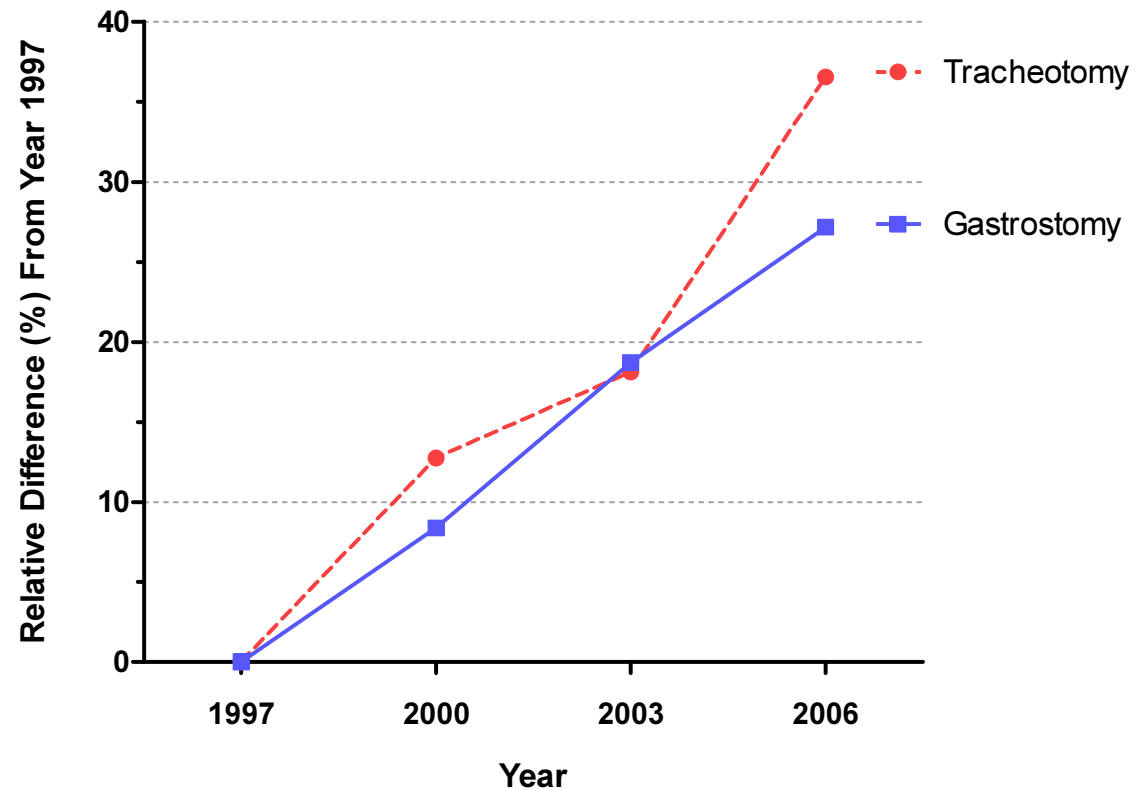
More Operations

Recurrent
Hospitalizations

Substandard
Outpatient Care



Children with Complex Neurologic Conditions



Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

**Recurrent
Hospitalizations**

Substandard
Outpatient Care

Many hospitalized children with medical complexity fail their transition home

```
graph LR; A[More Operations] --- B[Recurrent Hospitalizations]; B --> C[Many hospitalized children with medical complexity fail their transition home];
```

Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

**Recurrent
Hospitalizations**

Substandard
Outpatient Care

Many hospitalized children with medical complexity fail their transition home

- 30-day readmission rates = 20-30%¹

¹Berry *JAMA* (2011), *JAMA* (2013), *BMJ* (2017)

Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

**Recurrent
Hospitalizations**

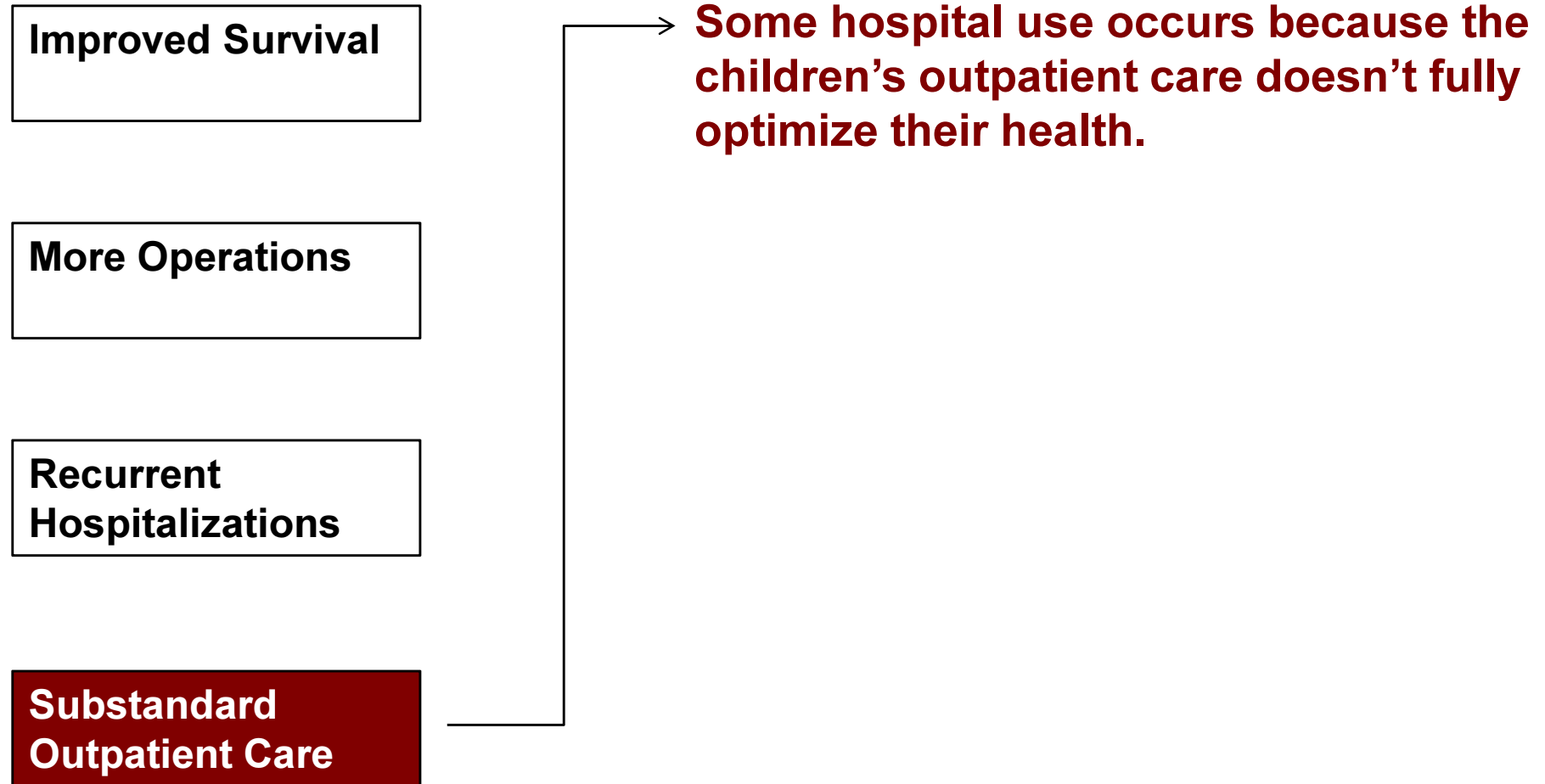
Substandard
Outpatient Care

Many hospitalized children with medical complexity fail their transition home

- 30-day readmission rates = 20-30%¹
- Many children and families are not prepared and ready for discharge²
 - “I felt that my child was not healthy enough to leave the hospital.”
Odds of readmission = 3.4 (95% CI 1.5-7.7)
 - “I did not understand how to manage my child’s health after discharge.”
Odds of readmission = 2.3 (95% CI 1.0-4.9)

Reasons for Increasing Hospital Use

Children with Medical Complexity



Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

Recurrent
Hospitalizations

Substandard
Outpatient Care

→ **Some hospital use occurs because the children's outpatient care doesn't fully optimize their health.**

Chronic conditions are not controlled.

