

2024 Survey of Children Served by MaineCare

November 2024

Prepared by:

Zach Croll
Clare Murray
Aaron Rose

Catherine Cutler Institute for Health and Social Policy
Muskie School of Public Service
University of Southern Maine

Acknowledgements

We would like to thank the parents and guardians of children enrolled in MaineCare who participated in survey interviews; this report would not be meaningful without their time and candid responses. We are also grateful to staff from the Maine Department of Health and Human Services Office of MaineCare Services who have provided valuable feedback on the survey instrument and report. A special thank you to the dedicated team of survey researchers and interviewers at the Cathrine Cutler Institute Survey Research Center who tested and administered the survey. And we would like to thank the Catherine Cutler Institute Measures Team who drew the survey sample.

This work was conducted under a Contract between the Maine Department of Health and Human Services and the Muskie School of Public Service at the University of Southern Maine (OMS-24-228 agreement, Contract CT-10A-2023080900000000304) and is funded under grant CFDA 93.767 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) authorized by Section 401(d) of the Children's Health Insurance Program Reauthorization Act (CHIPRA). The views and opinions expressed in this report are the authors' and should not be attributed to collaborating organizations, funders, or the University of Southern Maine.

Contents

ACKNOWLEDGEMENTS ERROR! BOOKMARK NOT DEFINED.

EXECUTIVE SUMMARY **3**

INTRODUCTION..... **6**

METHODS **6**

 TABLE 1. CHARACTERISTICS OF SURVEY SAMPLE AND ELIGIBLE POPULATION IN MAINECARE MEMBER FILE8

 TABLE 2. SURVEY-REPORTED CHILD RACE AND GENDER9

 TABLE 3. SURVEY-REPORTED DETAILED CHILD RACE AND TRIBAL STATUS..... 10

 TABLE 4. SURVEY-REPORTED CHILD LANGUAGE 11

 TABLE 5. CHARACTERISTICS OF ADULT SURVEY RESPONDENTS..... 12

HEALTHCARE ACCESS AND UTILIZATION **12**

 TABLE 6. HEALTHCARE ACCESS AND UTILIZATION 13

RATINGS OF OVERALL HEALTH **13**

 TABLE 7. RATINGS OF CHILD’S OVERALL HEALTH AND MENTAL OR EMOTIONAL HEALTH..... 14

OVERALL FINDINGS: CAHPS 5.1H CORE AND CHRONIC CONDITIONS ITEM SETS..... **14**

 TABLE 8. CAHPS 5.1H CORE ITEM SET: RESULTS FOR ENTIRE SAMPLE WITH NATIONAL MEDICAID COMPARISONS 16

 TABLE 9. EXPERIENCE WITH MAINECARE MEMBER SERVICES HELP LINE..... 17

 TABLE 10. CAHPS 5.1H CHILDREN WITH CHRONIC CONDITIONS ITEM SET: RESULTS FOR ENTIRE SAMPLE WITH NATIONAL MEDICAID COMPARISONS 19

 TABLE 11. CAHPS 5.1H CORE ITEM SET BY MAINECARE TITLE XIX AND TITLE XXI ELIGIBILITY..... 22

 TABLE 12. CAHPS 5.1H CHILDREN WITH CHRONIC CONDITIONS ITEM SET BY MAINECARE TITLE XIX AND TITLE XXI ELIGIBILITY.....23

 TABLE 13. CHILDREN WITH SPECIAL HEALTH CARE NEEDS SCREENER RESULTS 26

FINDINGS: OTHER TOPICS RELEVANT TO MAINECARE POLICY **27**

 TABLE 15. BEHAVIORAL HEALTH TREATMENT AND COUNSELING..... 29

 TABLE 16. TELEHEALTH ACCESS AND UTILIZATION 30

 TABLE 17. SATISFACTION WITH TELEHEALTH SERVICES 31

 TABLE 18. DENTAL CARE UTILIZATION AND PREVALENCE OF UNMET NEED FOR DENTAL CARE 32

 TABLE 19. REGIONAL DIFFERENCES IN MAINECARE PERFORMANCE..... 34

 TABLE 20. MEMBER EXPERIENCES WITH MAINECARE (N=373)..... 35

CONCLUSIONS AND RECOMMENDATIONS..... **37**

APPENDIX A: SUMMARY OF MAINECARE COVERAGE FOR CHILDREN **38**

APPENDIX B: 2024 SURVEY INSTRUMENT **39**

APPENDIX C: 2024 SURVEY WEIGHTS AND ESTIMATION PROCEDURES..... **54**

 TABLE C-1. 2024 SURVEY WEIGHT CONSTRUCTION 55

Executive Summary

The annual Survey of Children Served by MaineCare is designed to monitor the quality of services delivered by MaineCare, the State of Maine's Medicaid and Children's Health Insurance Program (CHIP). The 2024 survey used a standardized instrument — the Consumer Assessment of Healthcare Providers and Systems (CAHPS 5.1H) — as its primary means of examining the experiences of families with children enrolled in MaineCare. The CAHPS 5.1H is designed to provide feedback to Medicaid fee-for-service and managed care plans by identifying performance dimensions in which they excel and areas in which they need improvement.

The sample frame for the 2024 survey included children aged 17 or younger who were enrolled in MaineCare for at least 5 months, with no more than a 30-day break in enrollment, between April 1, 2023, and September 30, 2023. The survey instrument was initially distributed electronically via text message throughout January and February of 2024. Follow-up computer-assisted telephone interviews were conducted by trained interviewers from the Catherine Cutler Institute Survey Research Center from January to May of 2024. Of the 3,857 eligible families who were contacted, 1,015 interviews were completed for an overall response rate of 26.3%.

Ratings of Overall Health

- **Eighty-two percent of respondents rated their child's overall health as "excellent/very good," 14% as "good," and 4% as "fair/poor."** Ratings of "excellent/very good" were significantly higher for non-CSHCN compared to CSHCN (90% vs. 69%).
- **Sixty-eight percent of respondents rated their child's overall mental or emotional health as "excellent/very good," 20% as "good," and 12% as "fair/poor."** Non-CSHCN were significantly more likely than CSHCN to be reported to be in "excellent/very good" overall mental or emotion health (85% vs. 42%), as were children aged five or younger compared to those aged six to 12 and 13 or older (85% vs. 63% and 57%). Children in the Title XIX eligibility category were significantly more likely than those in Title XXI to be in "excellent/very good" mental or emotional health (69% vs. 66%).

CAHPS Core and Chronic Conditions Items

- **MaineCare met or exceeded the national median on many patient experience measures in both the core and chronic conditions CAHPS item sets.** MaineCare's 2024 scores compared favorably to other state child Medicaid programs (50th percentile or above) on CAHPS measures for getting needed care, tests, or treatment; getting appointments with specialists; getting urgent and non-urgent care quickly; personal doctors explaining things clearly; personal doctors listening carefully and respecting consumer comments; personal doctors spending enough time with the child; personal doctors seeming informed and up to date about care received from other providers; ease of accessing special therapy; personal doctors talking about how the child is feeling, growing, or behaving and how the child's health conditions affect the family's day-to-day life; and doctors and providers answering questions and providing needed help contacting school or daycare.
- **Scores for the chronic conditions item set were generally stable from 2023 to 2024 across all domains and items, and MaineCare showed improvement in Top Box ratings for four measures.** However, it appears MaineCare's improved Top Box ratings on these items can largely be attributed to decreases in other state scores, rather than improvements in 2024 MaineCare member ratings.
- **MaineCare ranked below the 25th percentile nationally on health plan information and customer service.** Of the 5% of respondents who contacted MaineCare Member Services for information or help, 36% indicated staff "always" gave them information or help they needed (the national median was 56%).
- **MaineCare ranked below the 25th percentile nationally for ratings of child's personal doctor, specialist, overall health care, and health plan:** personal doctor (64% vs. 75%), specialist (61% vs. 72%), overall health care (55% vs. 68%), and health plan (56% vs. 70%).

- **MaineCare ranked below the national median for several important chronic care services.** MaineCare ranked below the national median for how often it was always easy for members to obtain special medical equipment or devices and to obtain treatment or counseling (both in the 25th–50th percentile). MaineCare also ranked below the national median for the proportion of members who received help from their child’s health plan, doctor’s office, or clinic coordinating care among different providers/services (under 25th percentile).
- **There were modest differences between Title XIX and Title XXI program enrollee ratings of MaineCare on core CAHPS items.**¹ Both eligibility groups scored “fair” or higher on all measures within the getting needed care, getting care quickly, and doctor communication domains. In these three domains, there were no statistically significant changes compared to last year’s survey, but Top Box ratings were the same or better for each eligibility group than in 2023 (largely reflecting a decrease in national medians). However, Title XIX respondents were more likely than Title XXI respondents to agree that the child’s personal doctor always explained things clearly. And there were significant year-over-year declines from 2023 to 2024 on three measures in the overall ratings domain, with ratings for the child’s personal doctor and health plan declining for both eligibility groups, and ratings for all the child’s health care declining among Title XXI respondents.
- **Title XIX and Title XXI respondents ranked MaineCare similarly on most chronic conditions CAHPS items with some exceptions.** Title XIX enrollees were slightly more likely to report their child’s doctor seemed informed and up to date about care the child had received from other providers, and slightly less likely to always have easy access to counseling. Notably, Title XXI respondents were significantly less likely to have easy access to special medical equipment and devices compared to Title XIX respondents. And Title XIX enrollees rated MaineCare higher on the extent to which their child’s personal doctor talked about how the child was feeling, growing, or behaving.

Children with Special Health Care Needs (CSHCN)

- **Over one-third of all MaineCare children had special health care needs.** Thirty-nine percent of children enrolled in MaineCare had special health care needs in 2024. Of the five qualifying health consequences,² use or need of prescription medications was the most prevalent at 27%.
- **There were between-group differences when comparing children with special health care needs to those without.** Parents and guardians of CSHCN were significantly less likely than non-CSHCN to report it was easy to get needed care, tests, or treatment (54% vs. 67%) and prescription medicines (57% vs. 81%). They were also less likely to rate their child’s MaineCare “9 or 10” out of 10 (49% vs. 60%) or their child’s specialist “9 or 10” out of 10 (56% vs. 70%). However, parents of CSHCN were significantly more likely to report utilizing healthcare providers other than their child’s personal doctor (60% vs. 40%), and more likely to receive help from MaineCare, their child’s doctor’s office, or clinic in coordinating care among different providers or services (62% vs. 38%).

