

CHILDREN WITH MEDICAL COMPLEXITY IN THE COMMONWEALTH

REPORT TO THE MASSACHUSETTS LEGISLATURE

FEBRUARY 2022



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INTRODUCTION

To understand the population of children with medical complexity (“CMC”) and their health care landscape in the Commonwealth, the Massachusetts Legislature enacted Chapter 124 of the Acts of 2019: *An Act Relative to Children’s Health and Wellness*.¹ CMC are the most medically fragile subgroup of children with special health care needs,² and Section 7 of the Act directed the Massachusetts Health Policy Commission (“HPC”) to conduct an analysis estimating the number of CMC in Massachusetts, analyze their demographics, diagnoses, health coverage, access to and utilization of health care, and associated costs, and make recommendations for ongoing data collection and reporting.

As an independent state agency established by Chapter 224 of the Acts of 2012, the mission of the HPC is to advance a more transparent, accountable, and equitable health care system through its independent policy leadership and innovative investment programs. The HPC’s goal is better health and better care – at a lower cost – for all residents across the Commonwealth.

In conducting this study, the HPC used a variety of approaches. Claims and discharge data were analyzed to understand health care spending and utilization for children with medical complexities, though some care needs for CMC are not easily measurable or accessible in administrative data – including access to care, care continuity, social complexities for families, and the transition from pediatric to adult care. To understand additional health care needs and challenges for CMC, the HPC met with stakeholdersⁱ from December 2020–December 2021.

BACKGROUND: CHILDREN WITH MEDICAL COMPLEXITY

CMC are characterized by having serious, chronic, and often multiple medical, behavioral, or developmental health conditions, as well as significant functional limitations, considerable health service needs, and high utilization (see Methods section).³ An estimated 1-4% of U.S. children are CMC.^{4,5}

CMC are a heterogeneous and high-need population, with significant use of health and social services. CMC often require multi-specialty care, inpatient care, physical or occupational therapy, and behavioral health care; additionally, many CMC rely on medical technology, durable medical equipment (DME), or supplies. In addition to substantial hospital inpatient and ambulatory care spending, many CMC use at least one prescription medication – often to treat behavioral or developmental conditions.^{6,7} While pediatric health spending overall is relatively low,⁸ spending for this small subset of children is disproportionately high.⁹ Likewise, while CMC make up 5-6% of Medicaid-covered children nationally, research estimates that they account for over a third of pediatric Medicaid spending.^{10,11}

Although CMC and their families make frequent use of health and social services, such systems are not always set up to support them.¹² Health care and health coverage for CMC are often fragmented, requiring coordination across multiple medical and social service settings and systems.

Systems in the Commonwealth supporting CMC and their families include public and private health insurance, as well as a wide variety of public programs under the Massachusetts Department of Children and Families (“DCF”), Department of Developmental Services (“DDS”), Department of Elementary and Secondary Education (“DESE”), and Department of Public Health (“DPH”) (**Exhibit 1**). Fragmentation across health and social service systems can be difficult to navigate, as families and caregivers must coordinate across multiple systems.

HEALTH COVERAGE FOR CHILDREN WITH MEDICAL COMPLEXITY

CMC are covered by their families’ employer-sponsored commercial insurance (“ESI”), commercial insurance purchased on state marketplaces, or Medicaid. In Massachusetts, some CMC who are covered by their families’ ESI may also be eligible for MassHealth Premium Assistance,¹³ for services covered by MassHealth Standard, or supplemental MassHealth coverage under the CommonHealth program (which provides benefits to children and young adults with disabilities up to age 21¹⁴ and to eligible adults age 21 and over).¹⁵ MassHealth also offers additional supports such as Community Case Management to develop care plans and connect beneficiaries

i Baystate Health, Boston Children’s Hospital, Federation for Children with Special Needs, Franciscan Children’s, 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, Tufts Children’s Hospital

with services, or expanded services for children with autism in collaboration with DDS under the Autism Waiver program, as shown in **Exhibit 1**. There is a small population of children in Massachusetts who are eligible for both Medicaid and Medicare coverage.¹⁶

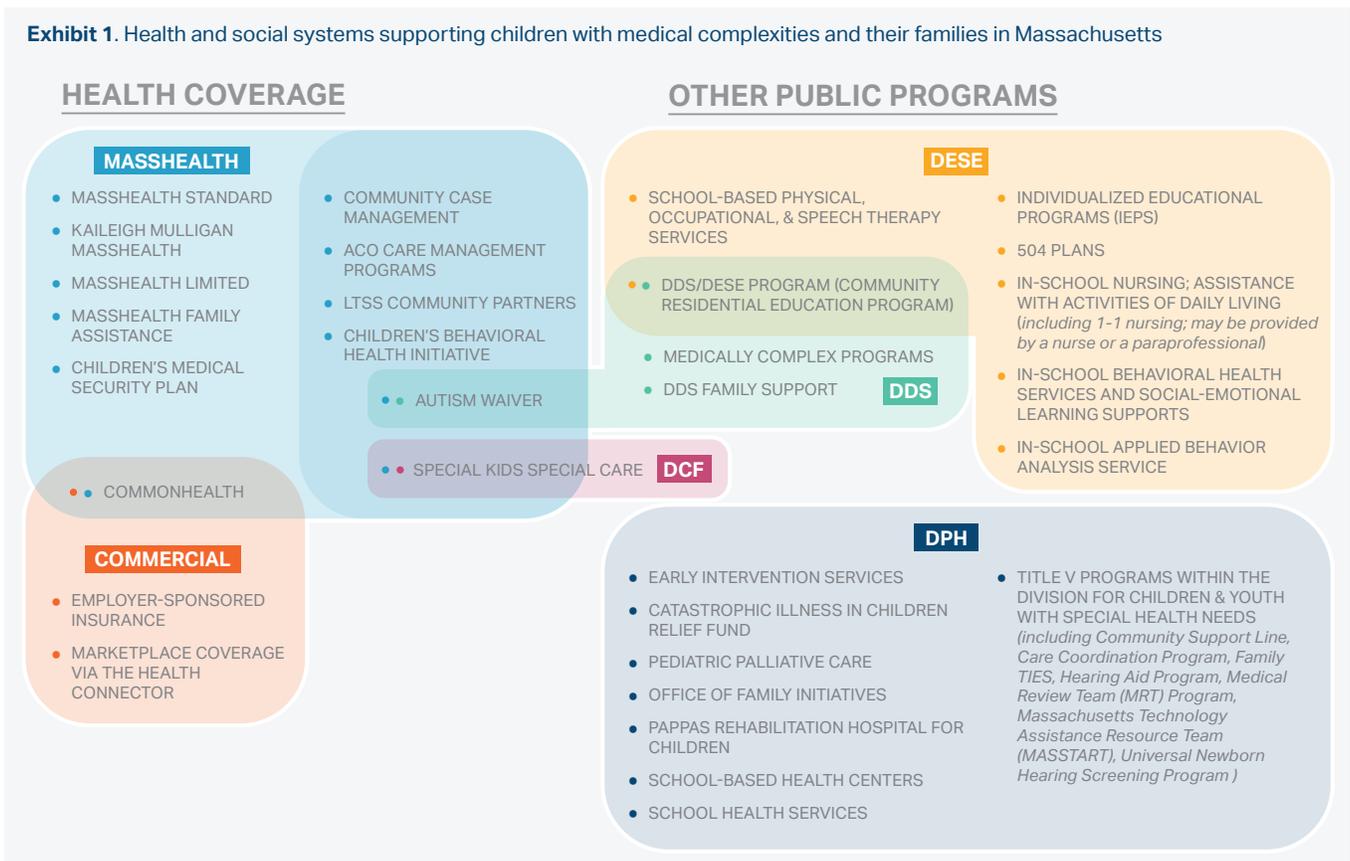
SCHOOL-BASED SERVICES

In addition to educational supports for children with disabilities, such as Individualized Educational Programs (“IEP”) to ensure access to specialized instruction, and 504 plans to ensure children receive any accommodations needed for equal access to education, many CMC receive health services while in school. These can include physical, occupational, and speech therapy, behavioral health supports, and nursing services for medical care or assistance with activities of daily living.

OTHER PUBLIC PROGRAMS

There are numerous other public programs that also support CMC. DDS provides case management and funding for families caring for young adults with complex health needs via their Medically Complex Programs, and helps families navigate services for children with disabilities via Family Support Centers. The DCF program “Special Kids Special Care” supports CMC who are involved in the foster system. Among other supports, DPH provides early intervention services for children under age 3 who have or are at risk of developmental delay, as well as pediatric palliative care, care coordination supports, services supporting children with special health care needs or who rely on medical technology in schools (MASSTART), financial assistance for hearing aids, and Medical Review Team screening and placement services for children and young adults in need of skilled nursing or rehabilitation care. DPH’s Catastrophic Illness in Children Relief Fund assists families with catastrophic medical and related expenses not covered by insurance or other financial sources.ⁱⁱ The Pappas Rehabilitation Hospital for Children is a pediatric chronic care hospital that also provides speech, occupational, and physical therapy, as well as educational services for children enrolled in MassHealth.