Medical technologies are not monitored.

Acute illnesses are not addressed.

Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

Recurrent
Hospitalizations

Substandard
Outpatient Care

→ **Some hospital use occurs because the children's outpatient care doesn't fully optimize their health.**

40% of children with medical complexity do not have an annual primary care visit¹

44% of children with medical complexity have one or more unmet healthcare needs²

¹Berry et al *Health Affairs* (2014)

²Kuo et al *Health Affairs* (2014)

Reasons for Increasing Hospital Use

Children with Medical Complexity

Improved Survival

More Operations

Recurrent
Hospitalizations

Substandard
Outpatient Care

→ **Some hospital use occurs because the children's outpatient care doesn't fully optimize their health.**

Caregiving burden of families:

- *Many spend 20+ hours per week*
- *Many experience loss of employment, marital discord, and mental/physical health impairments*

Parent Perceptions of Care

Children with Medical Complexity

“The inpatient team doesn’t talk with the outpatient team. No one talks to the doctors who are actually familiar with my child. When you add multiple specialists, you might as well forget it. It finally took me losing it after a medication error (which could have been fatal) to get them all in one room and talking to one another.”

Parent Perceptions of Care

Children with Medical Complexity

“Hours on hold trying to get needed medical supplies, often having to be transferred many times, never able to get a supervisor. When told to call back to ask for the supervisor, the supervisor is not able to be reached and I’m not allowed to leave a voice mail. I have even been hung up on.”