Other MaineCare Priority Areas

Maine’s 2024 survey also included supplemental questions focused on priority areas including emotional, developmental, and behavioral health treatment and counseling; availability and use of telehealth services; and access to and satisfaction with dental services. Key findings included:

Behavioral Health Treatment and Counseling

- **Twenty-eight percent of respondents indicated their child had an emotional, developmental, or**

¹ The Title XIX group includes children enrolled in the Medicaid eligibility category of MaineCare, while the Title XXI group comprises children in the Medicaid Expansion category. See Appendix A for data on family income eligibility limits, premium payments, and funding sources for each MaineCare eligibility group.

² The five qualifying health consequences for CSHCN include: 1) use or need of prescription medication; 2) above average use or need of medical, mental health or educational services; 3) functional limitations compared with others of the same age; 4) use or need of specialized therapies; 5) treatment or counseling for emotional, behavioral, or developmental problem.

behavioral problem for which they needed or got treatment or counseling. Of those children, 75% received at least some of the care needed over the last six months. Children aged 6 and older were more likely to need these services than those aged five or younger, as were CSHCN compared to non-CSHCN. Parents and guardians of White non-Hispanic children were more likely to report needing these services than were parents and guardians of BIPOC children (29% vs. 19%).

- **The most common types of treatment or counseling received were school-based (65%) and office-based treatment or counseling (59%).** Children living in the Southern region of the state, those aged six to 12 years old, and White non-Hispanic children were more likely to receive school-based treatment or counseling than those in other regions, age groups, or racial groups.
- **Forty-five percent of respondents indicated it was “always” easy to get the treatment or counseling they needed** while 28% “usually,” 22% “sometimes,” and 5% “never” found it easy.

Telehealth

- **Eighteen percent of respondents indicated their child was offered a telehealth appointment instead of an in-person appointment in 2024.** CSHCN were significantly more likely than non-CSHCN to have been offered a telehealth visit (36% vs. 6%), as were older age groups – 26% among children aged 13 or older compared to 17% among children aged six to 12 years old and 11% among children aged five or younger.
- **Fifty-three percent of respondents reported using telehealth for mental health services, 31% for primary care, 12% for school-related learning needs; and 17% for some other type of specialist.** Groups most likely to use telehealth appointments for mental health services were children aged 13 or older, CSHCN, and White non-Hispanic children. Those aged five or younger were the most likely to use telehealth for school-related learning needs.

Dental care

- **Rates of receiving dental care and rates of delayed or foregone dental care were similar in 2024 compared to 2023.** Sixty percent of all children enrolled in MaineCare reported receiving dental services in the past six months (compared to 55% in 2023), and 21% of children had dental care that was delayed or not received at some time in the past six months (compared to 23% in 2023).
- **Overall, most children served by MaineCare (73%) had a usual source of dental care.** More than half used a private dental office as their usual source of dental care (58%). Other sources of care included community-based (35%) and school-based (6%) clinics. Children aged six and older, CSHCN, and Title XXI enrollees were significantly more likely than other children to have a usual source of dental care.

Regional Differences in MaineCare Performance

- **Members in the Southern region of the state were significantly more likely to see specialists in a timely manner (68.3%)** than those in the Central/Western (43.2%) and Northern/Downeast regions (52.4%). They were also borderline significantly more likely to have received help coordinating their child’s care among different providers or services (65% vs. 51% and 44%, respectively).

Member Experiences with MaineCare

- **Positive feedback was the most common theme identified among responses to the survey’s open-ended question.** Many respondents (40.5%) expressed gratitude for the program’s support for children, particularly those with special healthcare needs. However, significant concerns were raised about limited access to dental services (34%), administrative barriers (18%), access to primary and generalist care (9%), and obtaining prescription medications (8%).

Introduction

The annual Survey of Children Served by MaineCare has two key purposes: (1) monitor the quality of services delivered to children enrolled in MaineCare, the State of Maine’s Medicaid and Children’s Health Insurance Program (CHIP), and (2) determine whether certain subgroups of MaineCare members have unmet health care needs that could be better addressed through targeted interventions.

The 2024 survey included a standardized instrument—the Consumer Assessment of Healthcare Providers and Systems (CAHPS 5.1H)—which is designed to provide feedback to Medicaid fee-for-service and managed care plans by identifying performance dimensions in which they excel, as well as areas in which they need improvement.³ Survey responses were used in multiple ways to generate insights into MaineCare’s performance. In addition to generating point estimates for 2024, we compared CAHPS results for MaineCare to those from child Medicaid programs in other states to assess how the MaineCare program ranked against national benchmarks.⁴ CAHPS results for children eligible for MaineCare through traditional Medicaid (Title XIX) and Medicaid Expansion CHIP (Title XXI) are compared to assess differences between these programs and to comply with Children’s Health Program Reauthorization Act (CHIPRA) reporting requirements.⁵ We also compared 2024 survey results across different subgroups of MaineCare members (e.g., race, geographic region) and to 2023 survey results. All references to 2023 survey results can be found in the 2023 Survey of Children Served by MaineCare report.⁶ Finally, we compared CAHPS responses provided on behalf of children with special health care needs to those for children without such needs to better understand how and to what extent member experience differs between the two groups.

In addition to the standardized CAHPS instrument, the 2024 survey incorporated supplemental questions designed to provide insight on topics of special interest selected by MaineCare program managers. In 2024, these topics included member experience with MaineCare Member Services; availability and use of telehealth services; emotional, developmental, and behavioral health treatment or counseling; and access to and satisfaction with dental services. Maine also integrated more detailed state-added questions on race, ethnicity, primary language, and gender to supplement the core demographic items included in CAHPS 5.1H.

Methods

The sampling and administration of the 2024 Survey of Children Served by MaineCare was conducted using a modified approach based on the 2023 Core Set of Children’s Health Care Quality Measures for Medicaid and CHIP (Child Core Set) technical specifications for administration of the CAHPS Health Plan Survey 5.1H, Child Medicaid version.^{7,8} The sample frame for the 2024 survey included children aged 17 or younger who were enrolled in MaineCare for at least 5 months, with no more than a 30-day break in enrollment, between April 1,

³ For more information on the CAHPS survey, see CAHPS Patient Experience Surveys and Guidance: <http://www.ahrq.gov/cahps/surveys-guidance/index.html>

⁴ National comparisons are based on the latest national CAHPS data available as of the writing of this report, which was for 2023.

⁵ See Center for Medicare and Medicaid Services. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey: Reporting Requirements and Data Submission for the Medicaid and the Children’s Health Insurance Program (CHIP) Core Sets and State CHIP Annual Reporting. <https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahpsfactsheet.pdf>

⁶ Croll, Z., Murray, C. (2023). 2023 Survey of Children Served by MaineCare. Catherine Cutler Institute for Health and Social Policy. University of Southern Maine. https://www.srcmaine.org/wp-content/uploads/2024/03/2023-Survey-of-Children-Served-by-MaineCare_FINAL.pdf

⁷ For a detailed description of the CAHPS survey methodology and administration plan please refer to the Center for Medicare and CHIP Services Core Set of Children’s Health Care Quality Measures for Medicaid and CHIP (Child Core Set) Resource Manual and Technical Specifications for Federal Fiscal Year 2023 Reporting at: <https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/child-core-set-reporting-resources/index.html>

⁸ Sampling and survey administration protocols modified as follows: (1) the continuous enrollment period is set to April 1st through September 30th in order to draw the sample in November and launch the survey in January of each year; (2) the methodology by which members living in single- versus multiple-child households are randomized for inclusion in the sample differs from the methodology outlined in HEDIS Volume 3 specifications; and (3) the survey was administered using one round of postcard outreach followed by email and text message distribution of an online survey with telephone follow-up.

2023 and September 30, 2023. One child per household was randomly selected so that no family would be interviewed about the experience of more than one child. Additionally, to reduce respondent burden, children living in households that participated in the 2023 survey were excluded from the sample. Children living in households where a child had recently died were also excluded, as were children with no identifiable adult parent or guardian (e.g., children in state custody). Finally, children who had MaineCare as their secondary source of health insurance coverage were also excluded.

To ensure that sample sizes would be sufficient to conduct separate analyses for children in Medicaid Expansion CHIP (Title XXI) and for children with chronic conditions, we used a stratified random sample design that oversampled these groups. Children with a chronic condition diagnosis were identified during the sampling process using diagnosis codes from MaineCare claims for outpatient, inpatient, and emergency department visits. However, the final determination of whether a child had a chronic condition was made based on responses to a five-item “children with special healthcare needs” (CSHCN) screener in the survey and not claims diagnoses. A detailed description of the CSHCN screening criteria can be found on page 25 of this report. The purpose of using diagnosis codes in the sampling process is to identify children in the sampling frame who are more likely to screen positive for a chronic condition, as this reduces the total sample size needed to obtain a sufficient number of children with chronic conditions for analysis and reporting. Using this sampling process, a group of 3,857 families were selected to be surveyed.

The 2024 survey instrument included core questions from the CAHPS 5.1H Child Medicaid Health Plan Survey as well as the Children with Chronic Conditions item set. Questions addressing additional priority topics identified by MaineCare Services were also included. The complete survey instrument can be found in Appendix B. Online survey respondents were asked to read a consent script, including a description of the survey, and to confirm their consent to participate. They were also required to enter the child’s birthdate in order to access the survey. Consent to participate in the telephone survey was obtained verbally through use of a script. All survey protocols including recruitment materials, the questionnaire, and consent script were reviewed and approved by the University of Southern Maine Institutional Review Board.

