Costs and Use for Children With Medical Complexity in a Care Management Program

David A. Bergman, MD, David Keller, MD, Dennis Z. Kuo, MD, MHS, Carlos Lerner, MD, MPhil, Mona Mansour, MD, MS, Christopher Stille, MD, MPH, Troy Richardson, PhD, Jonathan Rodean, MPP, Mark Hudak, MD

abstract

BACKGROUND AND OBJECTIVES: Children with medical complexity (CMC) comprise only 6% of the pediatric population, account for ∼40% of pediatric health care spending, and provide an important opportunity for cost saving. Savings in this group can have an important impact on pediatric health care costs. The objective of this study was to assess the impact of a multicenter care management program on spending and use in CMC.

DESIGN AND METHODS: We conducted a prospective cohort analysis of a population of 4530 CMC enrolled in a learning collaborative designed to improve care for CMC ages 0 to 21 years identified using 3M Clinical Risk Group categories 5b through 9. The primary outcome was total per-member per-year standardized spending; secondary outcomes included inpatient and emergency department (ED) spending and use. We used a 1:1 propensity score match to compare enrolled patients to eligible nonenrolled patients and statistical process control methods to analyze spending and usage rates.

RESULTS: Comparison with the matched group showed a 4.6% (95% confidence interval [CI]: 1.9%–7.3%) decrease in total per-member per-year spending (P = .001), a 7.7% (95% CI: 1.2%–13.5%) decrease in inpatient spending (P = .04), and an 11.6% (95% CI: 3.9%–18.4%) decrease in ED spending (P = .04). Statistical process control analysis showed a decrease in hospitalization rate and ED visits.

CONCLUSIONS: CMC enrolled in a learning collaborative showed significant decreases in total spending and a significant decrease in the number of hospitalizations and ED visits. Additional research is needed to determine more specific causal factors for the results and if these results are sustainable over time and replicable in other settings.

WHAT’S KNOWN ON THIS SUBJECT: In previous studies, researchers have demonstrated a variable impact of care management on spending and use in children with medical complexity. The generalizability of the results from these studies has been impacted by small size and limitation to one institution.

WHAT THIS STUDY ADDS: In this study, we show that a comprehensive care management program for children with medical complexity reduces spending and use across hospital and nonhospital costs in a study of multiple complex care clinics and primary care practices when compared with a propensity-matched comparison group.


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Drs Bergman, Keller, Kuo, Mansour, Stille, and Hudak made substantial contributions to design, analysis, and interpretation of the data and also participated in drafting and revising the article critically for important intellectual content; Dr Richardson designed the data collection instruments, coordinated data collection, made substantial contributions to design, analysis, and interpretation of the data, and also participated in drafting and revising the article critically for important intellectual content; Mr Rodean made substantial contributions to design, analysis, and interpretation of the data and also participated in revising the article critically for important intellectual content; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: https://doi.org/10.1542/peds.2019-2401
Improvements in public health and child health interventions have led to a dramatic increase in the prevalence of children with special health care needs.1–3 This population has been defined as children having or at increased risk for chronic physical, developmental, behavioral, or emotional conditions.4 Recently, a subset of children with special health care needs that has been termed “children with medical complexity” (CMC) has garnered increased attention.5 These children demonstrate medical fragility, substantial functional limitations, increased need for health care services, and increased health care costs.5

CMC disproportionately affect the health care system. Six percent of the population of children insured by Medicaid or Child Health Insurance Program account for ~40% of pediatric health care costs,6–8 41% of pediatric hospital days,7 and >40% of hospital deaths.3 CMC also have a profound impact on the families that care for them. These families experience an overall decrease in income, reduced employment, greater stress on relationships, and lifelong adverse impacts on the health and longevity of caregivers.9–11 These children also receive care from multiple providers and community agencies,6 requiring families to devote considerable time to communication with and coordination between providers.12,13

There have been numerous efforts to improve the health and well-being of CMC through hospital-based complex care programs designed to enhance care coordination. Evaluation of these programs has demonstrated a decrease in spending and use after program implementation.14–17 However, these have been single-site studies based in hospital-based complex care clinics that did not assess whether these results can be achieved across multiple sites and in primary care practices (PCPs).

