

# Children with Medical Complexity in the Commonwealth

**October 6, 2021** 

# Report Findings: Children with Medical Complexity in the Commonwealth

- Legislative Charge
- Defining Children with Medical Complexity
- Demographics, Spending, and Utilization
- Stakeholder Perspectives
- Next Steps



## **Legislative Charge**

To better understand the landscape of care for **children with medical complexity (CMC)** in the Commonwealth, the Massachusetts Legislature enacted Chapter 124 of the Acts of 2019: *An act relative to children's health and wellness.* 

Section 7 of Chapter 124 of the Acts of 2019 tasks the Massachusetts Health Policy Commission (HPC) with estimating the number of CMC in the Commonwealth, their demographics, primary diagnoses, health coverage, access to and utilization of health care, associated costs, and recommendations for ongoing data collection and reporting.



## **Background on Children with Medical Complexity**

#### **CHARACTERISTICS**

- Serious, chronic, and multiple medical and mental, behavioral, or developmental health conditions, including functional limitations, high health service needs, and high utilization.<sup>1</sup>
- A diverse and high-need population, representing the most medically fragile subgroup of children with special health care needs.<sup>2</sup>
  - Children with special health care needs have or are at risk of chronic physical, developmental, behavioral, or emotional conditions, requiring services beyond those required by children generally.<sup>3</sup>

#### **UTILIZATION**

- Often require surgery or inpatient services, or rely on DME and supplies, medical technology, or home health services.<sup>4-6</sup>
- CMC have disproportionately high health spending compared with healthy children.<sup>5</sup>

#### **PREVALENCE**

 Research estimates that nationally, CMC represent 1-4% of all children,<sup>8,9</sup> and 5-6% of children covered by Medicaid.<sup>5,7</sup>

<sup>1</sup> Berry JG, Agrawal RK, Cohen E, Kuo DZ. The Landscape of Medical Care for Children with Medical Complexity. Children's Hospital Association. June 2013. Available at: http://www.columbia.edu/itc/hs/medical/residency/peds/new\_compeds\_site/pdfs\_new/PL3%20new20readings/Special\_Report\_The\_Landscape\_of\_Medical\_Care\_for\_Children\_with\_Medical\_Complexity.pdf

<sup>2</sup> Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, Srivastava R. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. Pediatrics. 2011; 127(3):529-583.

<sup>3</sup> HRSA Maternal & Child Health. Children with Special Health Care Needs: NSCH Data Brief. Jul 2020. Available at: https://mchb.hrsa.gov/sites/default/files/mchb/Data/NSCH/nsch-cshcn-data-brief.pdf

<sup>4</sup> Doupnik SK, Rodean J, Feinstein J, Gay JC, Simmons J, Bettenhausen JL, Markham JL, Hall M, Zima BT, Berry JG. Health Care Utilization and Spending for Children With Mental Health Conditions in Medicaid. Academic Pediatrics. 2020; 20(5):678-686.

<sup>5</sup> Berry JG, Hall M, Neff J, Goodman D, Cohen E, Agrawal R, Kuo D, Feudtner. Children With Medical Complexity And Medicaid: Spending And Cost Savings. Health Affairs. 2014; 33(12): 2199-2206.

<sup>6</sup> Kuo DZ, Melguizo-Castro M, Goudie A, Nick TG, Robbins JM, Casey PH. Variation in Child Health Care Utilization by Medical Complexity. Maternal and Child Health Journal. 2015; 19: 40-48.

<sup>7</sup> Reuland CP, Collins J, Chiang L, Stewart V, Cochran AC, Coon CW, Shinde D, Harguani D. Oregon's approach to leveraging system-level data to guide a social determinants of health-informed approach to children's healthcare. BMJ Innovations. 2020; 7(1): 1-8.

<sup>8</sup> NASHP. National Care Coordination Standards for Children and Youth with Special Health Care Needs. Oct 16, 2020. Available at: <a href="https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#loggle-id-1">https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#loggle-id-1</a>

<sup>9</sup> Children's Hospital Association. Coordinating All Resources Effectively for Children with Medical Complexity (CARE Award): Early Lessons Learned from the Project. Sept 2016. Available at: <a href="https://www.childrenshospitals.org/">https://www.childrenshospitals.org/</a>/media/Files/CHA/Main/Programs and Services/Quality Safety and Performance/CARE/CARE award early lessons learned sept2016.pdf

## **About the Report**

- Children with medical complexity (CMC) are a high-need population, with significant use of health and social services.
- The health system is not always set up to adequately support CMC, for whom health care and health coverage are often fragmented, and who require coordination across multiple overlapping medical and social service settings and systems.
- To understand the population of CMC and their health care landscape in the Commonwealth, the HPC investigated demographics, health coverage, health service utilization, and spending.
- The HPC also met with stakeholders to understand issues of care not measurable in administrative data, including access, care continuity, and social complexity for families.