Of the 3,857 eligible families that were contacted, 1,015 interviews were completed – including 449 children with special health care needs based on survey responses – resulting in an overall response rate of 26.3%. The survey instrument was initially distributed via text message in January and February of 2024, yielding 130 completed online surveys (12.8% of respondents) and follow-up computer-assisted telephone interviews were conducted by trained interviewers from January through May of 2024, yielding an additional 885 completions (87.2% of respondents). The option to complete the survey online was introduced in 2024. However, with only 130 respondents who used the online survey option this year, preliminary analyses comparing differences between online and phone respondents on specific survey items were inconclusive and statistically unstable. Although the limited number of online respondents in 2024 made it difficult to determine if observed differences were meaningful, we hope to have a larger sample of online respondents next year to facilitate a more thorough investigation.

Table 1 summarizes the unweighted characteristics of children living in households with completed interviews (n=1,015) and compares them to the unweighted characteristics of the eligible population not surveyed (N=109,144) using the MaineCare member file. As noted above, children in Expansion CHIP (Title XXI) and those with a chronic condition diagnosis in claims data were oversampled to increase their likelihood of being included in the survey and to ensure adequate sample sizes to conduct subgroup analyses. Weights were developed to adjust for the unequal probability of selection and for non-response. More information on the development of sample weights is included in Appendix C.

Unless otherwise specified, all results are based on weighted data to more closely represent prevalence among the total population of children enrolled in MaineCare. All statistical tests were calculated using SAS version 9.4 with survey procedures that use the Taylor series linearization approach to account for sample design and yield valid standard errors for weighted data. Comparisons of 2024 to 2023 survey results were performed using Microsoft Excel.

Table 1. Characteristics of Survey Sample and Eligible Population in MaineCare Member File

Characteristics	Percent of Respondents*	Percent of Population Not Surveyed
	n = 1,015	N = 109,144
MaineCare Eligibility		
Expansion CHIP (Title XXI) [†]	46.5%	16.9%
Medicaid (Title XIX)	53.5%	83.1%
Household Density		
One enrolled child living in household	28.8%	30.8%
Two or more enrolled children	71.2%	69.2%
Chronic Condition Diagnosis		
Chronic condition diagnosis in claims [†]	52.7%	41.3%
No chronic condition	47.3%	58.7%
Age of Child		
1-5	26.5%	29.5%
6-12	41.6%	41.1%
13-18	31.9%	29.4%
Gender in Member File		
Female	48.8%	48.2%
Male	51.2%	51.8%
Race in Member File		
White, Not Hispanic, and Unknown Race	84.3%	84.9%
Black, Indigenous, and People of Color	15.7%	15.1%
Region of Residence (County)		
Southern (Cumberland and York)	29.2%	28.2%
Central/Western (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset, and Waldo)	43.1%	45.0%
Northern/Downeast (Aroostook, Hancock, Penobscot, Piscataquis, and Washington)	27.8%	26.8%
Response Mode		
Telephone	87.2%	-
Online	12.8%	-

* Unweighted sample characteristics shown here reflect the MaineCare member file and not self-reported survey data.

[†] Denotes subpopulations that were oversampled.

Survey-Reported Child Demographics

The population and sample characteristics shown in Table 1 reflect the demographic data available in the MaineCare member file used to draw the sample. Notably, race/ethnicity was recorded as “indetermined” or “none” in the member file for 14.5% of 2024 survey respondents, limiting the usefulness of the member file race data for exploring potential differences in member experience by race. Additionally, neither the MaineCare member file nor the standard CAHPS 5.1H questionnaire collect information on nonbinary gender identity. As of 2023, the Office of MaineCare Services began to collect more detailed information on the racial and gender identities of survey respondents to develop a better understanding of how experience of care may differ among Black, Indigenous, and People of Color (BIPOC) and non-binary members.

Results for the 2024 survey questions on race and gender are shown in Tables 2 and 3 below. Notably, survey-reported race data were missing for just 3% of respondents and showed greater representation of BIPOC members than suggested by the member file. Respondents identified 80% of children in the sample as White; 8% as Biracial or Multiracial; 6% as Black/African American; 1% as Asian; 0.7% as American Indian/Alaska Native; 0.1% as Native Hawaiian/Pacific Islander; and 0.7% as other. Among the 5.2% of children identified as Hispanic or Latino origin (n=53), 63% also identified as White, 24% as Biracial or Multiracial, 6% as Black/African American, 2% as American Indian/Alaska Native, and 6% as other (data not shown).

Table 2. Survey-Reported Child Race and Gender

Characteristics	Percent of Respondents **
	n = 1,015
Race	
White	79.4%
Biracial/Multiracial	8.1%
Black/African American	6.4%
Asian	1.3%
American Indian/Alaska Native	0.7%
Other	0.7%
Native Hawaiian/Pacific Islander	0.1%
Missing	3.3%
Dichotomous Race	
White	79.4%
Black, Indigenous, and People of Color	17.2%
Missing	3.3%
Hispanic or Latino origin	
Yes	5.2%
No	91.2%
Missing	3.5%
Gender	
Male	51.0%
Female	47.9%
Nonbinary	0.7%
Other	0.2%
Missing	0.2%

* Unweighted sample characteristics shown here reflect self-reported survey data.

† Column may not total to 100% due to rounding.

Follow up questions were asked of respondents who identified their child as Black/African American or Asian to collect more detailed information on the child's racial and ethnic identity. Among Black/African American children (n=113), 35% identified as Black, 31% as African American, 25% as multiple categories, 8% as African, and 1% as West Indian. Among Asian children (n=21), 24% further identified as Chinese, 19% as Vietnamese, 14% as Filipino, 14% as Asian Indian, 10% as multiple categories, 5% as Japanese, 5% as Cambodian, 5% as Korean, and 5% as other. We also asked respondents if their child is a member of a federally recognized tribe. As shown in Table 3, 2.2% of children were identified as members of a tribe.

Unweighted results for survey-reported gender show that 0.7% of respondents (n=7) reported that their child

identified as nonbinary and an additional 0.2% (n=2) as other. We asked separately whether the child identified as transgender and found that 1.2% of the sample (n=12) identified as transgender, 80.5% as cisgender, and the remaining 18.3% did not provide valid responses (data not shown). Although sample sizes were too small to conduct detailed sub-analyses across gender identities or racial and ethnic subgroups, we compared all survey items by dichotomous survey-reported race (BIPOC and White) and report statistically significant differences throughout the report. Demographically, there were no observed differences between BIPOC and White respondents with Title XIX versus Title XXI eligibility; however, BIPOC respondents were less likely than White respondents to be CSHCN (29% vs. 41%, $p \leq .01$) and more likely to be aged five or younger than six to 12 or 13 and older (23% vs. 16% and 13%, $p \leq .05$). This group was also more likely to live in the Southern region of the state compared to the more rural Central/Western and Northern/Downeast regions (28% vs. 13% and 13%, $p \leq .001$) (data not shown).

Table 3. Survey-Reported Detailed Child Race and Tribal Status

Characteristics	Percent of Respondents ^{*†}
Black or African American	n = 113
Black	35.4%
African American	31.0%
African	8.0%
West Indian	0.9%
Multiple	24.8%
Asian	n = 21
Chinese	23.8%
Vietnamese	19.1%
Filipino	14.3%
Asian Indian	14.3%
Multiple	9.5%
Japanese	4.8%
Cambodian	4.8%
Korean	4.8%
Other	4.8%
Tribal Status[‡]	n = 978
Not a member of a federally recognized tribe	97.8%
Penobscot Indian Nation	0.6%
A different tribe	0.5%
Houlton band of Maliseet Indians	0.5%
Aroostook band of Micmac Indians	0.3%
Passamaquoddy tribe at Pleasant Point – Sipayik	0.2%
Passamaquoddy tribe at Indian Township – Motahkomikuk	0.1%

* Unweighted sample characteristics shown here reflect self-reported survey data.

† Column may not total to 100% due to rounding.

‡ Demographic question asked of all respondents.

Parents and guardians were also asked to report the primary language spoken by their child (Table 4). Nearly all children in the survey (94.8%) spoke English as their primary language. Among non-English speakers, a diverse range of languages were reported including Portuguese, French, Spanish, Arabic, Kinyarwanda, Vietnamese, Croatian, Mandarin, Russian, Somali, Tibetan, and Zanze. Additionally, two respondents indicated their child was non-verbal.

Table 4. Survey-Reported Child Language

Characteristics	Percent of Respondents*†
English is child's primary language	n = 1,015
Yes	94.8%
No	2.5%
Missing	2.8%
Child's primary language (non-English)	n = 28
Portuguese	28.6%
French	14.3%
Spanish	14.3%
Arabic	7.1%
Kinyarwanda	3.6%
Vietnamese	3.6%
Other	28.6%
Other Language	n = 8
Non-verbal	25.0%
Croatian	12.5%
Mandarin	12.5%
Russian	12.5%
Somali	12.5%
Tibetan	12.5%
Zanze	12.5%

* Unweighted sample characteristics shown here reflect self-reported survey data.

† Column may not total to 100% due to rounding.

Respondent Characteristics

Table 5 below shows the unweighted distribution of adult survey respondent age, gender, educational attainment, and relationship to the child. In 2024, 89% of respondents indicated they were between the ages of 25 and 54, 84% were female, and 93% were the parent or stepparent of the child. Forty percent of respondents reported a high school education or less while 22% reported a four-year degree or more. Another 35% had completed some college.

Table 5. Characteristics of Adult Survey Respondents

Characteristics*	Percent of Respondents [†]
	(n = 1,015)
Respondent Age	
Under 18	0.7%
18-24	2.4%
25-34	29.8%
35-44	43.3%
45-54	15.9%
55-64	3.9%
65 or older	1.3%
Missing	2.9%
Respondent Gender	
Male	13.0%
Female	84.1%
Nonbinary	0.4%
Missing	2.5%
Other	0.0%
Respondent Education Level	
Less than high school	5.7%
High school graduate/GED	34.6%
Some college/two-year degree	34.8%
Four-year degree	16.9%
More than four-year degree	5.1%
Missing	3.0%
Relationship to Child	
Parent or stepparent	93.4%
Grandparent	3.2%
Legal guardian	0.4%
Missing	2.5%
Other	0.6%

* Unweighted sample characteristics shown here reflect self-reported survey data.