We sought to use Medicaid claims data to assess the impact of a comprehensive care management intervention on spending and use in CMC in a large multicenter study of children’s hospital-based complex care clinics and pediatric PCPs. We hypothesized that children enrolled in a care management program would have decreased spending and use when compared with a propensity-matched control group.

METHODS

The Coordinating All Resources Effectively (CARE) Award was part of the Center for Medicare and Medicaid Innovation–sponsored Health Care Innovation Awards designed to implement care transformation and payment reform. The CARE Award was a cohort study of CMC who participated in a National Learning Collaborative (LC). The LC was
composed of 10 children’s hospital complex care programs and 42 referring PCPs. Nine of the hospitals have hospital-based complex care clinics, and 1 children who had its complex care program embedded in 7 pediatric PCPs.

We analyzed health care claims for CMC enrolled in CARE complex care programs and referring pediatric PCP sites and for children who were eligible but not enrolled in the CARE Award because their primary care was in a nonreferring PCP. Health care claims were analyzed for the period of May 1, 2014, to April 30, 2017. Enrollment of CMC in CARE began May 1, 2015, so that claims analyzed during our study period represent expenditures during the 12 months before the launch of LC interventions and 24 months after LC launch. Claims were provided by 9 claims providers consisting of state Medicaid agencies, managed care organizations, or hospital health plans and were submitted to IBM Watson Health (Ann Arbor, MI) for standardization. One claims provider provided claims only through December 2016, so children insured under this plan were excluded from this analysis.

**Patient Population**

CMC age 0 to 21 years who were identified at each site using their own eligibility criteria were prospectively enrolled if their diagnoses were compatible with 3M Clinical Risk Group (CRG) categories 5b through 9. This population of children is characterized by high need for health services and high cost. Because of low enrollment numbers leading to irregular health care use patterns, we excluded CMC aged 19 to 21 years from this analysis.

**LC Interventions**

Care transformation in the context of the LC focused on redesigning care delivery models to enable the most appropriate coordinated care for CMC in the right setting. Proposed care redesign included implementation of the following 4 primary key change concepts that were developed from medical evidence and expert consensus: (1) establishment of a dynamic care team (DCT) that consisted of a list of providers jointly developed by the family and the complex care program, (2) the development of care plans based on needs and assets assessed in collaboration with family, (3) the use of individualized access plans that included a list of providers and how to access them as well as contingency plans for health care conditions identified by the family as likely to result in an emergency department (ED) visit or hospitalization, and (4) a patient registry. During the first 12 months after LC launch, hospitals simultaneously enrolled patients and implemented LC change concepts. Consequently, it was not until May 1, 2016 that the percentage of enrollees assigned a DCT surpassed 80% and