Exhibit 1. Health and social systems supporting children with medical complexities and their families in Massachusetts



ii Massachusetts families with children under age 22 whose medical and related expenses are more than 10% of the family’s yearly income from all sources up to \$100,000, plus 15% of any portion of the family income that is above \$100,000 in a given 12-month period, are eligible to apply for CICRF assistance. For more information, see: <https://www.mass.gov/service-details/check-eligibility-for-cicrf>

METHODS

In general, CMC have high health resource needs and significant cognitive or functional limitations that often require surgery, DME, or medical technology – frequently, though not always, as a result of multiple chronic conditions across several body systems.^{17,18} Examples of diagnoses among CMC may include cerebral palsy, cystic fibrosis, and cardiovascular and genetic conditions; examples of DME and medical technology needs include tracheostomy and gastrostomy tubes, dialysis, wheelchairs, and supplemental oxygen.^{19,20} CMC are likely to need inpatient care^{21,22,23} and – among families who are able to access it – home health services.²⁴ Distinct from healthier children who may have one-time high-cost health service needs, CMC are often characterized by multiple consecutive years of high spending.²⁵

There is ample research supporting the use of diagnosis codes to identify CMC in administrative data.^{26,27,28,29,30} The Pediatric Medical Complexity Algorithm (“PMCA”)³¹ is an algorithm designed to use diagnosis information to identify CMC in administrative data: it flags individuals as having conditions of varying levels of chronicity and complexity, including physical, behavioral, and developmental diagnoses. The PMCA sorts individuals ages 21 and younger into three categories: non-chronic, non-complex chronic, and complex chronic. The PMCA identifies medical complexity using more- and less-conservative definitions of complexity, based on the number of claims per body system of diagnosis for at least two body systems (**Exhibit 2**).³² The less-conservative definition identifies children with at least one claim as being complex chronic, while the more-conservative definition requires at least two claims.

Exhibit 2. Identification of children with medical complexity using the Pediatric Medical Complexity Algorithm

PMCA CATEGORY	INCLUDED INDIVIDUALS	EXAMPLES
NON-CHRONIC	Health care utilization but no diagnoses	Pediatric well visit
	Diagnoses that resolve in under one year	Ear infection, pneumonia
NON-COMPLEX CHRONIC	Chronic diagnoses lasting more than one year	Type I diabetes, ADHD
COMPLEX CHRONIC	Multiple chronic diagnoses	Type I diabetes and ADHD, developmental delay and a chronic pulmonary condition
	Progressive conditions	Cystic fibrosis, muscular dystrophy
	Continuous dependence on technology	Renal dialysis, tracheostomy with ventilator assistance
	Malignancies	Leukemia, Lymphoma

Source: 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.

However, diagnoses alone do not make individuals medically complex, because they do not account for health care needs or functional impairments. Relying only on diagnosis codes to identify CMC risks inaccurately counting largely asymptomatic children as CMC on the basis of their diagnoses, while excluding CMC whose conditions are not defined by coded diagnoses.³³ Likewise, when using administrative data such as claims and discharges, patients with difficulty accessing needed care or receiving a definitive diagnosis may appear less complex.³⁴ As a result, a diagnosis-based approach to identifying CMC may need refinement to ensure that children are not identified as CMC incorrectly, and that likely CMC are not overlooked. The HPC was able to take the most refined approach to identifying CMC in claims data, which includes ambulatory, inpatient, and pharmacy utilization and spending.

DATA SOURCES

The HPC uses both medical claims and hospital discharge data for this report.

For medical claims analysis, the HPC analyzed CHIA's All-Payer Claims Database. The commercial claims included the five largest commercial payers in Massachusetts. MassHealth claims included claims from MassHealth programs delivered via managed care plans (MassHealth MCO/ACO), as well as services covered by MassHealth on a fee-for-service basisⁱⁱⁱ for eligible individuals with primary commercial or managed care coverage, as listed in **Exhibit 3**.^{iv} These claims-based data sources provide a full picture of all health care utilization for covered members (office visits, hospital outpatient visits, prescription drugs, emergency department visits, etc.). However, they do not provide complete

view of care use among CMC in Massachusetts because some commercially-insured and MassHealth-covered children in Massachusetts are not included in the HPC's set of claims from the APCD.

In contrast, data from CHIA's Hospital Inpatient Discharge and Emergency Department Databases includes all discharges for inpatient stays and emergency department ("ED") visits in Massachusetts, regardless of payer or coverage. However, this dataset does not include information on amounts paid for care, in addition to not providing information on other types of health care used. Thus, the HPC uses each data source to address different questions.

Exhibit 3. Administrative data sources

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

Medical claims
 Hospital discharges

iii There are two aspects of MassHealth coverage: the MassHealth program for which a resident is eligible, and how the program's benefits are delivered. Benefits may be delivered either fee-for-service, or via managed care. In managed care, a beneficiary enrolls in a managed care organization ("MCO") or accountable care organization ("ACO"). In MassHealth MCO/ACO plans, MassHealth contracts with MCOs and ACOs run by commercial payers, which cover and coordinate beneficiaries' care. Individuals with primary commercial or MCO/ACO coverage may also be eligible for services covered by MassHealth on a secondary, fee-for-service basis. MassHealth estimates that 70% of CMC who are MassHealth beneficiaries are enrolled in ACOs and 4% are enrolled in MCOs (Source: Data on 2019 MassHealth program enrollment by children with medical complexities provided by the Massachusetts Executive Office of Health and Human Services). For more information, see <https://www.mass.gov/service-details/mashealth-health-plans>

iv The Massachusetts All-Payer Claims Database does not include claims from all self-insured plans, per *Gobeille v. Liberty Mutual Insurance Co., Inc.* Available at: https://www.supremecourt.gov/opinions/15pdf/14-181_5426.pdf

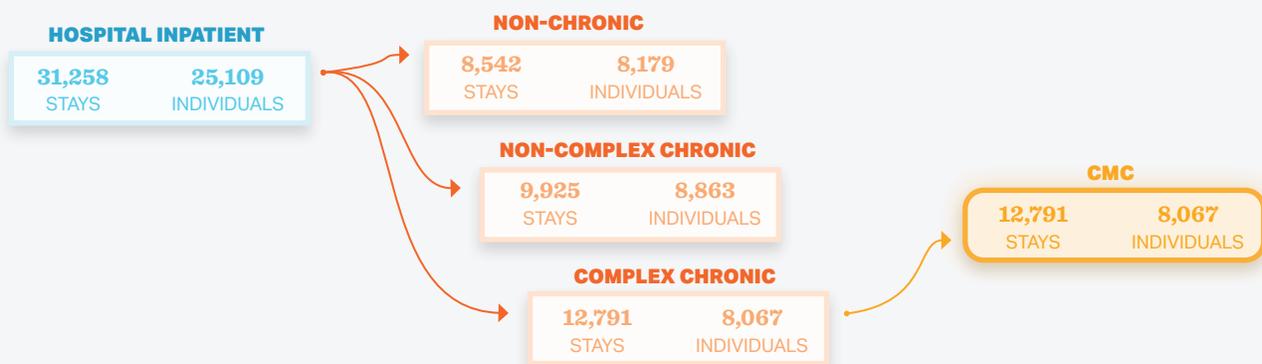
PREVALENCE OF CHILDREN WITH MEDICAL COMPLEXITY BY DATA SOURCE

The following sections discuss identification and prevalence of CMC in the data sources noted above: hospital inpatient discharge data, emergency department discharge data, and insurance claims data.

INPATIENT STAYS

Inpatient stays among children and young adults are rare events: individuals aged 1-21 represent about 4% of all inpatient stays in MA each year. For the purposes of identifying CMC in 2018 inpatient stays in the HIDD, the HPC used the less-conservative definition of the complex chronic group as identified by the PMCA to identify CMC.^v This approach identified 8,064 individuals as CMC, with 12,791 inpatient hospital stays (**Exhibit 4**). Among MA residents ages 1-21 in 2018, CMC represented 32% of individuals with hospital stays and 41% of hospital stays.

Exhibit 4. Identifying children with medical complexities in inpatient hospital stays:

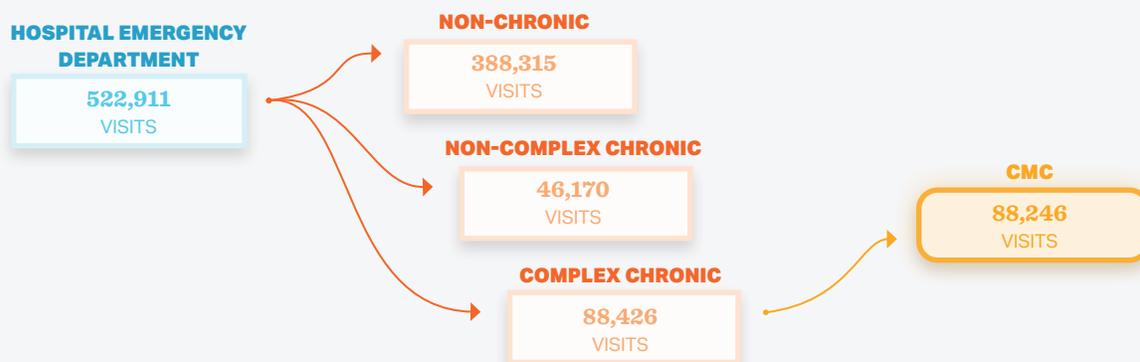


Source: HPC Analysis of the Center for Health Information and Analysis (CHIA), Hospital Inpatient Discharge Database, 2018

EMERGENCY DEPARTMENT VISITS

Visits to the ED may have numerous diagnoses recorded, and the PMCA sorts individuals by chronicity and complexity according to their diagnoses. As a result, the PMCA flagged a relatively large number of ED visits as associated with complex chronic diagnoses.^{vi} The HPC used the less-conservative definition of the complex chronic group as equivalent to CMC, resulting in 88,426 ED stays among CMC in 2018 (**Exhibit 5**). This represents 17% of all ED visits among individuals ages 1-21 in 2018.

Exhibit 5. Identifying children with medical complexities in emergency department visits



Source: HPC Analysis of the Center for Health Information and Analysis (CHIA), Emergency Department Discharge Database, 2018

^v The HPC excluded individuals younger than one year old from all analyses in order to omit conditions due to prematurity or complications of delivery that may not reflect true, ongoing medical complexity.