† Columns may not total to 100% due to rounding.

Healthcare Access and Utilization

The following section describes survey findings related to healthcare access and utilization. As shown in Table 6, 34% of respondents indicated that their child needed urgent care during the past six months, and 67% had a checkup or routine care. (The proportion of children who “always” received these services in a timely manner is described below under the “getting care quickly” domain in Table 7). Seventy-eight percent of children had one or more healthcare visits in the past six months. While nearly all respondents (97%) stated that their child had a personal doctor, this was a statistically significant ($p \leq .05$) increase from 2023 when 94% of children had a

personal doctor.⁹ Among those who had a personal doctor, 72% saw their doctor at least once. About one fifth (21%) needed care from a specialist and, of those children, 90% visited a specialist at least once.

Healthcare utilization was generally higher among children aged 12 or younger compared to those aged 13 or older. Seventy-nine percent of children aged five and younger and children aged six to 12 received some kind of healthcare at least once over the last six months compared to 76% of those aged 13 or older ($p \leq .01$) (data not shown).

Unsurprisingly, healthcare utilization was higher among CSHCN compared to non-CSHCN. CSHCN were more likely to need care right away (40% vs. 30%, $p \leq .01$), schedule a routine appointment (73% vs. 63%, $p \leq .01$), have any healthcare visits (86% vs. 73%, $p \leq .001$), visit their personal doctor (77% vs. 70%, $p \leq .01$), and have a specialist appointment (33% vs. 14%, $p \leq .001$) (data not shown). Additionally, BIPOC children were less likely than White children to make a routine appointment (58% vs. 69%, $p \leq .05$) and were less likely to have utilized any healthcare over the last 6 months (66% vs. 80%, $p \leq .05$) (data not shown).

Table 6. Healthcare Access and Utilization

Domain/Item	Results		
	n	Percent	95% CI
<i>Urgent Care</i>			
Needed care right away	1,011	34%	(31% - 38%)
<i>Checkup or Routine Care</i>			
Had checkup or routine care	1,001	67%	(63% - 70%)
<i>Number of Healthcare Visits in Past 6 Months</i>			
None	978	22%	(19% - 25%)
1	978	25%	(22% - 29%)
2 to 4	978	39%	(35% - 43%)
5 or more	978	14%	(11% - 16%)
<i>Personal Doctor</i>			
Child has a personal doctor	1,011	97%	(96% - 98%)
<i>Number of Visits to Personal Doctor in Past 6 Months</i>			
None	954	28%	(24% - 31%)
1	954	38%	(34% - 41%)
2 to 4	954	31%	(28% - 35%)
5 or more	954	3%	(2% - 5%)
<i>Specialty Care</i>			
Had specialist visit	1,005	21%	(18% - 24%)
<i>Number of Visits to Specialist(s) in Past 6 Months</i>			
None	241	10%	(5% - 15%)
1	241	60%	(53% - 68%)
2 to 4	241	25%	(19% - 31%)
5 or more	241	5%	(2% - 7%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare.

Ratings of Overall Health

As shown in Table 7, 82% of respondents rated their child's overall health as "excellent/very good," 14% as "good," and 4% as "fair/poor." Overall health ratings of "excellent/very good" were significantly higher among

⁹ A personal doctor is defined in the CAHPS 5.1H survey as the provider the child sees if they need a check-up, want advice about a health problem, or get sick or hurt.

non-CSHCN compared to CSHCN (90% vs. 69%, $p \leq .001$). For children’s overall mental or emotional health, 68% of respondents rated their child as “excellent/very good,” 20% as “good,” and 12% as “fair/poor” (Table 6). Again, non-CSHCN were more likely to be in “excellent/very good” overall mental or emotion health compared to CSHCN (85% vs. 42%, $p \leq .001$), as were children aged five or younger relative to those aged six to 12 and 13 or older (85% vs. 63% and 57%, $p \leq .001$) (data not shown). Finally, children with coverage through Title XIX were more likely than those eligible under Title XXI to be in “excellent/very good” mental or emotional health (69% vs. 66%, $p \leq .05$) (data not shown).

Table 7. Ratings of Child’s Overall Health and Mental or Emotional Health

Domain/Item	Results		
	n	Percent*	95% CI
<i>In general, how would you rate child’s overall health?</i>			
Excellent or very good	1012	82%	(79% - 84%)
Good	1012	14%	(12% - 17%)
Fair or poor	1012	4%	(3% - 5%)
<i>In general, how would you rate child’s overall mental or emotional health?</i>			
Excellent or very good	1006	68%	(65% - 71%)
Good	1006	20%	(17% - 22%)
Fair or poor	1006	12%	(10% - 15%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare.

* Columns may not total to 100% due to rounding.

Overall Findings: CAHPS 5.1H Core and Chronic Conditions Item Sets

CAHPS 5.1H Core Item Set

The Core CAHPS 5.1H questions focus on the following areas: Getting Needed Care, Getting Care Quickly, How Well the Child’s Doctors Communicate, Health Plan Information and Customer Service, and Overall Ratings (of child’s personal doctor, specialist, health care, and health plan). We compared results from the 2024 MaineCare survey with data on children served by other state Medicaid programs using the 2023 CAHPS data, which was the most recent year of data available in the national CAHPS Database.¹⁰ In Table 7, we display Top Box scores for each of the CAHPS 5.1H Health Plan survey items and domain scores. Top Box scores represent the percent of respondents reporting the most positive response for a given domain, rating, or question. For example, on scales that use “never” to “always” the Top Box score is the percentage of respondents who chose “always”; on rating scales where 0 is the worst and 10 is the best score, the Top Box score is the percentage selecting “9 or 10.” Domain scores are the average of all items within a given domain; they reflect the responses of participants who provided answers to any individual items in the domain. The last two columns in Table 7 provide summary ratings using comparative data obtained from the national CAHPS database. The summary ratings indicate how the MaineCare results compare to Top Box scores from respondents served by Medicaid managed care and fee-for-service plans in other states. The fourth column in the table gives MaineCare’s Top Box rating category, which indicates the program’s percentile rank relative to the Top Box scores of other state Medicaid programs for children. The fifth column contains the median Top Box scores for child Medicaid programs in 2023.

¹⁰ Consumer Assessment of Healthcare Providers and Systems Database: <https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

The Top Box summary rating categories are defined as follows.

Top Box Rating Categories:

Symbol	Rating	Percentile
◆◆◆◆	Excellent	Higher than 90th
◆◆◆	Very Good	75th – 90th
■ ■	Good	50th – 75th
■	Fair	25th – 50th
□	Poor	Less than 25th

As shown in Table 8 below, MaineCare’s domain scores for the core CAHPS items ranged from “poor” to “very good” in 2024, performing above the national median in three of the five domains. MaineCare performed best relative to the national median on the doctor communication domain (81% vs. 78%) receiving a rating of “very good” (75th-90th percentile), up from “fair” in 2023. Within this domain, respondents rated MaineCare as “very good” for the child’s personal doctor always explaining things clearly (85% vs. 79%) and for the child’s doctor always spending enough time with the child (76% vs. 68%). However, across eligibility categories, Title XIX respondents were less likely to report that the child’s personal doctor always explained things clearly compared to Title XXI respondents (80% vs. 86%, $p \leq .05$). MaineCare performed above the national median and increased the Top Box score from “fair” to “good” in both the getting needed care domain and the getting care quickly domain. There were significant regional differences in how often respondents got appointments with specialists as soon as they needed. The Central/Western region was the least likely to get timely appointments with specialists while the Northern/Downeast and Southern regions more likely to get timely appointments (43% vs. 52% and 68% respectively, $p \leq .05$). In the getting needed care domain, CSHCN were less likely to easily get needed care, tests, or treatment compared to non-CSHCN (54% vs. 67%, $p \leq .01$).

Although results for the Member Services help line should be interpreted with caution due to small sample sizes, the domain score for the MaineCare Member Services customer help line dropped 8 percentage points from its 2023 score and continued to rate as “poor” relative to the national median (53% vs. 67%). When asked how often MaineCare Member Services provided needed information or help there were significant regional differences (Southern with 56% vs. Central/Western at 45% and Northern/Downeast at 10%, $p \leq .05$), and experience with customer service also varied by race, with 96% of BIPOC compared to 65% of White respondents reporting always being treated with respect ($p \leq .05$) (data not shown).

MaineCare continued to rank under the 25th percentile for each of the four measures in the overall ratings domain. Moreover, a lower percentage of respondents chose the highest overall rating (“9” or “10” on a 10-point scale) for each rating measure in 2024 compared to 2023: personal doctor (64% in 2024 vs. 71% in 2023), specialist (61% vs. 63%), health care (55% vs. 58%), and health plan (56% vs. 64%). Additionally, parents and guardians of CSHCN were significantly less likely than those of non-CSHCN to rate their child’s health plan a “9” or “10” (49% vs. 60%, $p \leq .01$), and Title XIX respondents were more likely than Title XXI respondents to rate all of their child’s health care a “9” or “10” (56% vs. 46%, $p \leq .05$). Notably, unlike 2023, there were no statistically significant differences by region or race in overall ratings for 2024.