| TABLE 1 Patient Characteristics of Overall, Eligible, and Enrolled Patients |
|-------------------------------|-------------------------------|-----------------|-----------------|-----------------|
|                               | Overall                       | Eligible        | Enrolled        | P               |
| Total enrollees               | 194.751                       | 189.585         | 5168            | .001            |
| Median age, y, (IQR)          | 9 (5–14)                      | 9 (5–14)        | 6 (3–11)        | <.001           |
| Age group in y, n (%)         |                               |                 |                 |                 |
| 0–1                           | 14.552 (7.5)                  | 13.945 (7.4)    | 807 (11.7)      | .001            |
| 2–5                           | 43.620 (22.4)                 | 41.954 (22.1)   | 1666 (32.2)     |                 |
| 6–11                          | 62.446 (32.1)                 | 60.638 (32.0)   | 1806 (35.0)     |                 |
| 12–18                         | 74.133 (58.1)                 | 73.048 (38.5)   | 1085 (21.0)     |                 |
| Sex, n (%)                    |                               |                 |                 |                 |
| Male                          | 83.257 (42.8)                 | 81.030 (42.7)   | 2227 (43.1)     |                 |
| Female                        | 111.492 (57.2)                | 108.553 (57.5)  | 2639 (56.9)     |                 |
| CRG, n (%)                    |                               |                 |                 | <.001           |
| 5                             | 58.529 (30.1)                 | 57.703 (30.4)   | 826 (16.0)      |                 |
| 6                             | 119.253 (61.2)                | 118.455 (61.4)  | 2796 (54.2)     |                 |
| 7                             | 2361 (1.2)                    | 2112 (1.1)      | 249 (4.8)       |                 |
| 8                             | 2630 (1.6)                    | 2586 (1.4)      | 44 (0.8)        |                 |
| 9                             | 11.873 (6.1)                  | 10.724 (5.7)    | 1249 (24.2)     |                 |

| TABLE 2 Patient Characteristics of Propensity-Matched Eligible and Enrolled Groups |
|-------------------------------|-------------------------------|-----------------|-----------------|-----------------|
|                               | Eligible Matched              | Enrolled Matched| P               |
| Total enrollees, N            | 3885                          | 3885            |                 |                 |
| No. months pre-enrollment, median (IQR) | 12 (12–12)                  | 12 (12–12)      | .241            |
| No. months ramp-up enrollment, median (IQR) | 12 (12–12)                  | 12 (12–12)      | .865            |
| No. months postenrollment, median (IQR) | 12 (12–12)                  | 12 (12–12)      | .183            |
| Age in y in 2015, median (IQR) | 7 (5–11)                      | 7 (3–11)        | .965            |
| Age group in y in 2015, n (%)  |                               |                 |                 | .244            |
| 0–1                           | 424 (10.9)                    | 439 (11.3)      |                 |                 |
| 2–5                           | 1177 (30.3)                   | 1229 (51.6)     |                 |                 |
| 6–11                          | 1368 (35.2)                   | 1371 (35.5)     |                 |                 |
| 12–18                         | 916 (23.8)                    | 846 (21.8)      |                 |                 |
| Sex, n (%)                    |                               |                 |                 | .234            |
| Male                          | 1650 (42.5)                   | 1702 (43.8)     |                 |                 |
| Female                        | 2235 (57.5)                   | 2183 (56.2)     |                 |                 |
| CRG, n (%)                    |                               |                 |                 | 1.000           |
| 5                             | 629 (16.2)                    | 629 (16.2)      |                 |                 |
| 6                             | 2110 (54.3)                   | 2110 (54.3)     |                 |                 |
| 7                             | 161 (4.1)                     | 161 (4.1)       |                 |                 |
| 8                             | 32 (0.8)                      | 32 (0.8)        |                 |                 |
| 9                             | 953 (24.5)                    | 953 (24.5)      |                 |                 |
| CRG group                     |                               |                 |                 | 1.000           |
| CRG 5b through 6b             | 2323 (59.8)                   | 2323 (59.8)     |                 |                 |
| CRG 6c through 9              | 1562 (40.2)                   | 1562 (40.2)     |                 |                 |
| Inpatient hospitalization preaward, n (%) | 1068 (27.5)              | 1068 (27.5)     | 1.000            |
| ED visits preaward, n (%)      | 2208 (56.8)                   | 2232 (57.5)     | .582            |
the process of establishing and refining care plans and access plans began in earnest. We refer to the period from May 1, 2015, through April 30, 2016, as a “ramp-up” period and the period from May 1, 2016, through April 30, 2017, as the period of full implementation. Through a process of iterative Plan, Do, Study, Act cycles, >80% of enrollees had DCTs and individualized access plans and care plans by the end of the full-implementation period. A more-detailed description of the intervention is provided in the Supplemental Information.