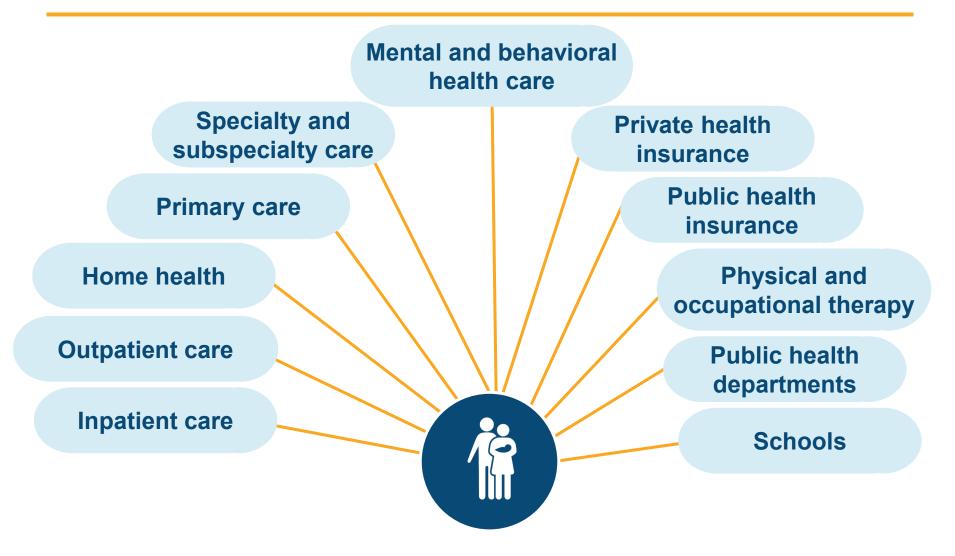


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Children with medical complexity and their families often rely on multiple health and social service systems.



Navigating across multiple sources of care can be burdensome for CMC and their families.



### There are many insurance coverage and public programs supporting CMC in Massachusetts.

#### **HEALTH COVERAGE**

#### MASSHEALTH

- MASSHEALTH STANDARD
- MASSHEALTH MCO/ACO
- KAII FIGH MULLIGAN MASSHEALTH
- MASSHEALTH LIMITED
- MASSHEALTH FAMILY ASSISTANCE
- CHILDREN'S MEDICAL SECURITY PLAN
  - COMMONHEALTH

#### **COMMERCIAL**

- EMPLOYER-SPONSORED **INSURANCE**
- MARKETPLACE COVERAGE VIA THE HEALTH CONNECTOR

# COMMUNITY CASE

MANAGEMENT

- ACO CARE MANAGEMENT **PROGRAMS**
- LTSS COMMUNITY PARTNERS
- CHILDREN'S BEHAVIORAL **HEALTH INITIATIVE** 
  - AUTISM WAIVER

SPECIAL KIDS SPECIAL CARE DCF

### OTHER PUBLIC PROGRAMS

#### DESE

- SCHOOL-BASED PHYSICAL, OCCUPATIONAL, & SPEECH THERAPY SERVICES
- DDS/DESE PROGRAM (COMMUNITY) RESIDENTIAL EDUCATION PROGRAM)
  - MEDICALLY COMPLEX PROGRAMS
  - DDS FAMILY SUPPORT
- DDS

- INDIVIDUALIZED EDUCATIONAL PROGRAMS (IEPS)
- 504 PLANS
- IN-SCHOOL NURSING: ASSISTANCE WITH ACTIVITIES OF DAILY LIVING (including 1-1 nursing; may be provided by a nurse or a paraprofessional)
- IN-SCHOOL BEHAVIORAL HEALTH SERVICES AND SOCIAL-EMOTIONAL LEARNING SUPPORTS
- IN-SCHOOL APPLIED BEHAVIOR **ANALYSIS SERVICE**

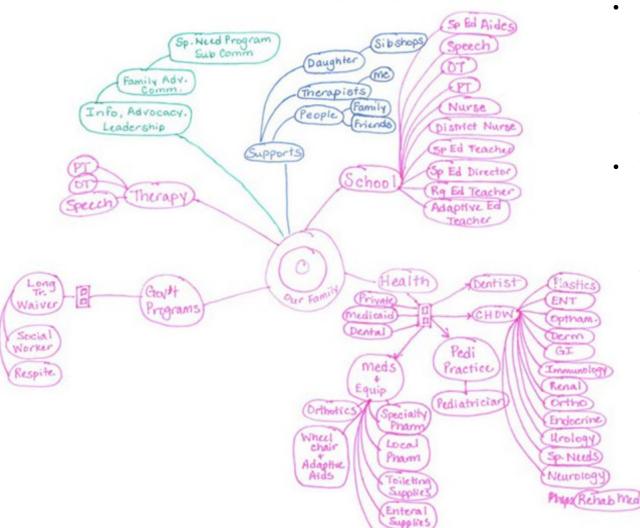
#### DPH

- EARLY INTERVENTION SERVICES
- CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND
- PEDIATRIC PALLIATIVE CARE
- PAPPAS REHABILITATION HOSPITAL FOR CHILDREN
- OFFICE OF FAMILY INITIATIVES