Table 8. CAHPS 5.1H Core Item Set: Results for Entire Sample with National Medicaid Comparisons

Domain/Item	2024 MaineCare Results*		National Comparisons†	
	MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Rating	2023 National Child Medicaid Median
Core CAHPS 5.1H Health Plan Item Set				
<i>Getting Needed Care</i>	57%		■ ■	56%
How often was easy to get needed care, tests, or treatment for child	61%	(57% - 65%)	■ ■	60%
How often was easy to get appointments with specialists for child	53%	(45% - 61%)	■ ■	51%
<i>Getting Care Quickly</i>	72%		■ ■	68%
Child got urgent care for illness, injury or condition as soon as wanted	78%	(73% - 84%)	■ ■	75%
Got non-urgent appointment for child at doctor's office or clinic as soon as thought needed	66%	(62% - 70%)	◆ ◆ ◆	61%
<i>How Well the Child's Doctors Communicate</i>	81%		◆ ◆ ◆	78%
Child's personal doctor explained things clearly	85%	(82% - 88%)	◆ ◆ ◆	79%
Child's personal doctor listened carefully	84%	(80% - 87%)	■ ■	81%
Child's personal doctor respected consumer comments	88%	(85% - 91%)	■ ■	86%
Child's personal doctor explained things in a way that was easy for child to understand	74%	(69% - 78%)	■	76%
Child's personal doctor spent enough time with child	76%	(72% - 79%)	◆ ◆ ◆	68%
<i>Health Plan Information and Customer Service</i>	53%		□	67%
Customer service at child's health plan gave information or help needed‡	36%	(20% - 52%)	□	56%
Customer service staff at child's health plan courteous and respectful‡	70%	(54% - 87%)	□	78%
Overall Ratings				
Rating of child's personal doctor	64%	(60% - 68%)	□	75%
Rating of child's specialist	61%	(52% - 70%)	□	72%
Rating of all child's health care	55%	(50% - 59%)	□	68%
Rating of child's health plan	56%	(51% - 60%)	□	70%

* Results are weighted to represent the entire population of children enrolled in MaineCare.

† Comparisons based on National 2023 Child Medicaid 5.1H Percentile Top Box Scores downloaded from CAHPS Database October 9, 2024: <https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

‡ Sample size less than 100. Use results with caution.

Experience with MaineCare Member Services Help Line

Beginning in 2016, additional questions were added to the core CAHPS items on health plan information and customer services to obtain more detailed information about member experience with the MaineCare Member Services help line. In 2024, approximately 5% of respondents (unweighted n=61) attempted to get information or help from the MaineCare Member Services telephone help line. Given the small number of respondents who used the help line, results should be interpreted with caution. Among help line users, 73% indicated they

“usually” or “always” got the information or help they needed, while 18% “sometimes” and 8% “never” got the information or help they needed (data not shown).

Table 9 shows the most common reasons respondents did not receive needed information or help. Because sample sizes were less than 100, results should be interpreted with caution. In 2024, 57% of respondents indicated they had to wait too long to speak with someone; 48% indicated that Member Services did not have the information they needed; and 47% had to call several times before they were able to speak with someone. Additionally, 36% indicated Member Services was unable to answer their questions, 27% were given the wrong information, 22% found the information they were given difficult to understand, 10% were never able to get through, and 1% indicated some other reason. This year, only 42% percent of respondents reported that if Member Services could not address their issue they were “usually” or “always” directed to the correct department, down from 71% in 2023 ($p < .05$).

Among members who called the help line in 2024, 26% rated MaineCare Member Services a “9” or “10” out of 10 compared to 42% last year. Although this appears to be a sizable difference, it is not statistically significant, likely due to the low number of responses to the question each year. This suggests that the observed change in satisfaction may be due to sampling variation rather than a meaningful shift in member sentiment. Additionally, 85% of respondents who spoke to Member Services indicated that staff “usually” or “always” treated them with courtesy and respect, statistically similar to the 90% reported in 2023.

Table 9. Experience With MaineCare Member Services Help Line

Domain/Item	Results		
	n	Percent	95% CI
<i>Reasons why needed help or information was not received after calling MaineCare Member Services (check all that apply)*</i>			
Had to wait too long to speak to someone	38	57%	(38% - 76%)
They did not have the information needed	38	48%	(24% - 72%)
Had to call several times before speaking to someone	38	47%	(35% - 59%)
Unable to answer questions	38	36%	(16% - 55%)
Was given wrong information	38	27%	(9% - 45%)
The information they gave me was hard to understand	38	22%	(5% - 39%)
Was never able to get through	38	10%	(0% - 27%)
Some other reason	38	1%	(0% - 3%)
Could not speak to someone in my preferred language	38	0%	(0% - 0%)
<i>If MaineCare Member Services could not address your issue, how often were you directed to the correct MaineCare department?*</i>			
Never	35	20%	(8% - 31%)
Sometimes	35	38%	(28% - 48%)
Usually	35	27%	(8% - 45%)
Always	35	15%	(1% - 30%)
<i>How often did MaineCare Member Services treat you with courtesy and respect?*</i>			
Never	59	3%	(0% - 7%)
Sometimes	59	13%	(0% - 25%)
Usually	59	14%	(3% - 26%)
Always	59	70%	(54% - 87%)
<i>MaineCare Member Services Top Box Score (Percent rating 9 or 10)*</i>	53	26%	(10% - 42%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare.

* Sample size less than 100. Use results with caution.

CAHPS 5.1H Children with Chronic Conditions Item Set

The CAHPS survey also includes a supplemental set of items designed to measure health plan performance in addressing topics that tend to be of more concern to families of children with chronic health conditions. These questions were asked of all survey participants, regardless of the chronic condition status of the child, allowing comparisons across groups of children with and without special health care needs. The measures in the supplemental chronic care item set include Access to Specialized Services, Access to Prescription Medicines, Family-Centered Care (including having a personal doctor who knows the child and getting needed information) and Coordination of Care and Services. We again computed the Top Box results for each measure and compared them to national results from the CAHPS Database (Table 10). Note that the findings in Table 10 pertain to all 2024 survey participants, including children with and without chronic conditions. Although statistically significant differences between CSHCN and non-CSHCN are noted throughout this report, a detailed discussion of the experience of care among children with and without special health care needs is also presented below (see section titled “MaineCare Member Experience of Children with Special Health Care Needs” on page 25).

Scores for the chronic conditions item set were generally stable from 2023 to 2024 across all items and domains, and MaineCare showed an improvement in Top Box rating for four of the measures. However, it is important to note that in the most recent national Medicaid comparison data, median scores dropped slightly for every measure across the chronic conditions item set. It appears MaineCare’s improved Top Box ratings in the chronic conditions item set can largely be attributed to decreases in other state scores, rather than improvements in 2024 member ratings. The exception to this was for the question asking how often it was easy to get treatment or counseling for the child. In 2024, 40% of respondents reported always getting these services easily compared to 32% of respondents in 2023, increasing the top box rating from “poor” to “fair”.

Sixty-four percent of respondents indicated that their child’s personal doctor seemed informed and up to date about care received from other doctors or providers, placing MaineCare in the 75th–90th percentile with a rating of “very good”. Regarding access to specialized services, 42% of respondents (down from 50% in 2023) indicated that it was always easy to get special medical equipment or devices for their child, and 55% indicated that it was always easy to get special therapy for their child. Sixty-six percent of respondents reported it was always easy to obtain prescription medicines through MaineCare, the same as national median, but CSHCN were less likely than non-CSHCN to do so (57% vs. 81%, $p \leq .001$). This difference between CSHCN and non-CSHCN in access to prescription medicines was larger and more statistically significant than it was in 2023 (61% vs. 74%, $p \leq .05$) (data not shown). Within the specialized services domain, Title XXI respondents were less likely than Title XIX respondents to have easy access to special medical equipment or devices (38% vs. 47%, $p \leq .05$, $n=46$).

MaineCare scored well on family centered care, with 90% of respondents reporting that their child’s doctor talked about how the child was feeling, growing, or behaving (a rating of “very good”); 93% indicating the doctor understood how the child’s health conditions affected the child’s day-to-day life (a rating of “good”); and 91% indicating the child’s doctor understood how the child’s health conditions affected the family’s day-to-day life (a rating of “very good”). The 2024 MaineCare scores for the family centered care and coordination of care and services domains are consistent with 2023 scores, with no significant year-over-year differences. Seventy-six percent of respondents indicated that their child’s healthcare providers always answered their questions. With regard to care coordination, 96% of families surveyed said they consistently got the help they needed from their child’s doctor or health providers when contacting their school or daycare (a rating of “good”). Fifty-three percent routinely got the help they needed to coordinate care among the child’s different providers and services, below the national median of 58%. Parents and guardians of CSHCN children were more likely than their non-CSHCH counterparts to report having help from their doctor’s office, clinic, or MaineCare coordinating care among different providers (62% vs. 38%, $p \leq .001$) (data not shown).

Table 10. CAHPS 5.1H Children with Chronic Conditions Item Set: Results for Entire Sample with National Medicaid Comparisons

Domain/Item	2024 MaineCare Results*		National Comparisons†	
	MaineCare Top Box Score	Confidence Interval	MaineCare Top Box Rating	2023 National Child Medicaid Median
Children with Chronic Conditions Item Set				
Child's personal doctor seemed informed and up to date about care received from other doctors or providers	64%	(58% - 71%)	◆◆◆	58%
Getting Specialized Services				
How often was easy to get special medical equipment or devices for child‡	42%	(29% - 56%)	■	45%
How often was easy to get special therapy for child	55%	(46% - 64%)	◆◆◆	48%
How often was easy to get treatment or counseling for child	40%	(33% - 46%)	■	45%
Getting Prescription Medicine				
How often was easy to get prescription medicines for child through health plan§	66%	(61% - 70%)	■	66%
Family Centered Care: Personal Doctor Who Knows Child				
Child's personal doctor talked about how child was feeling, growing, or behaving	90%	(87% - 93%)	■ ■	89%
Child's personal doctor understood how health conditions affected child's day-to-day life§	93%	(90% - 96%)	■	93%
Child's personal doctor understood how health conditions affected child's family's day-to-day life	91%	(87% - 94%)	■ ■	89%
Family Centered Care: Getting Needed Information				
How often questions answered by child's doctors or health providers	76%	(72% - 79%)	■ ■	72%
Coordination of Care and Services				
Got help needed from child's doctors or health providers in contacting child's school or Daycare	96%	(93% - 99%)	■ ■	91%
Got help from child's health plan, doctor's office, or clinic to coordinate child's care among different providers/services	53%	(46% - 59%)	□	58%

* Results are weighted to represent the entire population of children enrolled in MaineCare.