**Outcome Measures**

The primary outcome of this study was total per-member per-year (PMPY) standardized expenditures. We used standardized expenditures per unit of service to (1) remove the high interstate variation in Medicaid payments, (2) remove the influence of changing Medicaid payment over time, and (3) mitigate the impact of services reported under capitated payment arrangements (often reported as a value of $0)\textsuperscript{19,20} PMPY spending was calculated each month during the study period as the total standardized expenditures divided by number of enrollee years represented in a specified cohort of CMC (eg, enrolled versus eligible). Details on payment standardization can be found in the Supplemental Information.

Secondary outcomes in this study included service line–specific PMPY spending (eg, inpatient, outpatient, ED, pharmacy) and annualized use for the following services: inpatient admissions, ED visits, office visits, pharmacy claims, and home health days. Annualized use was calculated as the total number of visits and claims divided by the number of enrollee years represented in a specified cohort of CMC.

**Statistical Analysis**

Patient demographics and clinical characteristics were summarized by using frequencies for categorical variables and medians with interquartile range (IQR) for continuous variables. We compared patient demographic and clinical characteristics between enrolled and eligible patients using a $\chi^2$ test for association for categorical variables and a Wilcoxon rank-sum test for continuous variables.

We used statistical process control methods to assess changes in PMPY total spending and annualized use in

![Figure 2](https://example.com/f2.png) Reduction in spending: total PMPY.
CMC enrolled in CARE. The purpose of using statistical process control was to understand the magnitude and direction of trends in PMPY spending and use over the pre-enrollment, ramp-up, and full-use periods. Special cause variation was defined as 8 points occurring in a row on the same side of the centerline.\textsuperscript{21}

To enhance the internal validity of the study and to assure that observed changes in PMPY spending and annualized use were associated with LC interventions and did not represent a reduction in spending after a period of high use, we performed a propensity-matched difference-in-difference subanalysis of enrolled CMC and eligible CMC. We excluded one claims provider from our subanalysis who submitted claims only on enrolled CMC. Details of the propensity match can be found in the Supplemental Information. We modeled the geometric mean of PMPY spending using log-linear modeling techniques and fit first-order autoregressive covariance components to account for any serial correlation in PMPY spending over time.

To estimate the percentage of savings attributed to CARE interventions, we applied postenrollment slope estimates from the eligible population to the postenrollment period in the enrolled population. These imputed estimates represent the expected standardized PMPY spending in the enrolled population that had no LC interventions occur. Savings estimates at 24 months were then calculated as the percentage of change between imputed PMPY spending and observed PMPY spending in the enrolled population 24 months after LC launch.

All analyses were performed by using SAS (v.9.4; SAS Institute, Inc, Cary, NC). The $P$ values $<.05$ were considered statistically significant.

Seven programs obtained institutional review board (IRB) approval from a central IRB at the Children’s National Health Center, and 3 programs obtained approval through their local IRBs.

**RESULTS**

**Patient Characteristics**

There were 194,751 eligible subjects for the study. From this pool, 8,096 subjects were enrolled. As shown in the consort diagram in Fig 1, 4,530 subjects, 9 hospitals, and 8 claims providers had complete claims data for the study period. When compared with the eligible but not enrolled group, the patients in the enrolled group were younger and more likely to be classified in CRG categories 7, 8, and 9 (Table 1). Supplemental Table 6 shows that enrolled unmatched children were less likely to fall between 2 and 11 years of age, had fewer months of enrollment in the preaward period and the full-intervention period, were more likely to have a hospitalization during the preaward period, and were more likely to fall into CRG 6b through 8.