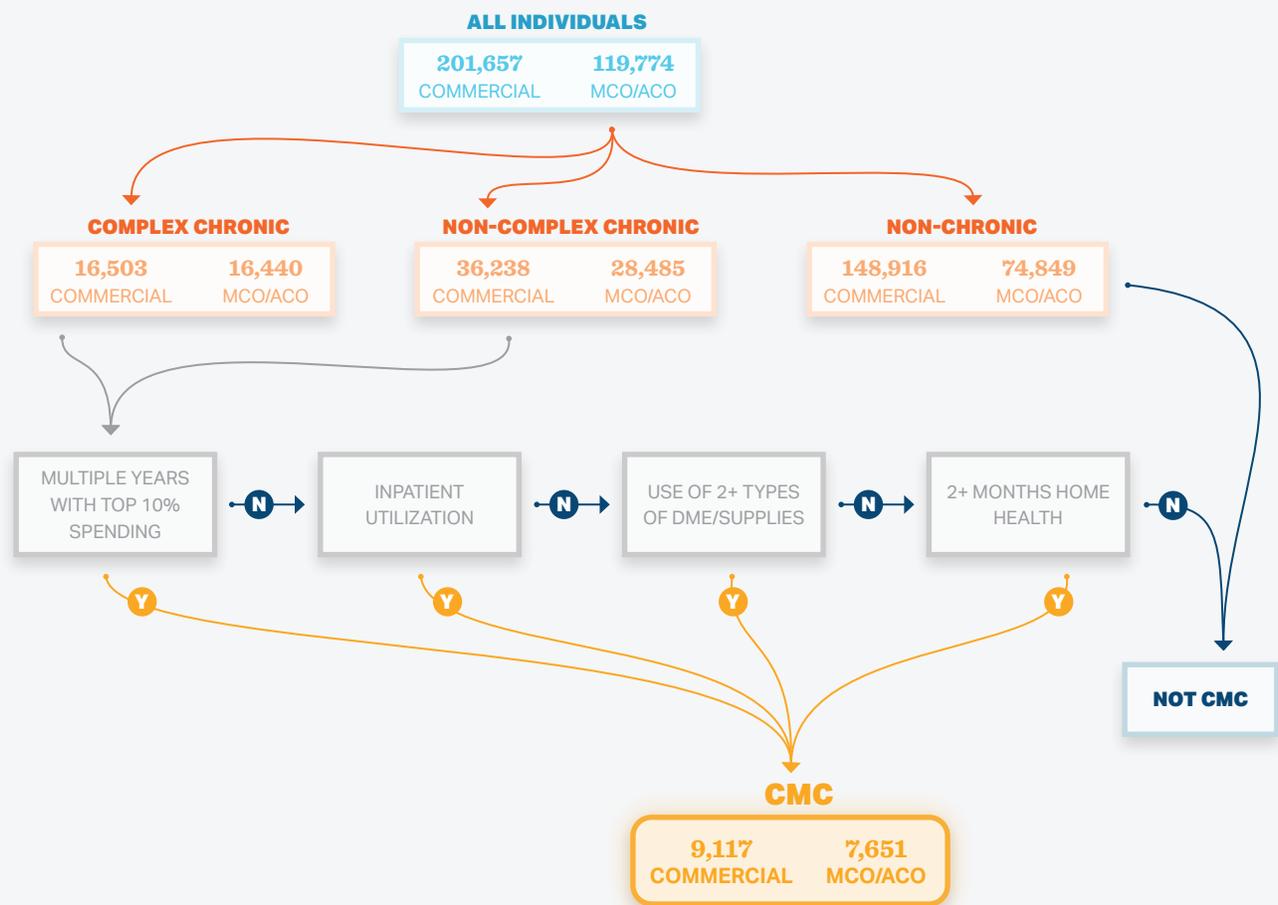
^{vi} Due to likely over-identification of CMC, the HPC did not use individual-level information from ED discharges for this report.

COMMERCIAL AND MASSHEALTH MCO/ACO CLAIMS DATA

Since claims data include ambulatory, inpatient, and pharmacy utilization as well as spending, HPC was able to refine claims data flagged with the PMCA to more precisely identify CMC. After retaining individuals with a full year of health coverage in both 2017 and 2018, the HPC used spending and utilization criteria to identify CMC among those who the PMCA flagged as either complex chronic or non-complex chronic using the less-conservative definition. Any individual in either the complex chronic or the non-complex chronic group with top 10% spending in both 2017 and 2018, inpatient utilization of any kind, utilization of two or more categories of DME and supplies,^{vii} or with two or more months of home health utilization was flagged as CMC (**Exhibit 6**). This approach identified 9,117 individuals with commercial coverage in 2018 (4.5% of the commercial population age 1-21) and 7,651 individuals with MassHealth MCO/ACO coverage in 2018 (6.4% of the MassHealth MCO/ACO population age 1-21).

As discussed above, some CMC may be eligible for services covered by MassHealth on a secondary, fee-for-service basis, such as personal care services, non-emergency transportation, therapeutic behavioral services, or occupational therapy. The HPC cross-referenced the CMC with MassHealth MCO/ACO coverage identified above to individuals who received services covered fee-for-service by MassHealth, and found that 65% of CMC with MassHealth MCO/ACO coverage had services covered by MassHealth fee-for-service in 2018.^{viii}

Exhibit 6. Identifying children with medical complexities in claims data



vii DME and supply categories were identified using 2021 Berenson-Eggers Type of Service (BETOS) code groupings, modified to include a category for enteral and paraenteral supplies.

viii Commercially-insured CMC with services covered by secondary fee-for-service MassHealth were not reliably identifiable.

DEMOGRAPHICS OF CMC IDENTIFIED FROM EACH DATA SOURCE

Similar to national-level findings on children with special health care needs,³⁵ the HPC found no significant differences in rates of CMC by race and ethnicity and found slightly higher rates of CMC among older age groups. The HPC also found that CMC in Massachusetts are approximately evenly distributed by sex, although national data indicates that boys are slightly more likely to have special health care needs than girls. CMC were found to live in all regions of the Commonwealth and represent a slightly larger proportion of Mass-Health beneficiaries age 1-21 compared to those with commercial health insurance.

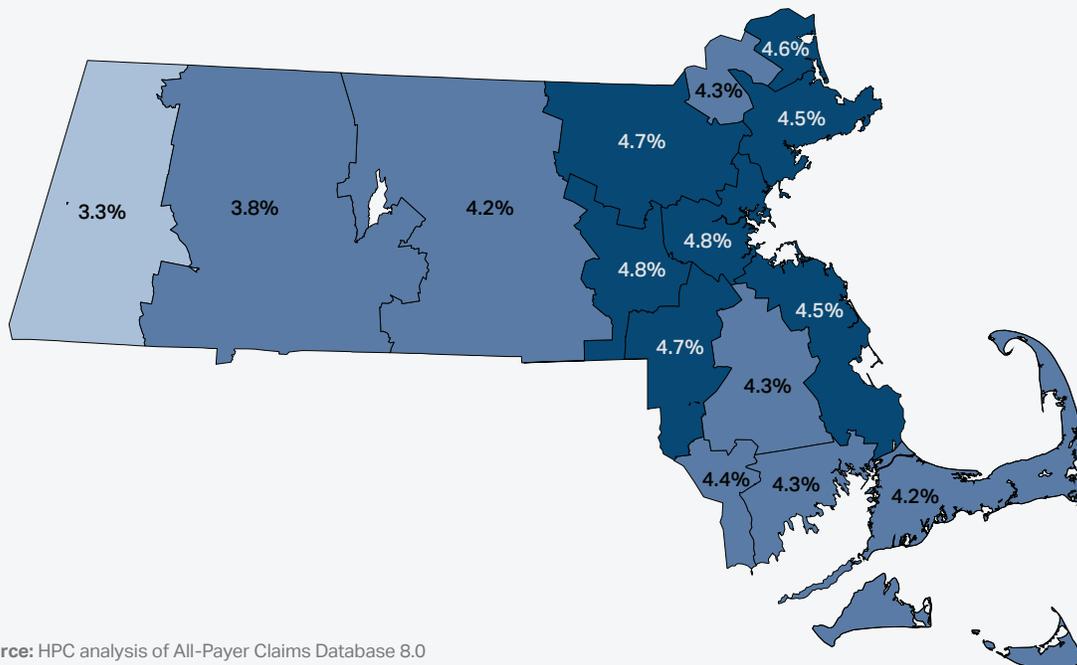
INPATIENT STAYS

Among CMC who received inpatient care in 2018, about half were female (52%) and about half were male (48%). There do not appear to be differences in use of inpatient care by patient race or ethnicity: among patients ages 1-21, similar proportions of CMC and non-CMC by patient race and ethnicity received inpatient hospital care in 2018. CMC who received inpatient care were slightly more likely to be in older age groups, and to live in lower-income areas: 55% were ages 15-21, and half lived in lower-income zip codes.

COMMERCIALLY-INSURED CMC

The HPC estimates that 4.5% of the commercial population age 1-21 are CMC. Among commercially-insured CMC as of 2018, about half were female (48%) and about half were male (52%). CMC made up 3-6% of each age group, with slightly higher proportions of CMC in older age groups: CMC represented 3-5% of individuals aged 1-14, and 5-6% of individuals aged 15-21. While CMC were evenly spread among income deciles – representing 4-5% of residents aged 1-21 in each income decile – half of commercially-insured CMC lived in higher-income areas, reflecting the overall demographics of the commercially-insured population. In terms of geography, CMC made up 3-5% of individuals aged 1-21 per region, with higher rates of CMC living in Eastern Massachusetts (**Exhibit 7**).

Exhibit 7. Rates of CMC among commercially-insured individuals ages 1-21 per region, 2018



Behavioral and developmental diagnoses were common among commercially-insured CMC: 38% of CMC had mental health diagnoses, such as anxiety or depression, and 38% had neurodevelopmental diagnoses, such as autism or ADHD.^{ix} The most common diagnoses among commercially-insured CMC were major depression diagnoses (2,726), anxiety diagnoses (2,311 individuals), autistic disorder (1,452), ADHD diagnoses (1,827), and Type 1 diabetes (904).