† Comparisons based on National 2023 Child Medicaid 5.1H Percentile Top Box Scores downloaded from CAHPS Database October 9, 2024:

<https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

‡ Sample size less than 100. Use results with caution.

§ Due to rounding, MaineCare Top Box Score does not align with MaineCare Top Box Rating category.

MaineCare Member Experience Among Title XIX and Title XXI Eligibility Categories

We also examined CAHPS results separately for Title XIX and Title XXI MaineCare eligibility categories to assess the extent to which the experience of children in these groups differed. The Title XIX group includes children enrolled in the traditional Medicaid eligibility category of MaineCare, and the Title XXI group includes children in Medicaid Expansion CHIP.¹¹ We analyzed differences by eligibility category for the core CAHPS items as well as the chronic conditions item set and summarize the results below.

CAHPS 5.1H Core Item Set

There were modest differences between Title XIX and Title XXI program enrollee ratings of MaineCare on the core CAHPS 5.1H survey items. As shown in Table 11 below, both eligibility groups scored “fair” or higher on all items within the getting needed care, getting care quickly, and doctor communication domains. In these three domains, there were no statistically significant changes compared to last year’s survey. But it is noteworthy that, for each eligibility group, every item’s Top Box rating was the same or better than 2023. Relative to the national median, Title XIX respondents scored “good” in getting needed care, “good” in getting care quickly, and “very good” in doctor communication. Title XXI scored “fair” in getting needed care, “very good” in getting care quickly, and “good” in doctor communication. In 2024, Title XIX respondents were more likely than Title XXI respondents to report that the child’s personal doctor always explained things clearly (86% vs. 80%, $p \leq .05$). For the health plan information and customer service domain, both Title XIX and Title XXI enrollees rated MaineCare as “poor.” However, as stated above, sample sizes were less than 100 for all items in this domain, so results should be interpreted with caution. Overall ratings for the child’s personal doctor, specialist, health care, and health plan were “poor,” below the 25th percentile nationally, for both eligibility categories. In the overall ratings domain, there were statistically significant differences both between groups and year over year by group. Title XXI enrollees were less likely than Title XIX enrollees to rate all their child’s healthcare with the top score in 2024 (46% vs. 56%, $p \leq .05$). There were also significant year-over-year differences for three of the items in the overall ratings domain. Ratings for the child’s personal doctor worsened significantly for both eligibility groups in 2024 compared to 2023 (Title XIX: 64% vs. 71%, $p \leq .05$; Title XXI: 61% vs. 68%, $p \leq .001$), as did ratings of the child’s health plan (Title XIX: 56% vs. 64%, $p \leq .01$; Title XXI: 52% vs. 60%, $p \leq .05$). Finally, Title XXI respondents rated all their child’s health care lower in 2024 than in 2023 (46% vs. 60%, $p \leq .001$).

CAHPS 5.1H Children with Chronic Conditions Item Set

Table 12 shows MaineCare performance by eligibility category on the CAHPS supplemental children with chronic conditions item set. As with the core items, results were consistent between the eligibility categories for the chronic conditions items with some slight variances. Title XIX enrollees were slightly more likely to report that their child’s doctor seemed informed and up to date about care the child had received from other providers compared to Title XXI enrollees, resulting in a “very good” rating among Title XIX enrollees compared to a “good” rating among Title XXI. Title XXI enrollees were also slightly less likely to always have easy access to counseling, resulting in a “poor” score compared to a “good” score among Title XIX enrollees. Although sample sizes were small and results should be interpreted with caution, there was one significant difference in 2024 between eligibility groups: Title XXI respondents were less likely to have easy access to special medical equipment and devices compared to Title XIX (38% vs. 47%, $p \leq .05$, $n=46$). Title XIX enrollees also rated MaineCare higher than their Title XXI counterparts on the extent to which their child’s personal doctor talked about how the child was feeling, growing, or behaving (91% vs. 86%), resulting in a rating of “good” for Title XIX compared to “poor” for Title XXI. Fifty-six percent of Title XIX enrollees reported that it was always easy to get

¹¹ See Appendix A for data on family income eligibility limits, premium payments, and funding sources for each MaineCare eligibility group.

special therapy for their child (“very good” relative to the national median) compared to 50% of Title XIX enrollees (“good” relative to the national median). In the coordination of care domain, Title XIX enrollees rated MaineCare as “very good” on the extent to which the family was able to get needed help from their child’s providers in contacting their school or daycare compared to “good” among Title XXI enrollees. Finally, there was one significant year over year difference in this domain. Title XXI enrollees in 2024 were significantly more likely to get help from their child’s health plan, doctor’s office, or clinic to coordinate care among different providers than they were in 2023 (56% vs. 38%, $p \leq .01$).

Table 11. CAHPS 5.1H Core Item Set by MaineCare Title XIX and Title XXI Eligibility

Domain/Item	2024 MaineCare Title XIX Results*			2024 MaineCare Title XXI Results*				
	MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Rating†		MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Rating†	
Core CAHPS 5.1H Health Plan Item Set								
<i>Getting Needed Care</i>	58%		■ ■		53%		■	
How often was easy to get needed care, tests, or treatment for child	62%	(57% - 67%)	■ ■		57%	(52% - 62%)	■	
How often was easy to get appointments with specialists for child	54%	(45% - 63%)	■ ■		49%	(39% - 59%)	■	
<i>Getting Care Quickly</i>	72%		■ ■		75%		◆ ◆ ◆	
Child got urgent care for illness, injury or condition as soon as thought needed	78%	(71% - 84%)	■ ■		82%	(76% - 88%)	◆ ◆ ◆	
Got non-urgent appointment for child at doctor's office or clinic as soon as thought needed	66%	(61% - 71%)	■ ■		67%	(62% - 73%)	◆ ◆ ◆	
<i>How Well the Child's Doctors Communicate</i>	81%		◆ ◆ ◆		80%		■ ■	
Child's personal doctor explained things clearly	86%	(83% - 90%)	◆ ◆ ◆ ◆		80%	(76% - 85%)	■ ■	
Child's personal doctor listened carefully	84%	(80% - 88%)	■ ■		82%	(77% - 86%)	■ ■	
Child's personal doctor respected consumer comments	88%	(84% - 91%)	■ ■		87%	(83% - 91%)	■ ■	
Child's personal doctor explained things in a way that was easy for child to understand	73%	(68% - 79%)	■		74%	(69% - 80%)	■	
Child's personal doctor spent enough time with child	75%	(71% - 80%)	◆ ◆ ◆		76%	(71% - 81%)	◆ ◆ ◆ ◆	
<i>Health Plan Information and Customer Service</i>	53%		□	‡	53%		□	‡
Customer service at child's health plan gave information or help needed	37%	(16% - 58%)	□	‡	33%	(17% - 49%)	□	‡
Customer service staff at child's health plan courteous and respectful	70%	(48% - 91%)	□	‡	72%	(58% - 87%)	□	‡
Overall Ratings								
Rating of child's personal doctor	64%	(60% - 69%)	□		61%	(56% - 66%)	□	
Rating of child's specialist	62%	(52% - 72%)	□	‡	55%	(44% - 66%)	□	‡
Rating of all child's health care	56%	(51% - 62%)	□		46%	(40% - 52%)	□	
Rating of child's health plan	56%	(51% - 61%)	□		52%	(47% - 57%)	□	

* Results are weighted to represent the entire population of children enrolled in MaineCare.

† Comparisons based on National 2023 Child Medicaid 5.1H Percentile Top Box Scores downloaded from CAHPS Database October 9, 2024:

<https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

‡ Sample size less than 100. Use results with caution.

Table 12. CAHPS 5.1H Children with Chronic Conditions Item Set by MaineCare Title XIX and Title XXI Eligibility

Domain/Item	2024 MaineCare Title XIX Results				2024 MaineCare Title XXI Results			
	MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Category*		MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Category*	
Children with Chronic Conditions Item Set								
Child's personal doctor seemed informed and up to date about care received from other doctors or providers	65%	(57% - 72%)	◆◆◆		62%	(54% - 70%)	■ ■	
Getting Specialized Services								
How often was easy to get special medical equipment or devices for child	41%	(24% - 58%)	■	‡	47%	(28% - 65%)	■ ■	‡
How often was easy to get special therapy for child	56%	(46% - 66%)	◆◆◆		50%	(38% - 62%)	■ ■	‡
How often was easy to get treatment or counseling for child	41%	(33% - 49%)	■		34%	(25% - 43%)	□	
Getting Prescription Medicine								
How often was easy to get prescription medicines for child through health plan	66%	(60% - 72%)	■ ■		63%	(57% - 69%)	■	
Family Centered Care: Personal Doctor Who Knows Child								
Child's personal doctor talked about how child was feeling, growing, or behaving	91%	(87% - 94%)	■ ■		86%	(83% - 90%)	□	
Child's personal doctor understood how health conditions affected child's day-to-day life [§]	93%	(90% - 96%)	■		93%	(89% - 97%)	■ ■	
Child's personal doctor understood how health conditions affected child's family's day-to-day life [§]	91%	(87% - 95%)	■ ■		89%	(84% - 94%)	■ ■	

* Results are weighted to represent the entire population of children enrolled in MaineCare.

† Comparisons based on National 2023 Child Medicaid 5.1H Percentile Top Box Scores downloaded from CAHPS Database October 9, 2024:

<https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

‡ Sample size less than 100. Use results with caution.

§ Due to rounding, MaineCare Top Box Score does not align with MaineCare Top Box Rating category.

Table 12. (continued) CAHPS 5.1H Children with Chronic Conditions Item Set by MaineCare Title XIX and Title XXI Eligibility

Domain/Item	2024 MaineCare Title XIX Results				2024 MaineCare Title XXI Results			
	MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Category*		MaineCare Top Box Score	95% Confidence Interval	MaineCare Top Box Category*	
<i>Family Centered Care: Getting Needed Information</i>								
How often questions answered by child's doctors or health providers	76%	(72% - 81%)	◆◆◆		72%	(67% - 77%)	■ ■	
<i>Coordination of Care and Services</i>								
Got help needed from child's doctors or health providers in contacting child's school or daycare	96%	(93% - 100%)	◆◆◆	‡	93%	(87% - 99%)	■ ■	‡
Got help from child's health plan, doctor's office, or clinic to coordinate child's care among different providers/services	52%	(44% - 59%)	□		56%	(48% - 64%)	■	

* Results are weighted to represent the entire population of children enrolled in MaineCare.