Parent Perceptions of Care

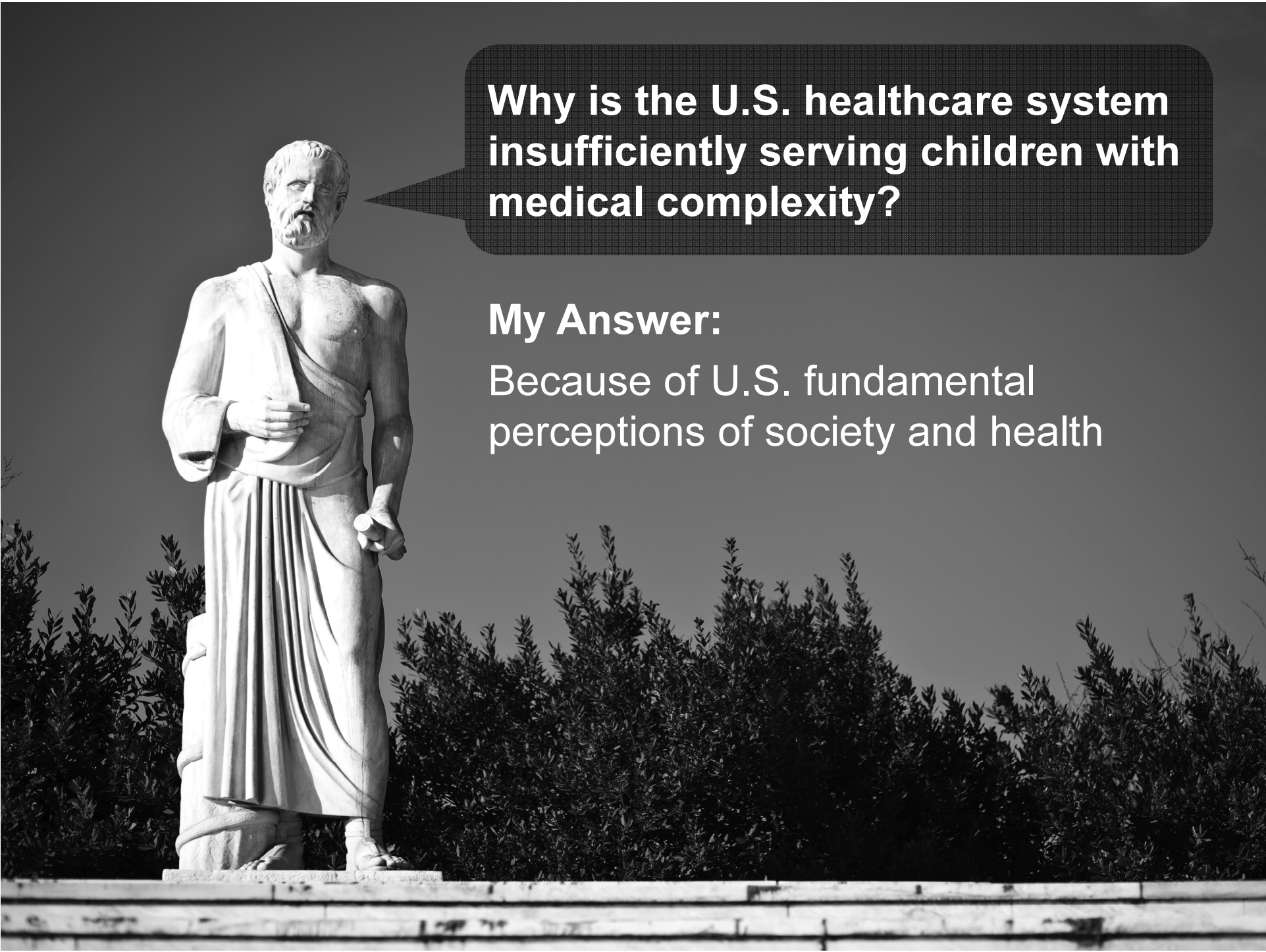
Children with Medical Complexity

“Frankly it’s beyond the doctor’s door that’s making my life hell. It’s a lot of work. The parents are probably the least able to do it at some level because [of the] work [necessary] to keep our kids alive at home. It’s grinding work...it just takes a lot of grueling vigilant effort and I get lost in it. There’s so much that the parents get lost.”



**Why is the U.S. healthcare system
insufficiently serving children with
medical complexity?**





**Why is the U.S. healthcare system
insufficiently serving children with
medical complexity?**

My Answer:

Because of U.S. fundamental
perceptions of society and health



Civilization has a simple choice: liberty, inequality, survival of the fittest, or not-liberty, equality, survival of the un-fittest. The former carries society forward and favors all its best members; the latter carries society downward and favors all its worst members.

William Graham Sumner, ca. 1890
President, American Sociologic Association

**survival of the fittest or
survival of the un-fittest**

**survival of the fittest or
survival of the un-fittest**



*Individuals with chronic, disabling conditions
have been historically disregarded by
U.S. society*

Historical Perspectives of Children with Medical Complexity from the U.S. Healthcare Populace

- Takes too much effort to help them
- They'll have minimal societal contributions
- Better to focus on other populations

U.S. Healthcare Policy

Children with Medical Complexity

- Community pediatricians can choose not to take care of them
- Private insurers can refuse to cover their health services
- U.S. States (Medicaid) cover the children, but often not at sufficient cost

U.S. Healthcare Policy

Effect on Children's Hospitals' Care for CMC

- Much of the care is not reimbursable
- Cost of providing care exceeds the payment received from it
- Difference in cost must be underwritten by philanthropy and other means

Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane.

Martin Luther King, Jr.

There comes a time when one must take a position because conscience tells him it is right.

Martin Luther King, Jr.

Standards of Care

Children with Medical Complexity

Managed by at least one provider knowledgeable of the child's overall health and well-being.