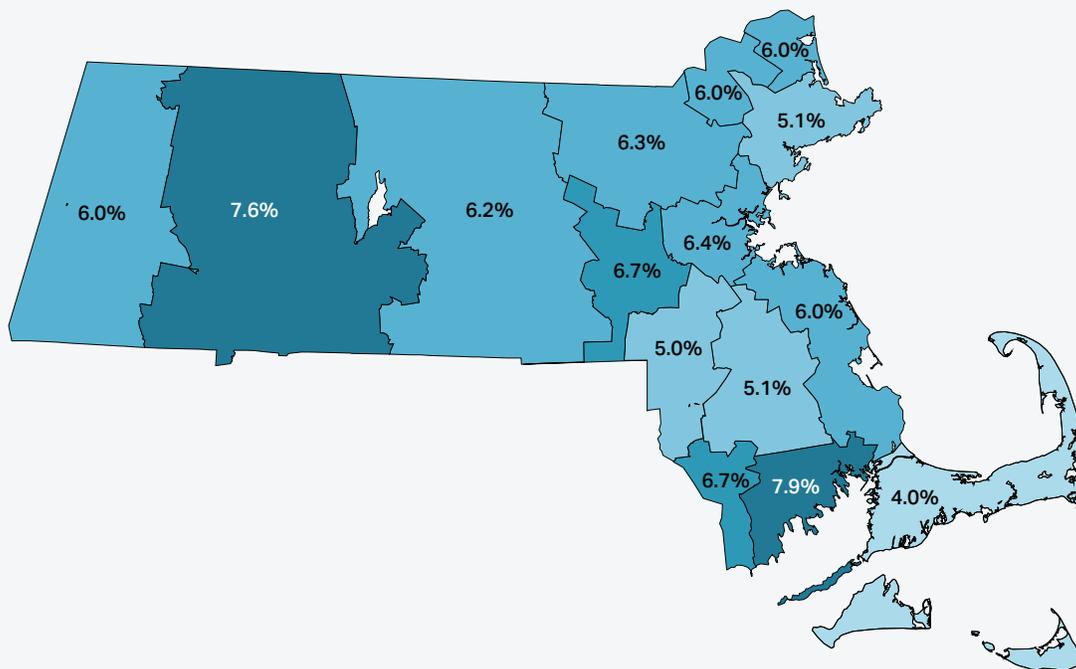
ix Mental, behavioral, and developmental diagnoses identified using AHRQ CCSR MBD001-MDB034.

MASSHEALTH BENEFICIARIES

CMC make up a greater proportion of children and young adults with MassHealth coverage. The HPC estimates that 6.8% of the MassHealth MCO/ACO population age 1-21 are CMC.

Among CMC with MassHealth MCO/ACO coverage as of 2018, 42% were female and 58% were male. CMC made up 6-11% of each age group, with the highest proportions of CMC among young adults: 6-7% of individuals ages 1-18 were CMC, while 11% of individuals ages 19-21 were CMC. CMC represented 5-7% of residents ages 1-21 in each income decile, with over two-thirds of CMC living in lower-income areas, reflecting the demographics of MassHealth beneficiaries. CMC represented 4-8% of individuals ages 1-21 per region, with higher rates of CMC in the Pioneer Valley and New Bedford (**Exhibit 8**).

Exhibit 8. Rates of CMC among individuals covered by MassHealth MCO/ACO plans ages 1-21 per region, 2018



Source: HPC analysis of All-Payer Claims Database 8.0

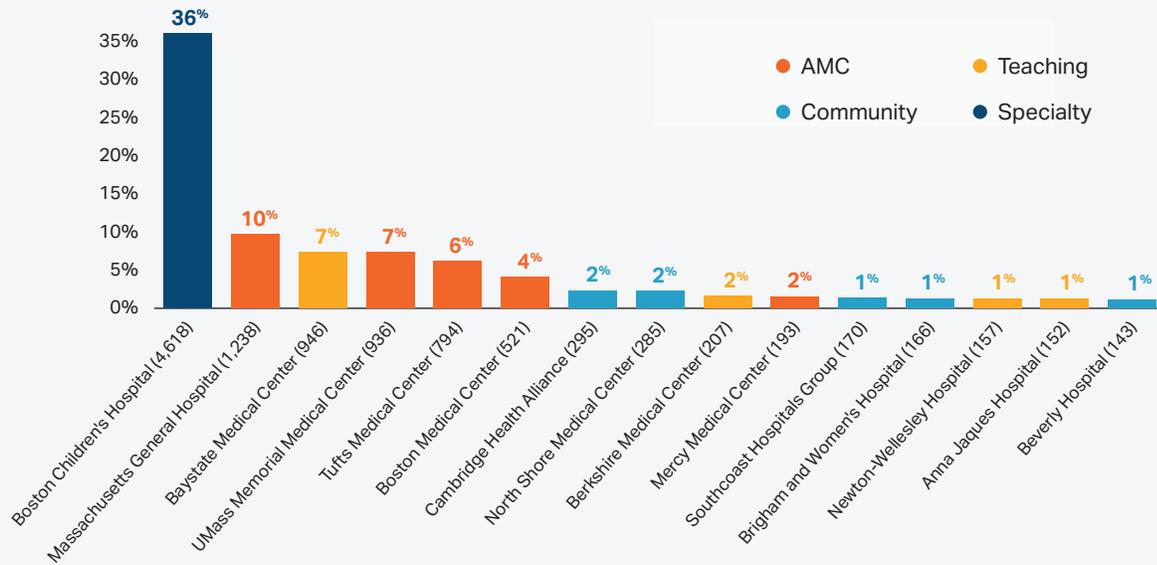
Many CMC with MassHealth MCO/ACO coverage had behavioral and developmental diagnoses. Forty-two percent had mental health diagnoses and 46% had neurodevelopmental diagnoses. The most common diagnoses among CMC with MassHealth MCO/ACO coverage were asthma diagnoses (3,051), ADHD diagnoses (2,491 individuals), autistic disorder (1,267), anxiety diagnoses (1,097), post-traumatic stress disorder (674), and oppositional defiant disorder (477).

UTILIZATION

INPATIENT

Pediatric inpatient utilization in Massachusetts is fairly rare, and CMC are overrepresented among children and young adults who receive inpatient hospital care relative to their overall prevalence. CMC made up nearly one-third of individuals ages 1-21 who were hospitalized in 2018 and spent longer in the hospital on average than children without medical complexities. Among children and young adults who were hospitalized in 2018, the average length of stay among CMC was 6.5 days, nearly double the average length of stay of healthier children, at 3.6 days. Most inpatient stays among CMC took place at only a few hospitals, with over one-third of stays in 2018 taking place at Boston Children's Hospital (**Exhibit 9**).

Exhibit 9. Proportion of Massachusetts CMC discharged per hospital at the top 15 hospitals for CMC discharges, 2018

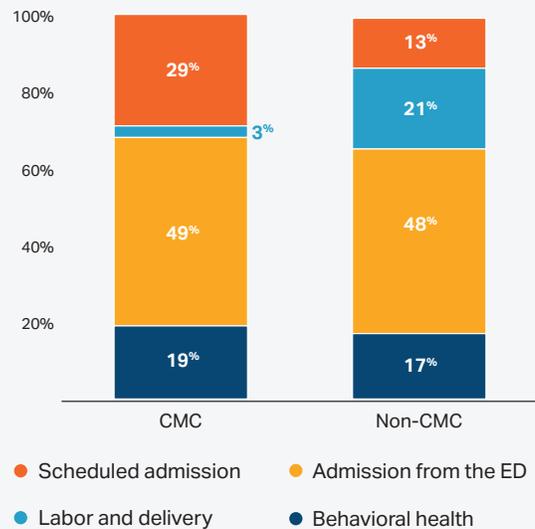


Notes: Includes CMC age 1-21 at the fifteen hospitals with the greatest proportion of CMC inpatient discharges in 2018 out of all CMC in Massachusetts.
Source: HPC Analysis of the Center for Health Information and Analysis (CHIA), Hospital Inpatient Discharge Database, 2018

Inpatient stays among individuals ages 1-21 are rare events, and while CMC represent under 10% of the pediatric population, they had 41% of the inpatient hospital stays in this age group in 2018. Despite different rates of hospitalization between CMC and non-CMC, the share of admissions for behavioral health conditions was similar between groups: 19% for CMC, 17% for non-CMC. Among CMC, the top categories of hospital admission were admission from the ED (49%) and scheduled admission (29%) (**Exhibit 10**). Among non-CMC, the top categories of hospital admission were admission from the ED (48%) and labor and delivery (21%).

Among pediatric patients with at least one hospital admission, CMC are more likely than non-CMC to have multiple hospital admissions in a year and have substantially higher rates of readmissions. CMC included for analysis of hospital readmissions^x represented 80% of 30-day readmissions among patients ages 1-21 (1,745 readmissions) and had a 30-day readmission rate of 14.7%, compared to a 3.1% readmission rate among non-CMC. Among CMC, top indications for readmission^{xi} were diseases of white blood cells (117 readmissions), epilepsy (81), sickle-cell anemia (80), diabetes mellitus with complications (64), and complication of surgical or other medical care (62).