† Comparisons based on National 2023 Child Medicaid 5.1H Percentile Top Box Scores downloaded from CAHPS Database October 9, 2024:

<https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

‡ Sample size less than 100. Use results with caution.

MaineCare Member Experience of Children with Special Health Care Needs

Children with special health care needs (CSHCN) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition that requires health care and related services of a type or amount beyond that required by children generally.¹² Several federal and state programs target CSHCN including children in foster care or adoption assistance programs (Title IV-E), Supplemental Security Income (SSI), Title V-funded care coordination services,¹³ and services under a 1903(3) option known as the Katie Beckett¹⁴ option.

Prevalence of CSHCN in MaineCare

We identified CSHCN in our survey sample using the CSHCN Screener developed by Bethell et al (2002).¹⁵ The CSHCN Screener is included in the Child Medicaid survey and identifies children who experience at least one of five different health consequences: (1) use or need of prescription medication, (2) above-average use or need of medical, mental health or educational services, (3) functional limitations compared with others of the same age, (4) use or need of specialized therapies, and (5) treatment or counseling for emotional or developmental problems. To qualify as a CSHCN, the following must all be present:

- The child must currently experience one (or more) of the five specific consequences noted above;
- The consequence must be due to a medical, behavioral, or other health condition; and
- The duration or expected duration of the condition must be 12 months or longer.

Based on the 2024 survey, an estimated 39% of children enrolled in MaineCare met the CSHCN screening criteria (Table 13), similar to the 40% identified in last year's study. Of the five qualifying health consequences, use or need of prescription medications was most prevalent at 27% followed by above average use or need of medical, mental health, or educational services at 22% and treatment or counseling for emotional, behavioral, or developmental problems at 21% (all statistically similar to rates found in the 2023 survey.)

The prevalence of children with special health care needs is higher among children enrolled in MaineCare than among the general population of children in Maine and nationally. Data from a national survey conducted in 2022 showed that 26.6% of all children in Maine and 20.8% of all children nationwide had special health care needs.¹⁶ Results from the 2024 survey do not suggest differences in rates of CSHCN across eligibility categories or region. However, White non-Hispanic children were more likely than BIPOC children to be identified as CSHCN (41% vs. 29%, $p \leq .01$) as were children aged 13 or older compared to ages six to 12 and five or younger (49% vs. 46% and 21%, $p \leq .001$).

As noted above in the "Ratings of Overall Health" section, when asked to rate their child's overall health, parents and guardians of CSHCN were significantly more likely ($p \leq .001$) than those of non-CSHCN to rate their child's

¹² McPherson, M., et al. (1998). A new definition of children with special health care needs. *Pediatrics*; 102: 137-40.

¹³ The Title V Maternal and Child Health Block Grant supports work in Maine to ensure the health of mothers, women, children and youth, including children with special health care needs and their families through the following programs: Birth Defects Program; Cleft Lip & Palate Program; Partners in Care Coordination; Newborn Hearing Program; Genetics Program; Newborn Bloodspot Screening Program; Maternal, Fetal & Infant Mortality Review; Perinatal Health; Women's Health; Adolescent and School Health; Public Health Nursing; Injury and Suicide Prevention; Oral Health. See Maine Center for Disease Control and Prevention. Maternal & Child Health. Federal Title V Maternal and Child Health Program: <https://www.maine.gov/dhhs/mecdc/population-health/mch/> and Health Resources and Services Administration. Title V Maternal and Child Health (MCH) Block Grant: <https://mchb.hrsa.gov/programs-impact/title-v-maternal-child-health-mch-block-grant>

¹⁴ Katie Beckett is a MaineCare option for children with serious health conditions. For more information go to: <https://www.maine.gov/dhhs/ocfs/support-for-families/childrens-behavioral-health/katie-beckett-option>

¹⁵ For more information, see Bethell, C.D., Read, D., Stein, R., et al. (2002). Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambulatory Pediatrics*; 2:49-57. <http://depts.washington.edu/dbpeds/Screening%20Tools/CSHCN-CAMHIScreener.pdf>

¹⁶ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). www.childhealthdata.org.

health as “fair/poor” (9% vs. 0.4%) or “good” (22% vs. 9%), and less likely to report “excellent/very good” health (69% vs. 90%). When asked to rate their child’s overall mental health, CSHCN respondents were again significantly more likely ($p \leq .001$) to rate it as “fair/poor” (29% vs. 2%) or good (29% vs. 13%), and less likely to rate it as “excellent/very good” (42% vs. 85%) (data not shown).

Table 13. Children with Special Health Care Needs Screener Results

Item	Results		
	n	%	95% CI
<i>Health consequence of child's chronic condition or special health care needs</i>			
Use or need of prescription medication	988	27%	(24% - 30%)
Above average use or need of medical, mental health or educational services	963	22%	(19% - 24%)
Treatment or counseling for emotional, behavioral or developmental problems	986	21%	(18% - 23%)
Functional limitations compared with others of the same age	975	14%	(11% - 16%)
Use or need of specialized therapies (occupational therapy, physical therapy, speech therapy, etc.)	990	14%	(11% - 16%)
<i>Child with Special Health Care Needs (experiences one or more of these health consequences)</i>	1,009	39%	(36% - 42%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare.

Differences in Experience of Care for CSHCN and non-CSHCN

Ensuring that children with special health care needs enrolled in MaineCare have adequate access to needed services is important not only for their health and well-being, but also for the management of current and future MaineCare expenditures. By helping children and families to better manage their chronic conditions, MaineCare can both improve member experience and help avoid the use of more costly emergency and hospital services.

To identify areas where MaineCare may be able to improve the quality of services delivered to CSHCN, we compared Top Box scores for CSHCN and non-CSHCN on the core and chronic condition CAHPS items (Table 14). For the core items, respondents in the CSHCN group were significantly less likely than their non-CSHCN counterparts to report a score of “9 or 10” for their MaineCare coverage (49% vs. 60%, $p \leq .01$). Although not statistically significant, parents in the CSHCN group were less likely to rate the specialist their child saw most often a “9 or 10” (56% vs. 70%). Parents of CSHCN were also less likely to report that it was “always” easy to get the care, tests, or treatment their child needed (54% vs. 67%, $p \leq .01$) and more likely to report that their child received care from a health provider besides their personal doctor (60% vs 40%, $p \leq .001$).

For the chronic conditions item set, parents of CSHCN were less likely to report that it was “always” easy to get prescription medicines (57% vs. 81%, $p \leq .001$), and more likely to report getting help from their child’s MaineCare plan, a doctor’s office, or clinic in coordinating care among different providers or services (62% vs. 38%, $p \leq .001$).

Of note, 8 categories (six of the core CAHPS items and two of the chronic conditions CAHPS items) showed notable differences between the two groups (CSHCN vs. non-CSHCN) in 2024, compared to ten categories (eight in the core and two in the chronic conditions items) in 2023.

Table 14. CAHPS 5.1H Select Results for Children with and without Special Health Care Needs

Domain/Item	Results				
	n	Non- CSHCN	CSHCN	CSHCN Comparison	2023 National Median CSHCN [†]
Core Item Set					
In general, how would you rate your child's overall health? (Excellent/Very Good)***	1,007	90%	69%	↓	-
In general, how would you rate your child's overall mental or emotional health? (Excellent/Very Good)***	1,001	85%	42%	↓	-
Using any number from zero to ten, how would you rate child's MaineCare? (% "9-10")**	841	60%	49%	↓	64%
How often was it easy to get care, tests, or treatment child needed? (% "Always")**	778	67%	54%	↓	58%
Did your child get care from a health provider besides their personal doctor? (% Yes)***	700	40%	60%	↑	-
Using any number from 0 to 10, how would you rate the specialist your child has seen the most often in the last 6 months? (% "9-10")	182	70%	56%	↓	70%
Children with Chronic Conditions Item Set					
How often was it easy to get prescription medicines for child through MaineCare? (% "Always")***	508	81%	57%	↓	65%
Did anyone from your child's MaineCare plan, doctor's office, or clinic help coordinate child's care among different providers or services? (% Yes)***	332	38%	62%	↑	59%
Legend:	CSHCN at least 10% lower than non-CSHCN				↓
	CSHCN at least 10% higher than non-CSHCN				↑

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare
Differences significant at p≤.05*, p≤.01**, p≤.001***

[†] Comparisons based on National 2023 Child Medicaid 5.1H Percentile Top Box Scores downloaded from CAHPS Database October 9, 2024: <https://datatools.ahrq.gov/cahps/?type=tab&tab=cahpscarhps>

Findings: Other Topics Relevant to MaineCare Policy

Behavioral Health

Beginning in 2023, several questions on behavioral health treatment and counseling were added to the survey to collect data on member need, access, utilization, and types of treatment or counseling used. For respondents who indicated their child had an emotional, developmental, or behavioral problem for which they needed or got treatment or counseling, follow up questions were asked about the type of treatment or counseling used, and how often it was easy to access those services. Development of good mental health practices, including during childhood and adolescence, is critical to overall health and wellbeing. Unfortunately, many children go without

needed care and support, despite increased recognition and emphasis in recent years of the importance of integrating mental and behavioral health services into pediatric primary care and other healthcare settings.^{17,18,19,20}

As shown in Table 15, 28% of respondents to the 2024 survey indicated their child needed behavioral health treatment or counseling, statistically similar to the rate of 26% in 2023. By comparison, a 2022 report published by the Agency for Healthcare Research and Quality found that nationally approximately 20% of children aged three to 17 had a mental, emotional, developmental, or behavioral disorder, and that suicidal behaviors among high school students had increased more than 40% in the decade prior to the COVID-19 pandemic which exacerbated these trends.¹⁶

In Maine's 2024 survey, need for treatment or counseling varied across age groups, as well as by race and CSHCN status. Specifically, only 14% of those aged five or younger needed treatment or counseling compared to 32% of children aged six to 12 and 36% aged 13 or older ($p \leq .001$). Also, a higher percentage of White non-Hispanic children reported needing treatment or counseling compared those who identified as BIPOC (29% vs. 19%, $p \leq .05$). Finally, a much higher percentage of CSHCN needed behavioral health services compared to non-CSHCN (66% vs. 3%, $p \leq .001$) (data not shown).