- PAPPAS REHABILITATION HOSPITAL FOR CHILDREN
- SCHOOL-BASED HEALTH **CENTERS**
- SCHOOL HEALTH SERVICES
- TITLE V PROGRAMS WITHIN THE DIVISION FOR CHILDREN & YOUTH WITH SPECIAL HEALTH NEEDS (including Community Support Line, Care Coordination Program, Family TIES, Hearing Aid Program, Medical Review Team (MRT) Program, Massachusetts Technology Assistance Resource Team (MASSTART), Universal Newborn Hearing Screening Program )



### **Example Family Care Map**



- Care maps are family-created diagrams depicting the constellation of providers, services, and supports needed to care for CMC.<sup>1</sup>
- This care map for a patient with a chromosomal disorder depicts public programs, speech, physical, and occupational therapy, public and private health insurance, health services including pediatric, other outpatient, hospital inpatient, medication, and DME, and school-based health and educational services and supports, as well as support from family and friends.

<sup>1</sup> Adams S, Nicholas D, Mahant S, Weiser N, Kanani R, Boydell K, Cohen E. Care maps for children with medical complexity. Developmental Medicine & Child Neurology. 2017; 59(12): 1299-1306.



# Research estimates that CMC make up about 1-4% of all children, or approximately 14,000 – 56,000 children in Massachusetts.



1.4 million in MA<sup>1</sup>

Children with special healthcare needs 18% of children<sup>2</sup> 252,000 in MA

> CMC 1-4% of children<sup>2,3</sup> 14,000-56,000 in MA

<sup>3</sup> Children's Hospital Association. Coordinating All Resources Effectively for Children with Medical Complexity (CARE Award): Early Lessons Learned from the Project. Sept 2016. Available at: https://www.childrenshospitals.org/-



<sup>1</sup> United States Census Bureau. Quickfacts: Massachusetts. Available at: https://www.census.gov/quickfacts/MA

<sup>2</sup> NASHP. National Care Coordination Standards for Children and Youth with Special Health Care Needs. Oct 16, 2020. Available at: https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-1

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# Data Sources: The HPC analyzed both all-payer hospital discharge data and medical claims from certain commercial and MassHealth plans.

PAYER	CARE									
	PROFESSIONAL	OUTPATIENT	PHARMACY	INPATIENT	EMERGENCY DEPARTMENT					
COMMERCIAL										
BCBS, HPHC, Tufts Health Plan, Allways, Unicare (Anthem)										
Other commercial payers										
MASSHEALTH										
MassHealth MCO/ACO										
Fee-For-Service										
MEDICARE										
OTHER PAYERS										



Hospital discharges

# Using the Pediatric Medical Complexity Algorithm to Identify CMC in Inpatient Stay and Claims Data

### The PMCA sorts individuals aged 21 and younger into three groups:

#### **NON-CHRONIC**

Individuals with no diagnoses or with acute non-chronic conditions lasting <1 year, such as ear infection

#### **NON-COMPLEX CHRONIC**

Individuals with chronic conditions lasting ≥1 year, such as Type 1 diabetes, ADHD

#### **COMPLEX CHRONIC**

Individuals with any of the following:

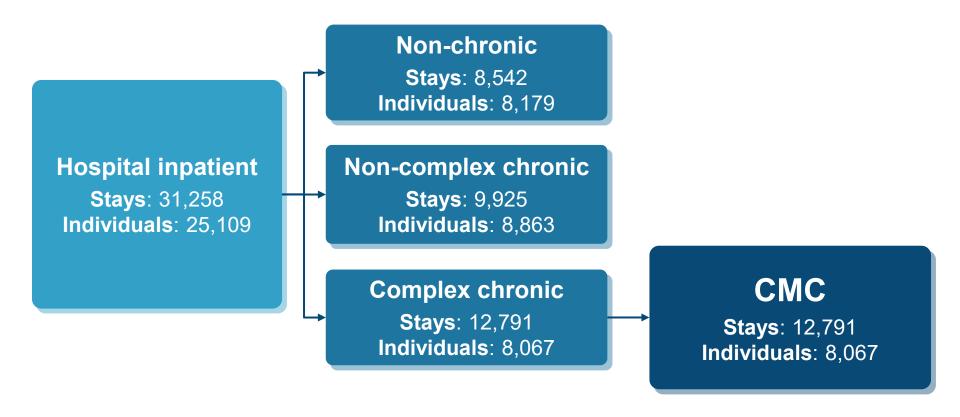
- Physical, mental, or developmental chronic conditions lasting ≥1 year, in at least 2 body systems
  - Includes Type 1 diabetes + depression, or developmental delay + a chronic pulmonary condition
- Progressive conditions associated with deteriorating health and decreased life expectancy
  - Includes muscular dystrophy, cystic fibrosis
- Continuous dependence on technology for at ≥6 months
  - Includes renal dialysis, or tracheostomy + ventilator assistance
- Malignancies
  - Includes leukemia, lymphoma, brain tumor