Exhibit 10. Category of hospital admission among CMC and non-CMC, 2018



Notes: Includes individuals age 1-21
Source: HPC Analysis of the Center for Health Information and Analysis (CHIA), Hospital Inpatient Discharge Database, 2018

x Readmissions analysis used CMS/Yale Hospital-Wide All-Cause Unplanned 30-day Readmission methodology, in which a set of index visits is identified and matched with readmissions within a 30-day time period. Hospital transfers, rehabilitation, admissions for labor and delivery care, discharges against medical advice, and deaths while hospitalized were excluded as index admissions. "Always planned" admissions for maintenance chemotherapy, rehabilitation, and transplant care were excluded as readmissions. Following methodology from CHIA, data cleaning and collapsing included removing duplicate records, collapsing overlapping stays, and combining adjacent admissions. For more information, see: <https://www.chiamass.gov/assets/docs/r/pubs/18/Readmissions-Technical-Appendix-2011-2017.pdf>

xi Based on analysis using AHRQ CCSR categories.

AMBULATORY CARE

Commercially-insured CMC have nearly three times the outpatient utilization of healthier children, with an average of 9.4 office visits per person each year compared to 3.3 visits for non-CMC. For MassHealth beneficiaries, CMC have 6.6 office visits per year, compared to 2.9 for non-CMC. The high frequency of office visits among CMC illustrates not only the relatively large amount of care needed among this group of children and young adults, but also the high time burden of accessing care for CMC and their families.

Ninety-nine percent of commercially-insured CMC and 94% of CMC with MassHealth MCO/ACO coverage had primary care utilization in 2018, including 1.1% of commercially-insured CMC and 0.6% of CMC with MassHealth MCO/ACO coverage who received at least some primary care services via home health.

EMERGENCY DEPARTMENT

Among both commercially-insured individuals and MassHealth beneficiaries, CMC are more likely to use the ED than non-CMC, and have more ED visits per person. Thirty-seven percent of commercially-insured CMC had at least one ED visit in 2018, compared to 12% of non-CMC. Likewise, 56% of CMC with MassHealth MCO/ACO coverage had at least one ED visit, compared to 30% of non-CMC.

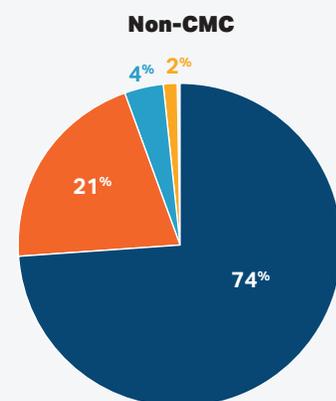
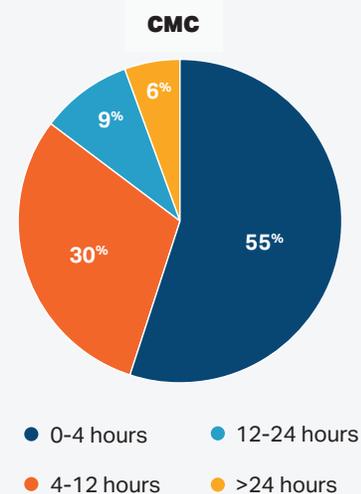
CMC also have nearly twice as many ED visits per person. Commercially-insured CMC had 2.7 ED visits on average per person, compared to 1.4 visits per person for non-CMC. Among MassHealth beneficiaries, CMC had an average of 3.1 visits per person, compared to 1.8 visits per person for non-CMC.

Often, CMC visited the ED for behavioral issues and acute physical complaints. Among commercially-insured CMC, the most common reasons for ED visits were depression (295 individuals), abdominal pain (279), fever (202), cough (193), chest pain (176), and suicidal ideation (149). CMC with MassHealth MCO/ACO coverage most often visited the ED for issues such as cough (298), upper respiratory infection (287), fever (273), abdominal pain (251), asthma (241), enterovirus (216), chest pain (179), shortness of breath (172), and depression (168).

CMC were more likely than children without medical complexities to spend longer than 12 hours in the ED (**Exhibit 11**). Spending 12 or more hours in the ED from the time of arrival to time of departure is considered “boarding” in the ED, which – when related to behavioral health needs – can be due to an inadequate supply of outpatient and inpatient behavioral health services, such as a shortage of emergency psychiatric providers or a lack of post-acute placement resources.^{36,37}

Prior HPC work has documented a rise in ED boarding for mental and behavioral health conditions in Massachusetts, especially among residents ages 12-17.³⁸ The shortage of beds in inpatient psychiatric facilities may be exacerbated for CMC, as many inpatient psychiatric facilities may not be equipped to care for children’s complex physical health needs.

Exhibit 11. Length of emergency department visits among CMC and non-CMC, 2018



Notes: Includes individuals age 1-21. May represent an overcount of CMC ED discharges (e.g. ED discharges of CMC may include some discharges of children who are not medically complex), but pattern of longer ED visits persists despite the potential overcount.

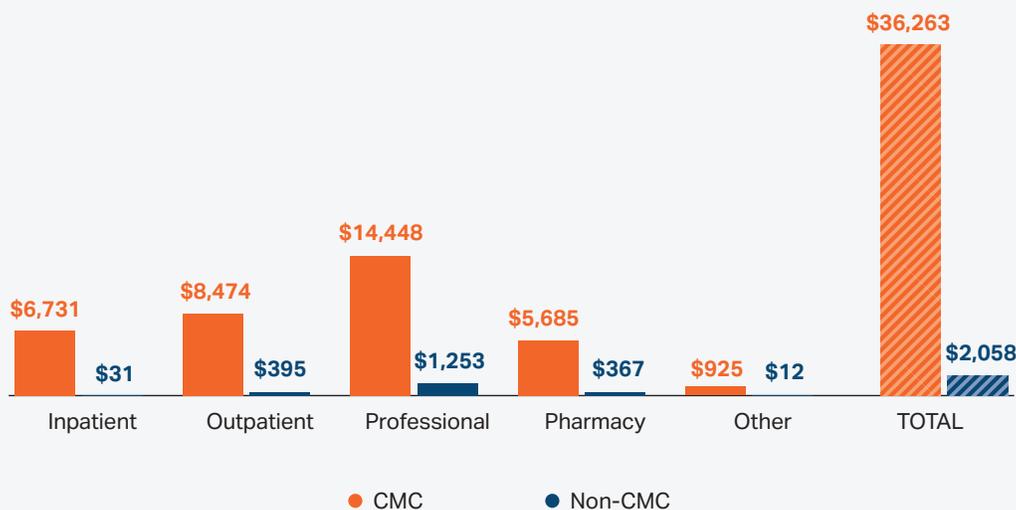
Source: HPC Analysis of the Center for Health Information and Analysis (CHIA) Emergency Department Discharge Database, 2018

SPENDING

COMMERCIAL

In all categories of spending, commercially-insured CMC have significantly higher spending per member per year than children without medical complexities (**Exhibit 12**). Commercially-insured CMC had over \$36,000 in spending per individual in 2018, compared to about \$2,000 for children without medical complexities. The HPC estimates that spending for commercially-insured CMC in 2018 represented 3.6% of spending by the five largest commercial payers that year,^{xii} and 46% of spending for individuals ages 1-21 who were insured by the five largest commercial payers.

Exhibit 12. Commercial spending per person per year by spending category for children with and without medical complexities, 2018



Notes: Includes individuals age 1-21. 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

Several conditions were both relatively common among commercially-insured CMC, and had high average spending associated with their treatment. These included autistic disorder (1,452 individuals, \$24,920), Crohn’s disease (178 individuals, \$28,736), spastic quadriplegic cerebral palsy (133 individuals, \$11,213), and anorexia nervosa (113 individuals, \$17,989).

A separate analysis^{xiii} of spending and utilization for DME and supplies found that commercially-insured CMC had \$2,285 on average in spending for DME and supplies each year, with enteral and paraenteral supplies (which supply nutrition via a feeding tube to the gastrointestinal tract or intravenously) and wheelchairs as the most costly categories of DME. Children without medical complexities had under \$300 each year on average in spending for DME.

Commercially-insured CMC also had much higher out-of-pocket (“OOP”) spending than children without medical complexities. OOP medical and pharmacy costs for CMC were 5.5 times greater than for non-CMC, with \$2,251 in OOP costs for CMC compared to \$407 for healthier children. However, OOP spending that is measurable from claims data does not capture the full spectrum of health care-related costs that families of CMC may need to bear. For example, much pediatric specialty and sub-specialty care in Massachusetts is