**Change in PMPY Spending**

We used propensity matching that resulted in a comparison group of matched but not enrolled (eligible) subjects ($n = 3,885$) who did not differ from the enrolled matched group ($n = 3,885$) with respect to age, sex, and CRG severity classification (Table 2). However, there were differences in the point values for spending between these 2 groups with the spending being much higher for both groups when compared with the eligible nonmatched group ($N = 159,297$) (Table 3). When we attempted to decrease the caliper width on spending so that there was no significant difference between the 2 groups, the number of subjects was reduced, which significantly decreased the power of the study.
Figure 2 shows a reduction in total PMPY spending that began during the ramp-up and full-implementation periods. There was a 4.6% (95% confidence interval [CI]: 1.9%–7.3%) decrease in total PMPY spending for the enrolled group when compared with the matched group (P < .001). Figures 3 and 4 show a 7.7% (95% CI: 1.2%–13.5%) decrease in inpatient spending (P = .04) and an 11.6% (95% CI: 3.9%–18.4%) decrease in ED spending (P = .04) when compared with the matched control group.

**Change in Rate of Spending**

Figure 5 shows downward special cause variation in the rate of PMPY spending over time. There was also special cause variation associated with the increase in PMPY prescription spending. The control chart for prescription spending is presented in Supplemental Fig 8.

**Change in Usage Rates**

Figures 6 and 7 show that for the 4530 patients for whom there were complete claims data, there was downward special cause variation for inpatient admissions and ED visits. There was also downward special cause variation for prescription claims and home health days and decrease in office visits. These control charts are presented in Supplemental Figs 9–11.

The impact of disease severity on spending was assessed by combining CRG 5b, 6a, and 6b into a chronic group and CRG 6c, 7, 8, and 9 into a severe chronic group. Table 4 shows a 4.1% decrease in spending for the chronic group (P = .002) versus a smaller 3.4% decrease in spending in the severe chronic group (P ≤ .001). Table 5 shows the changes in spending in 5 different age groups. For children 6 to 11 years, there was a 4.5% reduction in spending (P < .001), and for children 12 to 18 years, there was a 3.2% increase in spending (P < .001).

**Variation Between Sites**

Because of data use agreements, we were not allowed to provide site-specific data. However, the median and IQR of standardized PMPY spending across the 7 claims providers included in the propensity match analysis are shown in Supplemental Table 7 and suggest that there is considerable site-to-site variability.

**DISCUSSION**

The CARE Award is the first large multicenter study in which researchers assessed the impact of a comprehensive care management program in CMC. The study was notable for including both hospital-based complex care clinics and PCP sites, enrolling a broad population of CMC that enabled subanalyses of different groups, and the use of propensity scoring to define a comparison group. We were able to demonstrate a 4.6% reduction in total spending for the enrollee group compared with the matched group. The lower PMPY spending was primarily explained by reductions in inpatient, ED, and outpatient spending. We were also able to demonstrate a reduction in hospital admissions and ED and office visits. The unexpected decrease in office visits may have resulted in part from our use of individualized access plans, which empowered families to manage acute illnesses in the home setting. Our finding of an increase in home health days may be explained by the observed reduction in inpatient admissions, whereas the increase in pharmacy spending reflected both an increase in the cost and number of prescriptions.

Our findings of a reduction in total spending and a decrease in use are consistent with results of numerous
prospective cohort studies examining the impact of a comprehensive complex care program on children with CMC.14–17 However because these studies did not have a comparison group, it is possible that their findings can be explained by a natural regression after an initial period of high use. This issue has been addressed in 4 randomized controlled trials (RCTs) in which researchers have assessed the impact of a complex care program on use and spending.17,22–24 Our results were similar to the Mosquera et al17 study in which they demonstrated a significant decrease in spending and use in a population of CMC. Our findings are also consistent with the Slater et al23 study in which they randomized their care management intervention at the clinic level. In this study, they found reductions in spending and use in 4 clinic sites with embedded care coordinators compared with 4 other sites without care coordinators in a large multidisciplinary ambulatory practice. Our results differed from the Simon et al22 study in which they showed an improvement in the parent’s perception of health status but also increased total spending. This may be explained by the fact that Simon et al22 recruited subjects only from PCP sites who may have had more unaddressed needs and less severity and opportunity for improvement. Our results also differed from the Caskey et al24 study in which they found no change in Medicaid expenditures between a care management intervention group and a usual care group. This may be due to recruitment of subjects with less medical complexity.