# In 2018, there were over 8,000 children with medical complexity who had at least one inpatient hospital stay.

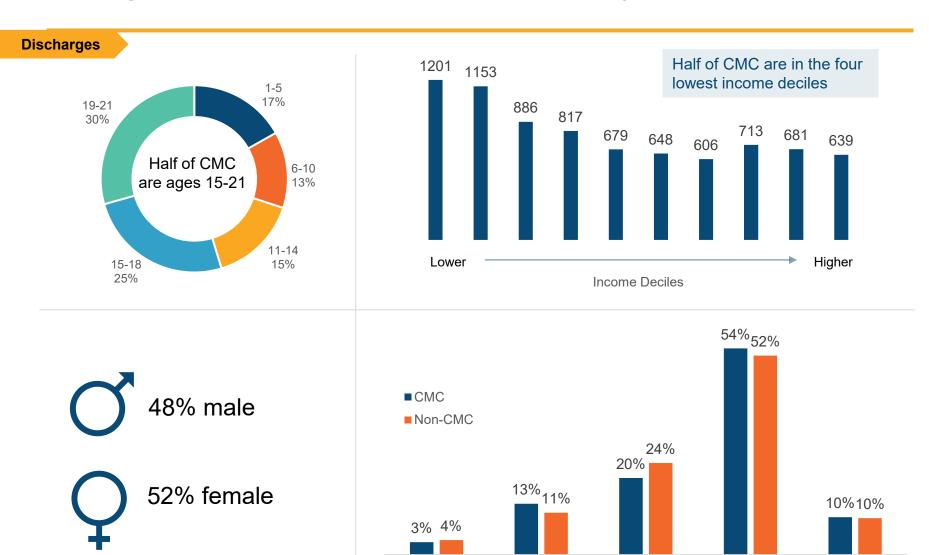
31,258 of the approximately 800,000 inpatient hospital stays in Massachusetts in 2018 were among people ages 1-21.

**41%** of the 31,258 stays were for children with medical complexity.





## **Demographics of CMC with Inpatient Hospital Stays, 2018**





Note: Analysis excludes individuals <1 year old. <11 American Indian/Alaska Native and Native Hawaiian or other Pacific Islander individuals not shown. Other race includes other race, non-Hispanic and unspecified race, non-Hispanic.