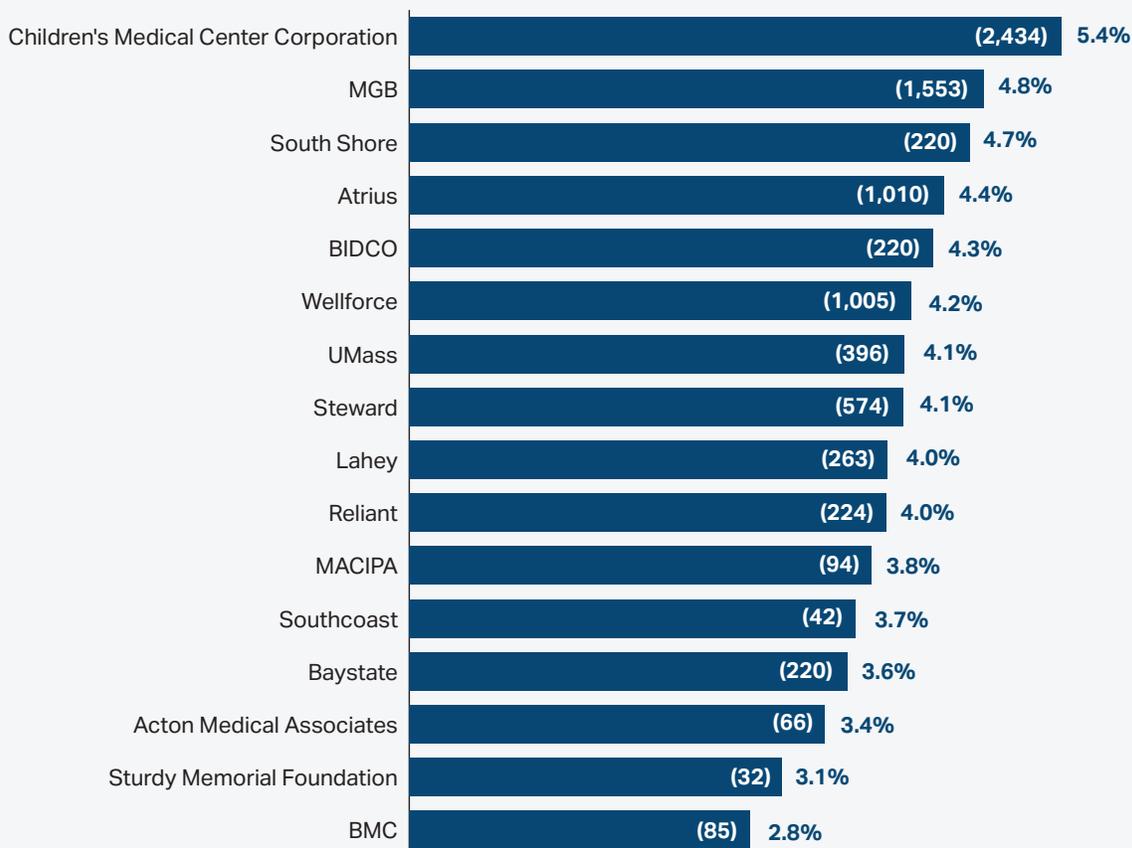
xii Total commercial spending by the five largest commercial payers in MA in 2018 was \$7,688,599,795. Spending for CMC covered by the five largest commercial payers accounted for \$278,635,164 in 2018. CMC covered by the five largest commercial payers represented 0.50% of all Massachusetts commercial members in 2018. Source: CHIA Annual Report TME Databook, available at <https://www.chiamass.gov/thce-tme-apm>

xiii Analysis used DME and supply categories identified using 2021 Berenson-Eggers Type of Service (BETOS) code groupings, modified to include a category of enteral and paraenteral supplies.

located in the Boston area, and families who need to travel from other parts of the Commonwealth may bear the costs of transportation, parking, food, lodging, and parent or caregiver time off from work, in addition to any OOP costs associated with the medical care itself. Other non-reimbursed costs related to health care for CMC may include home accessibility modifications, assistive technology, or specialized food preparation.³⁹

CMC are distributed relatively evenly among provider organizations, as measured by the organizational affiliation of their primary care providers. CMC represent about 3-5% of commercially-insured individuals ages 1-21 per provider organization, ranging from 2.8% of the pediatric population at Boston Medical Center to 5.4% at Children’s Medical Center Corporation (**Exhibit 13**). For detail on commercial spending for CMC and non-CMC by provider organization, see **Appendix A**.

Exhibit 13. Count and proportion of children with medical complexities among individuals age 1-21 by provider organization, 2018



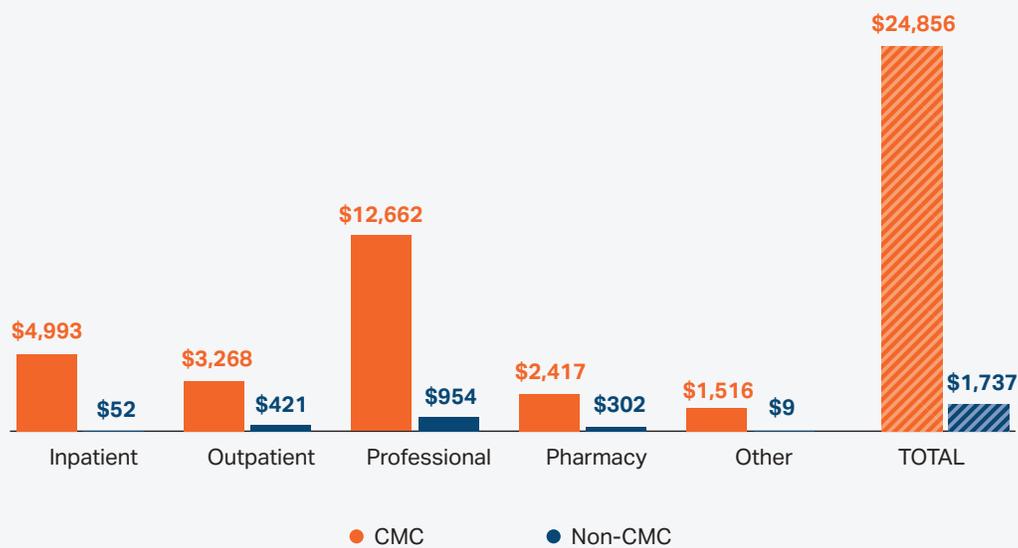
Notes: Includes individuals age 1-21. Individuals are attributed to provider organizations using the organizational affiliation of their primary care providers. Provider groups with <1000 lives observed in 2018 not included: Berkshire Health System, Community Care Cooperative, Franciscan Hospital for Children, Lawrence, Milford Regional Medical Center, New England Baptist Hospital, and Tenet Healthcare Corporation. Missing excluded.

Source: HPC analysis of All-Payer Claims Database 8.0

MASSHEALTH

Similar to children and young adults with commercial insurance, CMC with MassHealth MCO/ACO coverage have much higher spending per year than children without medical complexities (**Exhibit 14**). CMC had nearly \$25,000 in spending in 2018, compared to about \$1,700 among children without medical complexities. The HPC estimates that spending for CMC who are MassHealth MCO/ACO beneficiaries represented 2.4% of all MassHealth managed care spending in 2018,^{xiv} and 49% of all spending for individuals ages 1-21 with MassHealth MCO/ACO coverage. Those CMC who also received services covered by MassHealth on a fee-for-service basis had an additional \$9,793 in spending.

Exhibit 14. MassHealth MCO/ACO spending by spending category for children with and without medical complexities, 2018



Notes: Analysis includes individuals age 1-21. Other includes DME, home health, hospice, skilled nursing, and spending on services of unknown type.

Source: HPC analysis of All-Payer Claims Database 8.0

Common conditions with high average spending associated with their treatment included autistic disorder (1,267 individuals, \$12,079), post-traumatic stress disorder (674 individuals, \$5,701), oppositional defiant disorder (477 individuals, \$5,032), disruptive mood dysregulation disorder (400 individuals, \$6,218), and cerebral palsy (142 individuals, \$12,612).

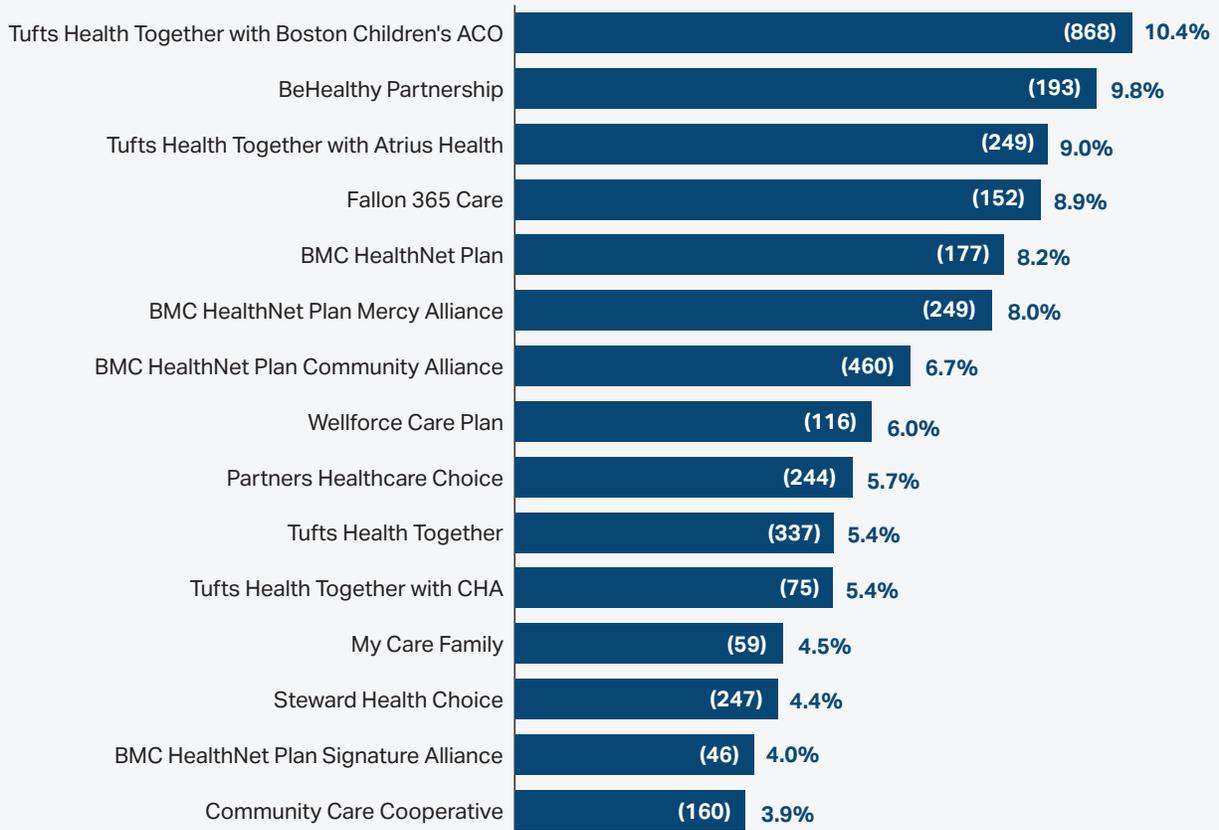
A separate analysis^{xv} of spending and utilization for DME and supplies found that CMC with MassHealth MCO/ACO coverage spent \$1,638 on average for DME and supplies each year, with enteral and paraenteral supplies, wheelchairs, and orthotics as the most costly categories of DME. Children without medical complexities spent an average of \$233 on DME each year.

xiv Total MassHealth managed care spending in 2018 was \$5,190,657,207. Spending for CMC with MassHealth MCO/ACO coverage in 2018 was \$124,001,518. Source: CHIA Annual Report TME Databook, available at <https://www.chiamass.gov/thce-tme-apm>

xv Analysis used DME and supply categories identified using 2021 Berenson-Eggers Type of Service (BETOS) code groupings, modified to include a category of enteral and paraenteral supplies.