Coordinated among the child's team members when making decisions.

Relentless in meeting the child's health needs in a timely manner.

Proactive in making plans to optimize the child's health and quality of life.

Accessible especially for health problems that require urgent attention.

Surge of Clinical Innovations

Care Management for Children with Medical Complexity

- Primary Care Medical Home
- Consultative Complex Care Clinic
- Perioperative Surgical Home
- Multi-disciplinary Disease-Based Clinic
- Rural Community Case Management
- Hospital-in-the-Home Program

When Hospitalists Go Outpatient

Children with Medical Complexity

CH Wisconsin Special Needs Program

MILWAUKEE | *Gordon Arch Pediatr Adolesc Med* (2007)

- Nurse care managers and ICU physician
- Up to 20 hours per patient per month spent
 - Attending specialty, ED, hospital, and home visits
 - Communicating among specialists and PCP
 - Arbitrating among competing treatments
 - Developing plans of care and health summaries
 - Working with community agencies and insurers

When Hospitalists Go Outpatient

Children with Medical Complexity

CH Wisconsin Special Needs Program

MILWAUKEE | *Gordon Arch Pediatr Adolesc Med* (2007)

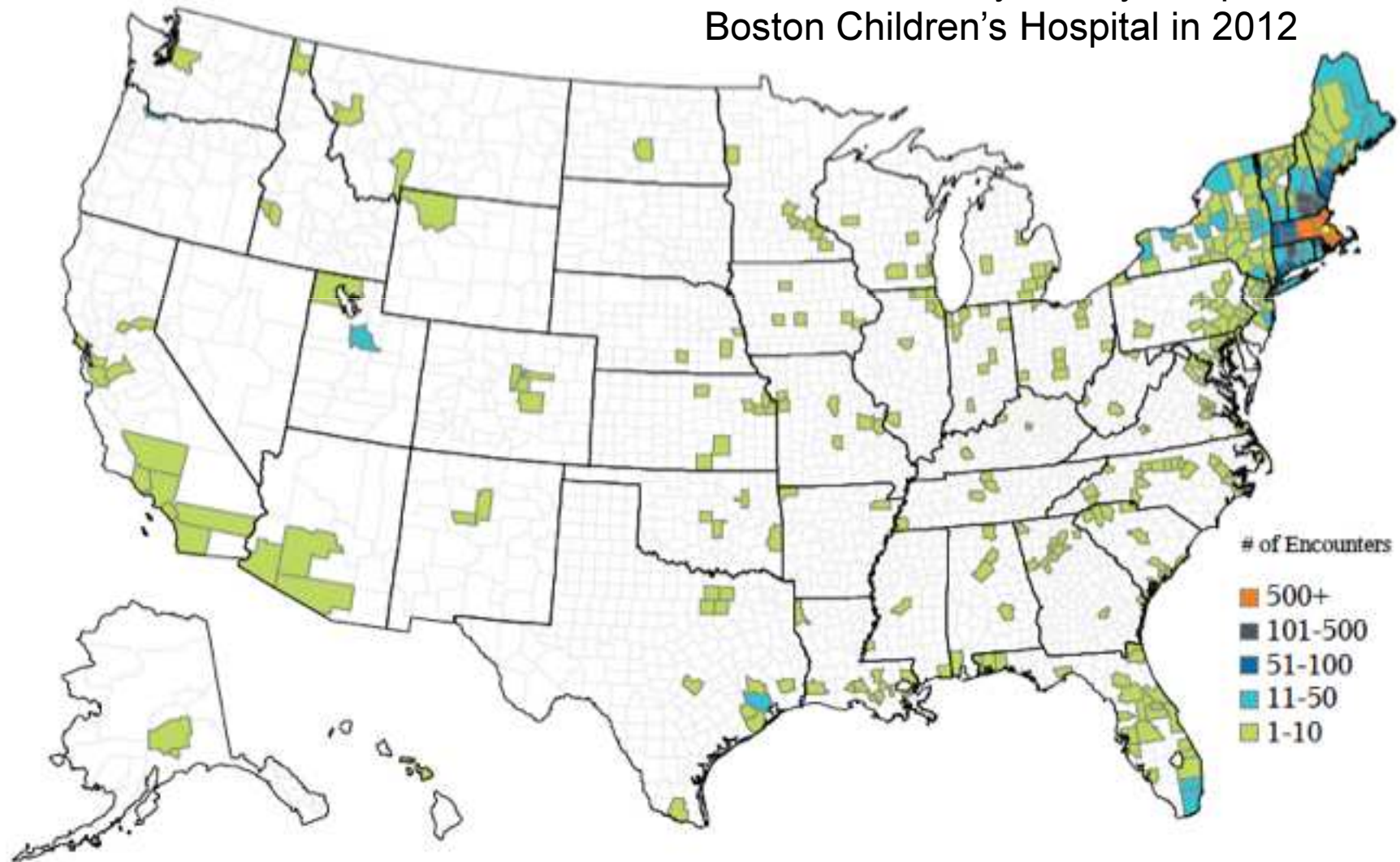
- Nurse care managers and ICU physician
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 - Attending specialty, ED, hospital, and home visits
 - Communicating among specialists and PCP
 - Arbitrating among competing treatments
 - Developing plans of care and health summaries
 - Working with community agencies and insurers