Only the 6 to 11 age group showed significant reductions in spending. The failure to show a reduction in spending in the younger age groups may be due to the inclusion of NICU patients in this group. Our intervention was not designed to affect care in the NICU. The increase in spending in the 12 to 18 group may stem from the fact that this group had more stable chronic conditions that afforded less opportunity for improvement. The greater cost reduction in the chronic versus severely chronic group may be due to an increased likelihood to improve health status in this group. Children...
afflicted with severe chronic conditions often have static or deteriorating health status.

Although the CARE Award study was not an RCT, one of its strengths was the use of a comparison group defined by propensity matching. This allowed us to address the problem found in before and after study designs in which decreased spending and use can be explained by regression from a period of high use. Additionally, the use of statistical process control and control charts demonstrated that the major impact of our intervention occurred at the end of the ramp-up period and continued throughout the full-intervention period. This again strengthens the inference that the reductions in spending and use were causally related to program interventions.

This study has a number of limitations. First, our patient population may not be representative of the greater population of CMC. Because this was not an RCT, patients enrolled in CARE may not be representative of the CMC population in participating states. Patients enrolled (and propensity-matched controls) were likely selected during a period of high spending and use, and the savings associated with care management demonstrated in this analysis may not hold in populations with lower and more-consistent levels of health care spending.

Second, although our propensity-matched comparison group was comparable to the enrolled group across demographic and disease variables, the spending in the enrolled group was significantly greater than the matched group. However, it is not likely that this would impact the degree of difference in spending found in this study. Third, our claims data include NICU hospitalizations if the subject was enrolled in the same year as the hospital discharge. In this population, baseline spending would have been predictably greater before the intervention. However, selection of a similar population in the propensity-matched group should have balanced this effect. Fourth, because our intervention period was only 24 months with only partial implementation during the ramp-up period, it was not possible to assess the sustainability of our intervention over time. It may be that impact of the intervention will plateau after 12 months unless the change concepts are consistently reassessed and evolved to meet needs of CMC and their families. Lastly, in this study, we only reached out to CMC who are cared for in hospital-based complex care clinics and their associated PCPs. Yet the vast majority of these children (albeit the children who are less severely ill) are cared for in PCPs without the involvement of a complex care clinic. Expansion of this model to reach these children will require more of a consultative and educational approach to these practices.

**CONCLUSIONS**

The CARE Award is the first study able to demonstrate a reduction in total spending for a large population of CMC cared for in both hospital-based complex care clinics and

**TABLE 4 Actual Versus Projected PMPY Spending by CRG Groups**

<table>
<thead>
<tr>
<th>CRG 5b, 6a, 6b</th>
<th>Eligible Modeled PMPY Spending, $</th>
<th>Enrolled Modeled PMPY Spending, $</th>
<th>Reduction per Enrollee, $</th>
<th>Reduction, %</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Project Start</td>
<td>Project End 24 mo</td>
<td>Project Start</td>
<td>Project End 24 mo</td>
<td></td>
</tr>
<tr>
<td>CRG 5b, 6a, 6b</td>
<td>17,096</td>
<td>14,807</td>
<td>26,947</td>
<td>21,102</td>
<td>2051</td>
</tr>
<tr>
<td>CRG 6c through 9</td>
<td>71,220</td>
<td>62,319</td>
<td>89,503</td>
<td>72,794</td>
<td>5648</td>
</tr>
</tbody>
</table>
pediatric PCPs. The greatest impact was on inpatient and ED spending. Further work is needed to determine which components of the intervention most contributed to improvements in outcome. In addition, further studies are needed to determine the feasibility of scaling and spreading this intervention to other integrated health care systems as well as the sustainability of improvements over time.