The distribution of CMC varies somewhat across MassHealth MCOs and ACOs, as measured by the affiliation of their primary care providers. Approximately 4-10% of individuals ages 1-21 in each MassHealth MCO or ACO are CMC, ranging from 3.9% at Community Care Cooperative to 10.4% at Tufts Health Together with Boston Children’s ACO (**Exhibit 15**). For detail on MassHealth MCO/ACO spending for CMC and non-CMC by provider organization, see **Appendix B**.

Exhibit 15. Count and proportion of children with medical complexities among individuals age 1-21 by MassHealth Managed Care Organizations and Accountable Care Organization, 2018



Notes: Analysis includes individuals ages 1-21. Individuals are attributed to MCOs and ACOs using the MassHealth Enhanced Eligibility file. Analysis includes only those individuals with 12 full months of enrollment in 2018, who changed MCO/ACO enrollment ≤1 time during the year, and who had at least 10 months of enrollment in the same MCO/ACO. This specification resulted in 4,423 CMC retained for analysis, or 58% of CMC. ACOs and MCOs with <1000 lives observed in 2018 not included: Berkshire Fallon Health Collaborative, BMC HealthNet Plan Southcoast Alliance, Commonwealth Care Alliance, Evercare, Tufts Health Together with BIDCO. Missing excluded.

Source: HPC analysis of HPC analysis of All-Payer Claims Database 8.0

RESOURCES AND CHALLENGES FOR CHILDREN WITH MEDICAL COMPLEXITY

The HPC was able to measure demographics, health care utilization, and health care spending for CMC in the Commonwealth. However, administrative data does not capture many key aspects of the daily reality of CMC and their families and caregivers. Meetings with stakeholders and analysis of the research literature highlighted important issues: care continuity, access to primary and specialty care, care coordination, and pediatric-to-adult care transitions.

CARE CONTINUITY

CMC may lack adequate care continuity due to coverage churn, and due to insurance benefit designs that can be a poor fit for a high-need pediatric population.

Changes in parental employment can make care continuity difficult for families with ESI or families who churn between ESI and Medicaid coverage, when specialists and subspecialists are covered by different plans and networks. Research has found that parents of CMC typically spend 11-15 hours each week providing direct home care,⁴⁰ and changes, interruptions, or reductions in employment are frequent among parents^{41,42} who must balance employment with their significant caretaking responsibilities.

Additionally, benefit designs intended to reduce avoidable health spending, such as prior authorization or annual eligibility redeterminations for DME and supplies, can create administrative burdens for providers and lead to interruptions in care or supplies for CMC. For example, stakeholders noted that annual eligibility redetermination for diapers that children will need on an ongoing basis is time-consuming for providers and interrupts families' access to supplies.

Likewise, stakeholders pointed out that families may resort to seeking care in the ED when children require more supplies than their plans cover per year. For example, several providers cited ED visits to replace tracheostomy or gastrostomy tubes after children had used all their covered tubes mid-year. Providers also noted that plans may cover DME at a frequency that would be appropriate for adults, but not for children – such as only covering replacement wheelchairs every few years, even though a child will outgrow a wheelchair before a new one is covered.

ACCESS TO PRIMARY AND SPECIALTY CARE

Access to both primary and specialty care can be challenging for CMC and their families due to the time commitment involved for providers caring for CMC, a need for more pediatric specialists who accept MassHealth, and the regional concentration of pediatric specialty care.

On primary care, stakeholders noted that caring for CMC can be time consuming due both to children's high health needs and to administrative complexity related to insurance benefit designs such as prior authorization or annual eligibility redetermination. As a result of the time investment and administrative challenges associated with caring for medically complex patients, community pediatricians experienced at caring for CMC may only be able to treat a few CMC patients at a time as part of their patient panel.⁴³

On access to specialty care, many CMC require treatment from hard-to-find specialists or subspecialists or may require inpatient treatment. Stakeholders noted that a shortage of pediatric specialists who accept MassHealth can lead to waiting lists and access delays for CMC who are MassHealth beneficiaries, including a domino effect of delays in qualifying for other types of support. For example, several stakeholders described long waiting lists for neuropsychological evaluation as leading to delays in qualifying for educational supports.

Distance can also be a barrier to accessing both primary and specialty care. Children's hospitals with clinics designed to care for CMC are often located in regional hubs; in Massachusetts, much pediatric tertiary and quaternary care is concentrated in the Boston metropolitan area. The challenges community pediatricians face in caring for CMC, combined with the regional concentration of specialty care, means that families may lack access to needed care close to where they live. Although this report finds that nearly all CMC have at least some primary care utilization, that statistic does not capture any distance-related difficulties families may encounter in securing care for their children. Distance to care can be especially challenging for CMC who have difficulty traveling, and for families who lack access to reliable transportation or transportation that can accommodate their children (such as those who rely on medical technology).

CARE COORDINATION

CMC interact with numerous providers and systems and require coordination not only across multiple settings and systems of care, but also among medical, educational, and social services. Families often become de facto care coordinators and case managers while also managing day-to-day parenting and medical caregiving in the home.⁴⁴ Effective care coordination could help to improve communication among providers, avoid duplicative services and screenings, and decrease the burden on families of navigating health and social service systems on their own.⁴⁵

Stakeholders noted that insurer-based care coordination may be an imperfect fit for CMC, who often have significant churn, and suggested that families need an “air traffic controller” to provide a high level of coordination across health, educational, and social service systems. Stakeholders agreed that this level of coordination would be appropriate at regional public health agencies.

SOCIAL COMPLEXITY

Families of CMC often face substantial emotional and financial costs, including social marginalization and parental exclusion from the workforce. These additional social complexities may exacerbate the other difficulties families face in caring for their children. Families of CMC can face an array of financial hardships, such as loss of parental income as parents leave employment to care for their children, significant care-related costs not covered by health insurance, difficulty paying for rent or a mortgage, or forgoing their own medical care due to cost.^{46,47,48}

Many families of CMC also face additional social complexity challenges, such as poverty, housing instability, food insecurity or insufficiency, lack of transportation (including transportation that can accommodate their children), foster system involvement, or language barriers.⁴⁹ Parents of CMC are also at increased risk of poor mental health.⁵⁰ Stakeholders agreed that these types of social complexity only make it more difficult for families to navigate the many health and social systems involved in caring for their children.

Some Massachusetts public programs are able to help families with the financial challenges of caring for CMC. For example, the Catastrophic Illness in Children Relief Fund (DPH) has aided 2,336 families since its initiation in 2001, assisting an average of 123 families each year with catastrophic medical and related expenses not covered by insurance or other financial sources.⁵¹ Other public programs also offer financial assistance for specific care needs, such as hearing aids.⁵²

Additionally, the COVID-19 pandemic has disproportionately affected CMC, who rely on frequent medical, school-based, and home health or personal care services, and has further isolated them and their families.⁵³ Stakeholders noted that CMC have missed much needed care due to caution about exposure, and explained that the unravelling of in-person services has increased hardships for families. MassHealth has adopted several of CMS’s COVID-era state Medicaid program policy changes,^{54,55} including streamlined eligibility processes and coverage of telehealth for home and community-based services.^{56,57} While telehealth has helped many CMC access care without risking exposure to COVID and has alleviated transportation burdens for families, it is not appropriate for all children and remains inaccessible to many families – especially lower-income families, those in rural areas without broadband access, or with language barriers.⁵⁸

PEDIATRIC-TO-ADULT CARE TRANSITIONS

As advances in medical treatment have enabled a growing number of CMC to reach adulthood,^{59,60} an increasing area of concern is the transition to adult care for young adults with complex medical needs. Care transitions for CMC encompass multiple challenges: variation in program eligibility expiration, access to providers equipped to care for young adults with childhood-onset complex health conditions, and difficulties for young adults with complex medical needs as they begin managing their own care.

Number of CMC transitioning to adult care. It is difficult to precisely estimate the number of CMC who will transition to adult care each year because pediatric-to-adult care transitions for CMC generally do not occur all at once: transitioning to adult care takes place gradually between the ages of 18 and 22, as described in the following sections.⁶¹ The HPC estimates that in 2018, there were about 3,385 CMC aged 18-21 years old in Massachusetts, representing 20% of CMC.

Additionally, as detailed earlier in this report, CMC tend to be concentrated in older age groups, which may have implications for transitioning to adult care. Older children and young adults are likely to have more precise diagnoses as a result of more years of contact with the medical system, especially for behavioral or mental health conditions that may initially be misdiagnosed in young children. Older children may also see an increase in service use as they grow and experience puberty.