Black/African

American

Hispanic

White

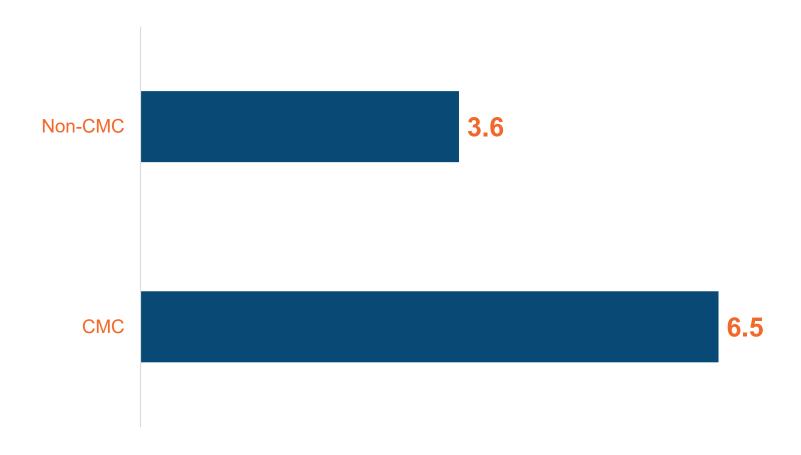
Asian

Other or Unspecified Race

# The average length of an inpatient stay for CMC was 6.5 days, nearly double the length of stay for non-CMC.

#### **Discharges**

Mean hospital inpatient length of stay in days for CMC and non-CMC, 2018

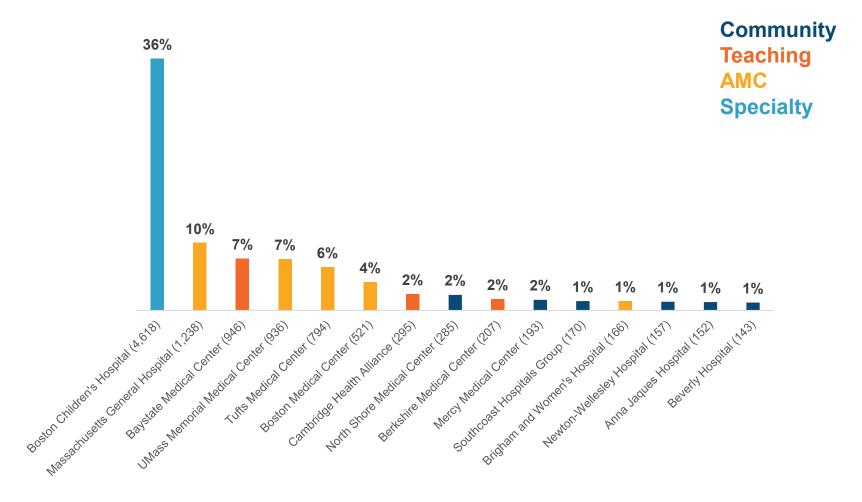




# CMC inpatient stays were concentrated at a few hospitals, with nearly 70% of stays taking place at five hospitals.

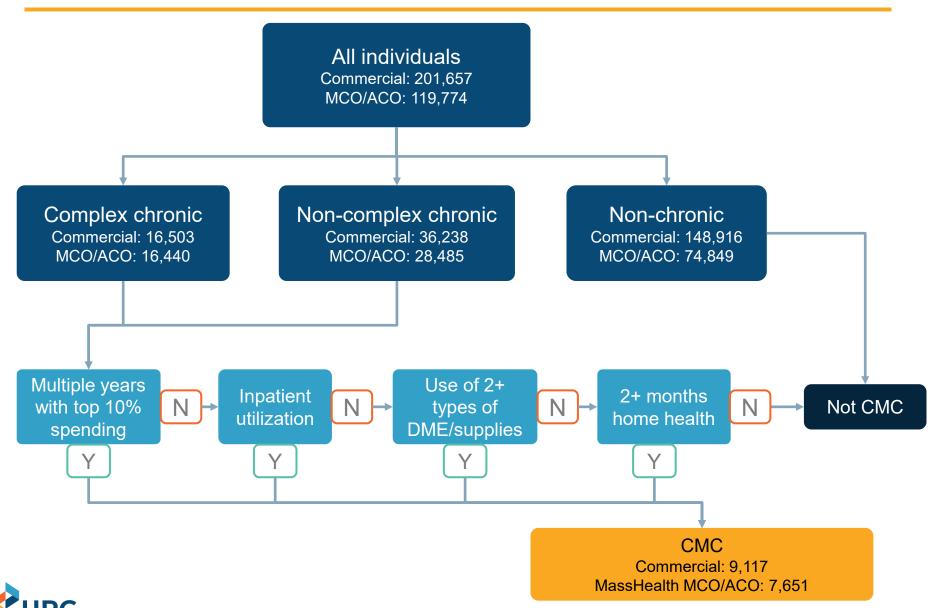
#### **Discharges**

Proportion of CMC discharged per hospital at the top 15 hospitals for CMC discharges, 2018





Identifying CMC in 2018 Claims Data: 4.5% of children with commercial coverage and 6.4% of children with MassHealth MCO/ACO primary coverage are CMC.



Notes: See appendix for more detail

## Demographics of Commercially-Insured CMC, 2018

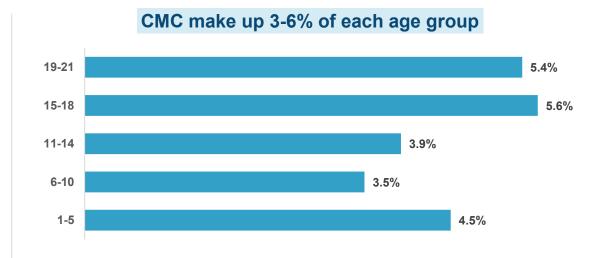
**Claims** 



### 1 in 5

#### CMC have mood disorders

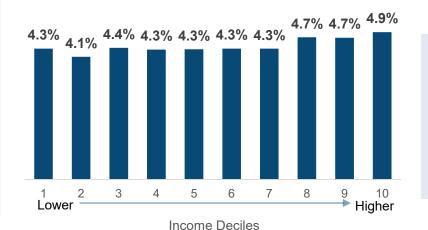
such as anxiety and depression. Other common behavioral diagnoses include autism and ADHD.







**48%** of CMC are female



income decile is CMC. Half of commerciallyinsured CMC are in the three highest income deciles.

4-5% of each



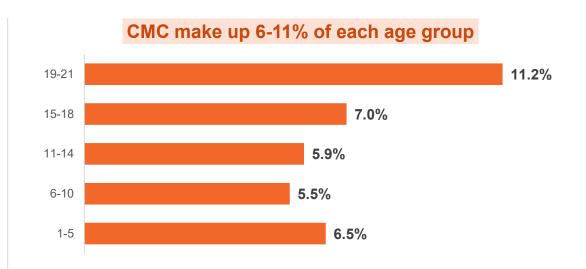
## Demographics of CMC covered by MassHealth MCO/ACO plans, 2018