ACKNOWLEDGMENTS
We acknowledge the important contributions of the medical directors at each of our participating sites: Christy Sandborg, MD, Stanford Children’s Health, Stanford, CA; Carlos Lerner, MD, MPhil, Mattel Children’s Hospital, Los Angeles, CA; Chris Stille, MD, Children’s Hospital Colorado, Aurora, CO; Ingrid A. Larson, MBA, DNP, RN, APRN, Children’s Mercy Hospital, Kansas City, MO; Jose Gonzalez, MD, JD, MSEd., MSHQSM, Cook Children’s Hospital, Ft. Worth, TX; David Rubin, MD, MSCE, Children’s Hospital of Philadelphia, Philadelphia, PA; Mona Mansour, MD, MS, and John Morehous, MD, Cincinnati Children’s Hospital, Cincinnati, OH; Jeffrey Goldhagen, MD, MPH, Wolfson Children’s Hospital, Jacksonville, FL; and Daniel Plasencia, MD, St. Joseph Children’s Hospital, Tampa, FL. We would also like to acknowledge the tremendous contribution from the Children’s Hospital Association staff: Susan Dull, RN, MSN, MBA, CAE, Director of Child Health and Financing; Lorna Morelli, RN, LNCC, manager, collaboratives and CARE; Lowrie Ward, MPH, consultant for quality improvement; Kate Conrad, FACHE, vice president, delivery system transformation; and Jacqueline Kueser, Children’s Hospital Association leader, transformation informatics.

ABBREVIATIONS
CARE: Coordinating All Resources Effectively
CI: confidence interval
CMC: children with medical complexity
CRG: Clinical Risk Group
DCT: dynamic care team
ED: emergency department
IQR: interquartile range
IRB: institutional review board
LC: learning collaborative
PCP: primary care practice
PMPY: per-member per-year
RCT: randomized controlled trial

TABLE 5 Actual Versus Projected PMPY Spending by Age Groups

<table>
<thead>
<tr>
<th>Eligible Modeled PMPY Spending, $</th>
<th>Enrolled Modeled PMPY Spending, $</th>
<th>Projected PMPY Spending at 24 mo, $</th>
<th>Reduction per Enrollee, $</th>
<th>Reduction, %</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project Start</td>
<td>Project End 24 mo</td>
<td>Project Start</td>
<td>Project End 24 mo</td>
<td>Project Start</td>
<td>Project End 24 mo</td>
</tr>
<tr>
<td>0–2 y</td>
<td>71 571</td>
<td>57 804</td>
<td>116 347</td>
<td>49 669</td>
<td>61 455</td>
</tr>
<tr>
<td>2–5 y</td>
<td>40 314</td>
<td>35 240</td>
<td>53 283</td>
<td>45 076</td>
<td>46 577</td>
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<tr>
<td>6–11 y</td>
<td>31 711</td>
<td>32 309</td>
<td>40 485</td>
<td>37 619</td>
<td>41 249</td>
</tr>
<tr>
<td>12–18 y</td>
<td>33 980</td>
<td>31 980</td>
<td>40 284</td>
<td>40 340</td>
<td>37 278</td>
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Accepted for publication Jan 8, 2020
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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).
Copyright © 2020 by the American Academy of Pediatrics
FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.
FUNDING: Funded by Award 1C1CMS331335 from the Department of Health and Human Services, Centers for Medicare and Medicaid Services. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the US Department of Health and Human Services or any of its agencies.
POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.
COMPANION PAPER: A companion to this article can be found online at www.pediatrics.org/cgi/doi/10.1542/peds.2019-3982.
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_Pediatrics_ 2020;145;
DOI: 10.1542/peds.2019-2401 originally published online March 30, 2020;

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Pediatrics 2020;145;
DOI: 10.1542/peds.2019-2401 originally published online March 30, 2020;

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