Variation in eligibility expiration. Different public programs that support CMC and their families have different eligibility cutoffs for young adults, meaning that young adults with complex medical needs will transition out of various forms of public assistance at different times. While preferable to reaching a single eligibility “cliff” at which young adults with complex medical needs become ineligible for all forms of public support at once, this variation in age cutoff by program can increase care coordination challenges by creating an extended period of time in which a young adult’s network of providers is in flux. For example, DPH’s Pediatric Palliative Care program covers children under 19 years old.⁶² Eligibility for several MassHealth programs expires when young adults turn 21, including Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services,⁶³ as well as behavioral health services for children and young adults with significant mental health needs or serious emotional disturbance who are enrolled in the MassHealth Standard or CommonHealth programs.⁶⁴ Eligibility cutoffs for Title V-funded programs at DPH, as listed in **Exhibit 1**, vary by program: for instance, financial assistance for hearing aids is available up to age 21,⁶⁵ while the Medical Review Team provides services to children and young adults with disabilities or cognitive impairments up to age 22,⁶⁶ and care coordination for children and young adults with special health care needs is available up to age 23.⁶⁷ Services offered under DDS’s Medically Complex Programs are available up to age 25.⁶⁸ Young adults may also age out of services provided in schools, such as physical or occupational therapy.⁶⁹ Young adults with complex medical needs who benefit from these services need to assemble a new network of services and providers as they age out of eligibility for the programs and services that supported them as children.

Access to adult providers. Assembling a new network of adult providers can be challenging for young adults with complex medical needs, because young adults with complex medical needs transitioning from pediatric to adult health care often have trouble finding providers able to care for them. A survey of providers who care for adults with pediatric-onset chronic conditions found that adult providers are often unequipped to care for their complex patients.⁷⁰ Adult providers are typically siloed away from pediatric providers, meaning that relatively few have experience managing pediatric-onset chronic conditions; additionally, providers report a lack of expertise, care coordination capabilities, and time to spend with their complex patients. Compounding the difficulty of finding a clinician, adult providers may offer limited flexibility on appointment times for patients who do not control their own transportation (such as those who use medical transport), meaning that patients may be treated as no-shows or have difficulty rescheduling, and therefore have trouble accessing timely care.⁷¹ Young adults with complex medical conditions may remain with their pediatricians for an extended period of time if they or their families are unable to find adult providers who can manage complex conditions that begin in childhood; similarly, they may continue receiving care at specialized clinics for conditions, such as cerebral palsy or cystic fibrosis, that are often considered to be pediatric.⁷²

Self-management. Adult health care assumes patient independence, self-direction, and self-advocacy, all of which can be a challenging learning curve for young adults beginning to navigate the health system on their own.⁷³ Adult institutions may also have fewer interdisciplinary providers, such as social workers, who can assist young adults with managing their care. Transitioning to adult care may require developing new medical routines, and the network of services managed by pediatric providers and parents or caregivers may start to fall apart when a young adult takes over managing their own care, transitions to adult providers, and begins managing a whole new set of medical relationships and routines more independently.⁷⁴

Additionally, the transition to self-managed care may take place at the same time as young adults become more independent in other ways. Young adults may move to independent living, employment, or higher education. In addition to the challenges inherent in these life transitions, workplaces or colleges may lack supports for employees or students with complex chronic health conditions.⁷⁵

RECOMMENDATIONS

An Act Relative to Children's Health and Wellness charges the HPC with developing recommendations for data collection and reporting of measures related to CMC. An ongoing focus on CMC by the Commonwealth is needed to improve access, continuity, coordination, and quality of care, as well as quality of life for children and families. Timely and relevant data collection will help to identify needs and gaps in services for CMC and improve how care is delivered, and is essential for tracking progress towards these goals. To advance these goals, the HPC recommends the following areas of focus:

CARE COORDINATION

CMC are cared for by numerous providers and systems. Care coordination is required not only across multiple settings and systems of care, but also as CMC grow up and transition from pediatric to adult providers. Increased collaboration among state agencies, especially information-sharing and coordination, could help the Commonwealth to better support CMC and their families. The Commonwealth should further explore appropriate care coordination structures and data needs to support care coordination for CMC, including at both the regional and state level. As noted previously, multiple stakeholder interviews suggested that regional public health systems are likely to be the most appropriate places for the high level of coordination CMC and their families need. Further exploration of the capacity of regional public health systems to support CMC could be useful.

CENTRAL DATABASE

To support care coordination efforts, the Commonwealth should consider creating a central database on children receiving multiple public services, to facilitate information-sharing, coordination, and service integration across programs and settings. This type of information hub could allow the Commonwealth to better assist families of CMC in caring for their children, and provide assistance with social complexity challenges such as housing instability or food insecurity. Such a database could build on current Commonwealth data collection and coordination practices, such as MassHealth's tracking of beneficiaries who interact with other state agencies. Future data collection should not be limited to MassHealth beneficiaries, however, as CMC may have either public or commercial health coverage and may transition between programs. One barrier to centralized data collection is differing data privacy requirements in educational and medical settings. The federal government has provided guidance on the relationship between educational and medical privacy laws.⁷⁶

PERFORMANCE MEASUREMENT

The Commonwealth should also track and report on measures related to CMC to ensure their timely access to needed care. Key measures may include wait times for services, regional availability of primary and specialty providers, distances traveled for care, and hurdles such as language barriers.

DEDICATED HUB

Lastly, the Commonwealth should identify a dedicated hub for this work. An entity such as a Children's Cabinet, a collaborative action body composed of agencies from inside and outside of government with responsibilities for assessing and aligning the interests of children, currently proposed in pending legislation,⁷⁷ may be able to support data collection and coordination efforts.

APPENDIX A:

Prevalence and spending for commercially-insured children with and without medical complexities by provider organization, 2018

	Non-CMC	CMC	Non-CMC spending (Mean)	CMC spending (Mean)	CMC spending (Median)	Percent CMC
Acton Medical Associates	1,851	66	\$1,655	\$24,610	\$12,080	3.4%
Atrius	21,741	1,010	\$1,543	\$30,192	\$13,479	4.4%
BIDCO	4,838	220	\$1,644	\$27,380	\$14,265	4.3%
BMC	2,922	85	\$1,452	\$31,891	\$16,242	2.8%
Baystate	5,837	220	\$1,343	\$28,927	\$14,829	3.6%
Children's Medical Center Corporation	42,552	2,434	\$1,834	\$31,599	\$14,145	5.4%
Lahey	6,365	263	\$1,671	\$28,993	\$15,951	4.0%
MACIPA	2,359	94	\$1,713	\$28,118	\$13,243	3.8%
MGB	31,011	1,553	\$1,872	\$28,798	\$14,121	4.8%
Reliant	5,434	224	\$1,518	\$30,020	\$16,191	4.0%
South Shore	4,509	220	\$1,739	\$29,075	\$13,616	4.7%
Southcoast	1,093	42	\$1,474	\$22,189	\$14,027	3.7%
Steward	13,418	574	\$1,647	\$34,651	\$13,435	4.1%
Sturdy Memorial Foundation	1,002	32	\$1,696	\$21,788	\$12,973	3.1%
UMass	9,238	396	\$1,520	\$37,844	\$17,243	4.1%
Wellforce	23,129	1,005	\$1,658	\$29,349	\$13,908	4.2%

Notes: Analysis includes individuals ages 1-21. Provider groups with <1000 lives in observed in 2018 not included: 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-Payer Claims Database 8.0

APPENDIX B:

Prevalence and spending for children with and without medical complexities by MassHealth managed care organization and accountable care organization, 2018

	Non-CMC	CMC	Non-CMC spending (Mean)	CMC spending (Mean)	CMC spending (Median)	Percent CMC
BeHealthy Partnership	1,775	193	\$ 1,763	\$ 21,054	\$ 14,593	9.8%
BMC HealthNet Plan	1,970	177	\$ 1,164	\$ 56,936	\$ 19,000	8.2%
BMC HealthNet Plan Community Alliance	6,436	460	\$ 1,462	\$ 20,349	\$ 13,018	6.7%
BMC HealthNet Plan Mercy Alliance	2,845	249	\$ 1,401	\$ 20,215	\$ 12,286	8.0%
BMC HealthNet Plan Signature Alliance	1,095	46	\$ 1,191	\$ 17,437	\$ 12,437	4.0%
Community Care Cooperative	3,963	160	\$ 1,640	\$ 14,586	\$ 9,650	3.9%
Fallon 365 Care	1,562	152	\$ 1,603	\$ 21,778	\$ 11,390	8.9%
My Care Family	1,246	59	\$ 1,110	\$ 9,188	\$ 7,451	4.5%
Partners Healthcare Choice	4,041	244	\$ 1,391	\$ 20,087	\$ 10,546	5.7%
Steward Health Choice	5,314	247	\$ 1,303	\$ 16,126	\$ 10,470	4.4%
Tufts Health Together	5,936	337	\$ 1,281	\$ 15,832	\$ 10,770	5.4%
Tufts Health Together with Atrius Health	2,521	249	\$ 1,579	\$ 20,832	\$ 15,679	9.0%
Tufts Health Together with Boston Children's ACO	7,474	868	\$ 1,469	\$ 23,433	\$ 12,732	10.4%
Tufts Health Together with CHA	1,323	75	\$ 1,231	\$ 19,911	\$ 13,355	5.4%
Wellforce Care Plan	1,812	116	\$ 1,613	\$ 27,324	\$ 16,446	6.0%

Notes: Analysis includes individuals ages 1-21. Individuals are attributed to MCO/ACOs using the MassHealth Enhanced Eligibility file. Analysis includes only those individuals with 12 full months of enrollment in 2018, who changed MCO/ACO enrollment ≤ 1 time during the year, and who had at least 10 months of enrollment in the same MCO/ACO. This specification resulted in 4,423 CMC and 58,179 non-CMC retained for analysis, or 58% of CMC and 52% of non-CMC. ACOs and MCOs with <1000 lives observed in 2018 not included: Berkshire Fallon Health Collaborative, BMC HealthNet Plan Southcoast Alliance, Commonwealth Care Alliance, Evercare, Tufts Health Together with BIDCO. Missing excluded.

Source: HPC analysis of All-Payer Claims Database 8.0

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The HPC met with the following stakeholders in preparing this report: Baystate Health, Boston Children’s Hospital, Federation for Children with Special Needs, Franciscan Children’s, 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, and Tufts Children’s Hospital.

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