**Claims** 



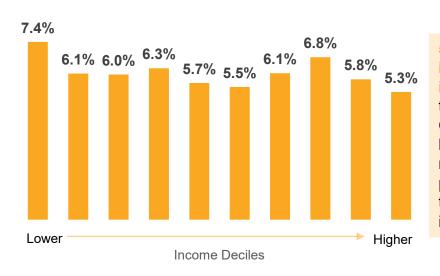
# 1 in 5 CMC have mood disorders

such as anxiety. Other common behavioral diagnoses include autism and ADHD









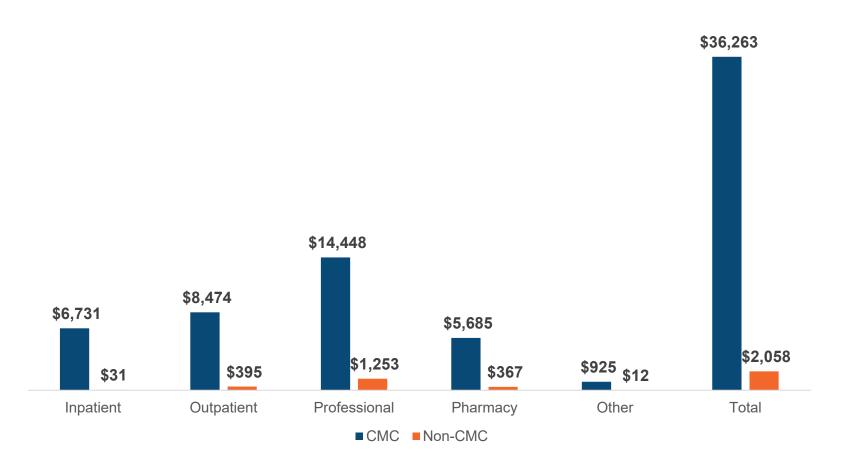
5-7% of each income decile is CMC. Nearly two-thirds of CMC covered by MassHealth managed care plans are in the three lowest income deciles



# Average total annual spending for commercially-insured CMC was \$36,263, compared to \$2,058 for non-CMC.

#### **Claims**

Mean commercial inpatient, outpatient, professional, pharmacy, and other spending for CMC and non-CMC per member per year, 2018





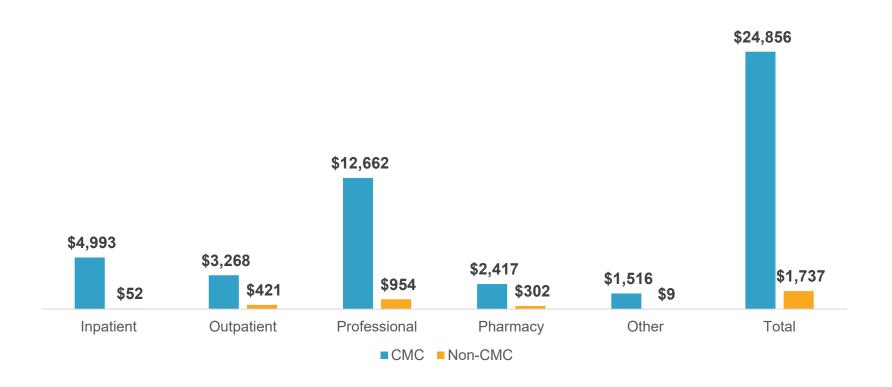
Notes: Analysis excludes individuals <1 year old Other includes DME, home health, hospice, skilled nursing, and spending on services of unknown type. Pharmacy spending was not available for 25% of children in the APCD due to carveouts. Pharmacy spending represents the average among children with non-missing data. Total spending is shown using that average as if it represents the average for all children.

Source: HPC analysis of All-Payer Claims Database 8.0

# Average total annual spending for CMC with MassHealth MCO/ACO coverage was \$24,856, compared to \$1,737 for non-CMC.

#### **Claims**

Mean MCO/ACO inpatient, outpatient, professional, pharmacy, and other spending for CMC and non-CMC per member per year, 2018





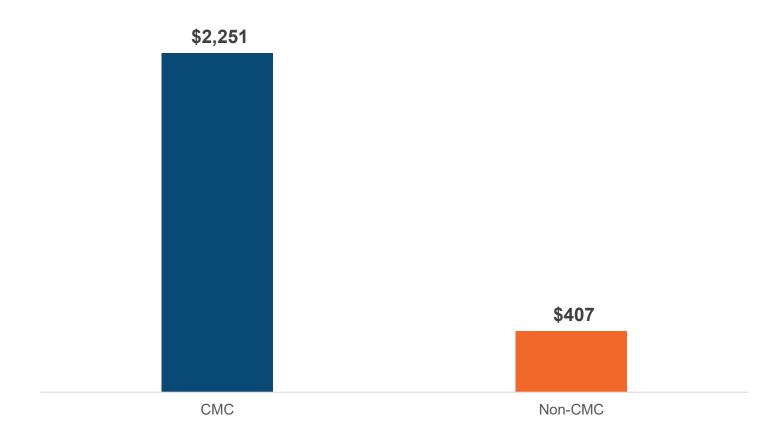
Notes: Analysis excludes individuals <1 year old Other includes DME, home health, hospice, skilled nursing, and spending on services of unknown type. All individuals had a full year of pharmacy coverage.