Program runs on an annual \$400,000 deficit

Travel Distance to Children's Hospitals

Children with Medical Complexity

Count of CMC, by county, hospitalized at Boston Children's Hospital in 2012



Rural Community Care

Children with Medical Complexity

Targeted Case Management Program

ALABAMA | www.medicaid.alabama.gov

- Case manager assigned to each CMC
 - Embedded into primary and community care
 - Access to primary care EHR & Medicaid data
 - Ability to perform home visits
 - Ability to coordinate care with specialists

Impact on Health and Wellbeing

Care Management for Children with Medical Complexity

- For the Child
 - Reduces unmet healthcare needs
 - Improves health & functional status
- For the Family
 - Increases knowledge of child's health
 - Helps with coping
 - Reduces caregiving burden
 - Improves family satisfaction with care

Impact on Health Resource Use

Care Management for Children with Medical Complexity

- More Outpatient Care
 - Outpatient visits increase by 72%
- Fewer Hospitalizations
 - Admissions reduced by 26-59%
 - Hospital days reduced by 52%
- Less Emergency Department Use
 - ED visits reduced by 18-55%

Palfrey et al *Pediatrics* (2004)

Casey et al *Arch Pediatr Adolesc Med* (2011)

Gordon et al *Arch Pediatr Adolesc Med* (2007)

Mosquera et al *JAMA* (2014)

U.S. Federal Healthcare Policy

Care Management for Children with Medical Complexity

113th CONGRESS
2D SESSION

H.R. 4930

To amend titles XIX and XXI of the Social Security Act to provide States with the option of providing services to children with medically complex conditions under the Medicaid program and Children's Health Insurance Program through a care coordination program focused on improving health outcomes for children with medically complex conditions and lowering costs, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

June 20, 2014

Advancing Care for Exceptional Kids

Legislation for Children with Medical Complexity in Medicaid

- **Purpose of the legislation**
 - To create clinical health homes that include a regional group of clinicians, clinics, healthcare entities, etc. across the care continuum
 - To provide states with federal money (9:1 match) to increase payment for care delivery within the health home

Advancing Care for Exceptional Kids

Legislation for Children with Medical Complexity in Medicaid



Hope



Goals of This Discussion

Convey U.S. experiences of caring for children with medical complexity

- 1. Epidemiology and impact**
- 2. Quality of care**
- 3. Views on society and health**
- 4. Clinical innovations and policy**

Thank you!

jay.berry@childrens.harvard.edu