Source: HPC analysis of All-Payer Claims Database 8.0

# Average annual commercial out-of-pocket spending for CMC was 5.5 times (\$2,251) that of non-CMC (\$407).

#### **Claims**

Commercial out-of-pocket medical and pharmacy spending for CMC and non-CMC per member per year, 2018

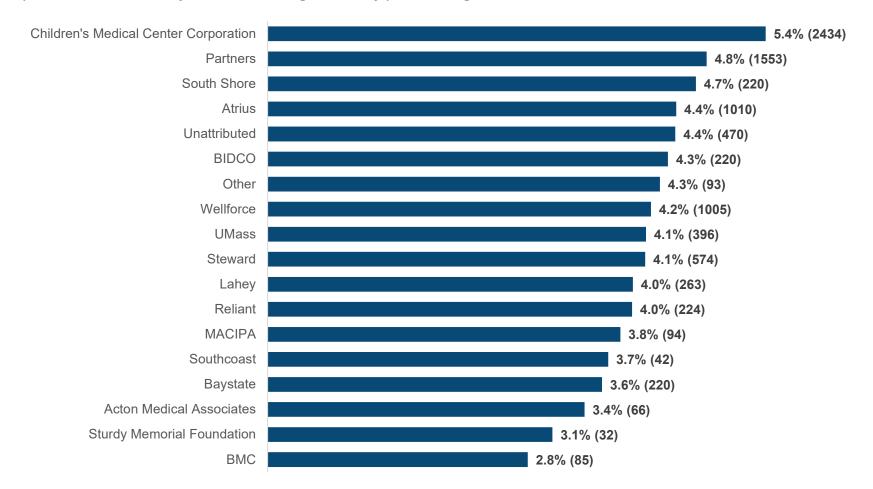




# CMC make up 3-5% of commercially-insured pediatric patients per provider organization.

#### **Claims**

Proportion of commercially-insured CMC ages 1-21 by provider organization, 2018





Notes: Analysis excludes individuals <1 year old Total individuals: 201,657. "Other" includes provider groups with <1000 lives in observed in 2018: Berkshire Health System, Community Care Cooperative, Franciscan Hospital for Children, Lawrence, Milford Regional Medical Center, New England Baptist Hospital, and Tenet Healthcare Corporation. Missing excluded.

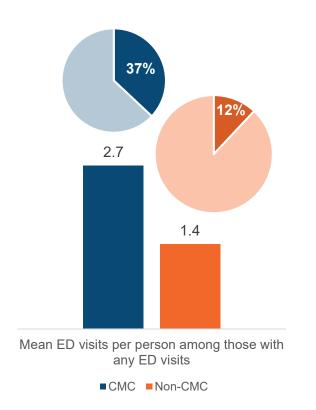
Source: HPC analysis of All-Paver Claims Database 8.0

# CMC are more likely to use the ED than non-CMC and have almost twice as many ED visits per person.

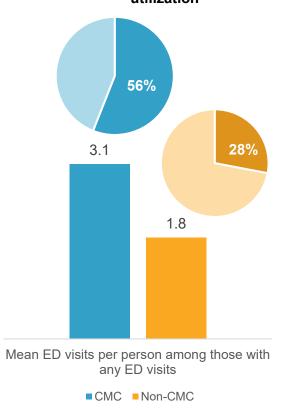
#### **Claims**

Proportion of commercially- and MassHealth ACO/MCO-insured CMC and non-CMC with any ED utilization and mean ED visits per person among individuals who used the ED, 2018

Commercial
Proportion of CMC and non-CMC with ED
utilization



MCO/ACO
Proportion of CMC and non-CMC with ED
utilization





### **Summary of Key Findings**

- 4.5% of commercially-insured children and 6.4% of children with MassHealth MCO/ACO coverage are children with medical complexity (CMC).
- About half of CMC in Massachusetts have commercial insurance, and about half are covered by MassHealth.
  - Preliminary findings do not capture children with primary commercial and secondary MassHealth coverage.
- CMC who are hospitalized have nearly double the length of inpatient stay of healthier children who are hospitalized (6.5 vs. 3.6 days). A plurality of CMC (36%) are hospitalized at Boston Children's Hospital.
- Annual commercial spending for CMC is 18 times that of healthier children (\$30,578 vs. \$1,691), and annual MassHealth MCO/ACO spending for CMC is 16 times that of healthier children (\$22,439 vs. \$1,435).
- Annual commercial out-of-pocket spending for CMC is 5.5 times that of healthier children (\$2,251 vs. \$407).
- 21% of CMC have an identified mood disorder, such as anxiety or depression.
- CMC are all types of children and live in all parts of Massachusetts: similar rates of CMC are found across all demographic groups and regions of the Commonwealth.



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## Stakeholders Consulted in the Development of the Report

- Baystate Health
- Boston Children's Hospital
- Federation for Children with Special Needs
- Health Care for All
- MassGeneral Hospital for Children
- Massachusetts Center for Health Information and Analysis (CHIA)
- Massachusetts Department of Public Health (DPH)
- MassHealth
- Reliant Medical Group
- Assorted researchers and clinicians



### Stakeholders discussed access concerns for CMC.

### **Primary Care**

Community pediatricians may only be able to treat a few CMC at a time.

### **Specialty Care**

- According to stakeholders, a shortage of pediatric specialists who accept MassHealth can create access delays.
- Many CMC require specialty and sub-specialty treatment or inpatient care, which is concentrated in the Boston area; stakeholders noted challenges for CMC who have difficulty traveling or who lack transportation.
- Transportation difficulties can lead to missed appointments and families being denied further appointments as no-shows.

#### COVID-19

- Caution about exposure has led to missed in-person care, including fewer home health or PCA visits.
- Providers noted that telehealth has helped to resolve some access issues but is not appropriate for all children or available to all families.



### Stakeholders identified care continuity and coordination concerns.

### **Coverage and Benefit Design**

- Stakeholders described frequent changes or interruptions in employment for parents of CMC, making care continuity difficult for families with commercial insurance.
- Providers noted that benefit designs intended to reduce avoidable spending can lead to interruptions in care for CMC.
- Likewise, avoidable emergency department (ED) utilization and spending can occur when benefit design limits access to DME and supplies.

#### **Care Coordination**

- Stakeholders explained that families need an "air traffic controller" a high level of coordination across systems.
- Stakeholders agreed this level of coordination belongs at regional public health agencies.



# Stakeholders reflected that social complexity for families with CMC likely contributes to additional challenges.



Families of CMC often face financial and social marginalization.<sup>1</sup>



Parents of CMC are at increased risk of poor mental health.<sup>2</sup>



Some families face additional social complexity challenges including poverty, housing instability, food insecurity or insufficiency, lack of transportation, language barriers, or foster system involvement.<sup>3</sup>



Stakeholders agreed that social complexity can make it more difficult for families of CMC to navigate systems involved in caring for their children.



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### The HPC anticipates releasing a final report in the coming months.

## Additional topics may include:



Pediatric to adult care transitions



Behavioral health



**Emergency Department boarding** 



30-day hospital inpatient readmissions



Additional spending analyses





# **Appendix**

### **Detail on Identifying Children with Medical Complexity**

- Identified CMC in claims and discharge data using a combination of diagnoses and utilization
- The Pediatric Medical Complexity Algorithm¹ is a diagnosis code-based tool to identify CMC in administrative data, using medical, mental, and behavioral diagnoses to flag individuals under 22 years old as having *non-chronic*, *non-complex chronic*, or *complex chronic* conditions
  - Healthy individuals with utilization but no diagnoses (e.g., well visits) are flagged as non-chronic
- The PMCA flags medical complexity using a more- and less-conservative definition of complexity, based on the number of claims per body system of diagnosis for at least two body systems. Less-conservative flags with at least one claim, more-conservative flags with at least two
- However, diagnosis codes alone may inaccurately flag largely asymptomatic children as CMC while omitting CMC without clear diagnoses<sup>2,3</sup>
  - Diagnoses alone do not account for health service needs or functional impairments
  - Diagnoses exclude individuals whose conditions are not defined by clear diagnoses or who have trouble accessing needed care
- Identifying CMC in the APCD:
  - Refined the complex chronic and non-complex chronic cohorts flagged with the less-conservative definition to flag individuals with multiple years in the top 10% of spending, any inpatient utilization, ≥2 months home health spending, or ≥2 types of DME or supplies as CMC
- Identifying CMC in the Hospital Inpatient and Emergency Department Discharge Databases:
  - Treated discharges flagged by the PMCA with the less-conservative as complex chronic as equivalent to CMC

<sup>2</sup> Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, Srivastava R. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. Pediatrics. 2011; 127(3): 529-538.



<sup>1</sup> Simon TD, Cawthon ML, Stanford S, Popalisky J, Lyons D, Woodcox P, Hood M, Chen, AY, Mangione-Smith R. Pediatric Medical Complexity Algorithm: A New Method to Stratify Children by Medical Complexity. Pediatrics. 2014; 133(6): e1647-e1654.

# Commercially-insured CMC and non-CMC and Medical Spending per Member per Year by Provider Organization, 2018

	Non-CMC	СМС	Non-CMC spending (Mean)	CMC spending (Mean)	CMC spending (Median)	Percent CMC
Acton Medical Associates	1851	66	\$1655	\$24610	\$12080	3.4%
Atrius	21741	1010	\$1543	\$30192	\$13479	4.4%
BIDCO	4838	220	\$1644	\$27380	\$14265	4.3%
BMC	2922	85	\$1452	\$31891	\$16242	2.8%
Baystate	5837	220	\$1343	\$28927	\$14829	3.6%
Children's Medical Center Corporation	42552	2434	\$1834	\$31599	\$14145	5.4%
Lahey	6365	263	\$1671	\$28993	\$15951	4.0%
MACIPA	2359	94	\$1713	\$28118	\$13243	3.8%
Other	2089	93	\$1642	\$30756	\$13185	4.3%
Partners	31011	1553	\$1872	\$28798	\$14121	4.8%
Reliant	5434	224	\$1518	\$30020	\$16191	4.0%
South Shore	4509	220	\$1739	\$29075	\$13616	4.7%
Southcoast	1093	42	\$1474	\$22189	\$14027	3.7%
Steward	13418	574	\$1647	\$34651	\$13435	4.1%
Sturdy Memorial Foundation	1002	32	\$1696	\$21788	\$12973	3.1%
UMass	9238	396	\$1520	\$37844	\$17243	4.1%
Unattributed	10142	470	\$1592	\$30812	\$13366	4.4%
Wellforce	23129	1005	\$1658	\$29349	\$13908	4.2%