Seventy-five percent of those who needed treatment or counseling received the service. There were no observed differences between respondents who received the care they needed across race, eligibility group, or region. However, older children received needed treatment or counseling at a considerably higher rate than their younger counterparts: 83% of those aged 13 or older, 76% of those ages six to 12, and 56% of those aged five or younger received the care they needed ($p \leq .05$).

Respondents whose children received behavioral health treatment or services were also asked which types of treatment or counseling services they received (office-based, school-based, home and/or community-based, and inpatient or residential). Notably, 48% of respondents to the behavioral health module indicated their child received more than one type of care (unweighted, data not shown).

The most frequently used type of behavioral health treatment or counseling was school-based services (65%), with results varying by age, region, and race. Children aged six to 12 were most likely to use school-based services (75% vs. 64% under age five, and 53% aged 13 or older, $p \leq .05$), as were those in the Southern compared to the Central/Western and Northern/Downeast regions of the state (80% vs. 54% and 67%, $p \leq .01$). Finally, White non-Hispanic children were more likely than BIPOC children to utilize school-based treatment or counseling (82% vs. 62%, $p \leq .05$) (data not shown).

With regard to other types of behavioral health treatment or counseling, 59% of children received office-based services, 29% received home and/or community-based services, 6% received inpatient or residential treatment or counseling, and 4% received other types of services including medication management, telehealth, and in-hospital treatments. Overall, females were more likely than males to receive office-based treatment and counseling (68% vs 50%, $p < .05$), as were children aged 13 or older compared to those aged six to 12 and five or younger (74%, 50%, 41%, $p < .01$). Five percent of respondents "never," 22% "sometimes," 28% "usually," and

¹⁷ Agency for Healthcare Research and Quality. (2022, October). 2022 National Healthcare Quality and Disparities Report. AHRQ Pub. No. 22(23)-0030. Rockville, MD. <https://www.ncbi.nlm.nih.gov/books/NBK587174/>

¹⁸ Galbreath, L., Wilkniss, S., and Rohrer, J. (2024, March 22). Modernizing Behavioral Health Systems: A Resource for States. National Academy for State Health Policy Toolkit. <https://nashp.org/modernizing-behavioral-health-systems-a-resource-for-states/>

¹⁹ Kim, J., Sheldrick, R.C., Gallagher, K., et al. (2023). Association of Integrating Mental Health into Pediatric Primary Care at Federally Qualified Health Centers With Utilization and Follow-up Care. *JAMA Netw Open*, 6(4):e239990. doi:10.1001/jamanetworkopen.2023.9990.

²⁰ U.S. Department of Health and Human Services. HHS Roadmap for Behavioral Health Integration. (2022, December 2). <https://www.hhs.gov/about/news/2022/12/02/hhs-roadmap-for-behavioral-health-integration-fact-sheet.html>

45% “always” found it easy to get the treatment or counseling that their child needed.

Table 15. Behavioral Health Treatment and Counseling

Domain/Item	Results		
	n	%	95% CI
<i>Needed Treatment or Counseling</i>			
Child has any kind of emotional, developmental, or behavioral problem for which they need or get treatment or counseling	989	28%	(25% - 30%)
<i>Received Treatment or Counseling</i>			
Yes	306	75%	(70% - 81%)
No	306	25%	(19% - 30%)
<i>Types of Treatment or Counseling</i>			
School-based	232	65%	(57% - 72%)
Office-based	232	59%	(51% - 66%)
Home and/or community-based	232	29%	(23% - 36%)
Inpatient or residential	232	6%	(3% - 9%)
Other	232	4%	(1% - 6%)
<i>How Often it was Easy to get Treatment or Counseling</i>			
Never	228	5%	(2% - 8%)
Sometimes	228	22%	(15% - 28%)
Usually	228	28%	(21% - 34%)
Always	228	45%	(38% - 53%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare

Telehealth

The COVID-19 pandemic led to increased telehealth service use to ensure continued patient access to routine and specialty care. Preliminary data suggested that rates of telehealth use in the early months of the pandemic were higher among children enrolled in MaineCare than in any other state Medicaid program.²¹ Additionally, MaineCare has long had a robust telehealth policy, and both CMS and the state of Maine created additional flexibilities to encourage the continued expansion of telehealth services during and beyond the COVID-19 emergency period.^{22,23} However, persistent challenges such as limited access to providers and broadband availability pose significant barriers, particularly in rural areas of the state,²⁴ and telehealth may be less effective for serving children with special healthcare needs.²⁵ In order to better understand the experience of telehealth service use among children enrolled in MaineCare, a telehealth module has been included in the survey since 2021. The 2024 telehealth module included questions on telehealth access, utilization, and

²¹ Service use among Medicaid & CHIP beneficiaries ages 18 and under during COVID-19. (2020). Preliminary Medicaid & CHIP Data Snapshot: Services through May 31, 2020. <https://www.medicaid.gov/resources-for-states/downloads/medicaid-chip-beneficiaries-18-under-COVID-19-snapshot-data.pdf>

²² Maine Department of Health and Human Services. (2020). MaineCare Guidance Relating to Telehealth and Telephone Services During COVID-19 Emergency Period. https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/documents/pdfs_doc/COVID-19/041620-Telehealth-Guidance.pdf

²³ Centers for Medicare and Medicaid Services. (2020). State Medicaid & CHIP Telehealth Toolkit. Policy Considerations for States Expanding Use of Telehealth. COVID-19 Version. <https://www.medicaid.gov/medicaid/benefits/downloads/medicaid-chip-telehealth-toolkit.pdf>

²⁴ Jonk, Y.C., Burgess, A., Williamson, M.E., Thayer, D., Mackenzie, J., McGuire, C., ... Coburn, A. F. (2020). Telehealth Use in a Rural State: A Mixed-Methods Study Using Maine's All-Payer Claims Database. *The Journal of Rural Health*. <https://doi.org/10.1111/jrh.12527>

²⁵ Landry, T.A. (2020, August 18). NAHSP Virtual Annual Conference. State Health Policy: Flexibility and Resiliency through COVID-19 and Beyond: Telehealth for Vulnerable Populations.

satisfaction with services. For subgroup comparisons of telehealth use described below, results with small sample sizes should be interpreted with caution.

As shown in Table 16 below, 18% of respondents (n=205) indicated their child was offered a telehealth appointment instead of an in-person appointment in 2024. Telehealth use among child MaineCare members has declined in recent years, down from 34% in 2021 and 24% in 2022, but seems to have plateaued at 18% since 2023. Seventeen percent of respondents reported five or more telehealth visits; 32% reported two to four visits; 23% reported one visit; and 28% reported zero visits.

Notably, CSHCN were significantly more likely than non-CSHCN to have been offered a telehealth visit (36% vs. 6%, $p \leq .001$). This was true for older children as well, with 26% of those aged 13 or older offered telehealth compared to 17% of children aged six to 12 and 11% of children aged five or younger ($p \leq .001$). On the other hand, BIPOC children were significantly less likely than White children to be offered a telehealth visit (10% vs. 19%, $p \leq .01$) (data not shown). CSHCN (n=168) were more likely than non-CSHCN (n=37) to report five or more telehealth visits (19% vs. 8%, $p \leq .05$), whereas non-CSHCN were more likely to report zero telehealth visits (51% vs. 22%, $p \leq .05$) (data not shown).

Table 16. Telehealth Access and Utilization

Domain/Item	Results		
	n	%	95% CI
<i>Telehealth appointment offered</i>			
Child was offered telehealth instead of in-person appointment	989	18%	(15% - 20%)
<i>Number of telehealth visits in past 6 months</i>			
None	205	28%	(21% - 35%)
1	205	23%	(16% - 30%)
2-4	205	32%	(24% - 40%)
5 or more	205	17%	(11% - 23%)
<i>Types of telehealth services used in past 6 months</i>			
Primary care	155	31%	(22% - 40%)
Mental health	155	53%	(45% - 62%)
Therapy for school-related learning needs	155	12%	(6% - 19%)
Other type of specialty care	155	17%	(10% - 23%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare

Among respondents whose child used telehealth services, 31% used it for primary care (statistically similar to the rate of 24% in 2023); 53% to access mental health services (similar to the rate of 51% in 2023); 12% for school-related learning needs; and 17% to see a wide range of other providers specializing in areas such as neurology, nutrition and diet, weight management, and medication management (Table 16).

Non-CSHCN (n=20) were more likely than CSHCN (n=134) to have used telehealth for mental health services (64% vs. 2%, $p \leq .001$), as were White children (n=135) relative to BIPOC children (n=19) (56% vs. 27%, $p \leq .05$). Children aged 13 or older (n=71) and six to 12 (n=57) were more likely than those aged five or younger (n=27) to have used telehealth for mental health visits (74% and 50% vs. 14%, $p \leq .001$). Additionally, children aged five or younger were more likely than those ages six to 12 and 13 or older to use telehealth for school related learning needs (28% vs. 6% and 10%, $p \leq .05$) (data not shown).

Interestingly, while respondents could select more than one type of telehealth service, those who used it for primary care reported fewer total telehealth visits (55% had one visit only and 45% had 2 or more) than those who used telehealth for mental health (18% had one visit while 82% had two or more) (data not shown).

We also asked respondents about their satisfaction with the care received through telehealth, and how likely they were to continue using telehealth services (Table 17). Seventy-one percent indicated they were “very satisfied” with the care their child received through telehealth (a significant increase from the rate of 57% in 2023, $p \leq .05$) while 22% were “somewhat satisfied” and 7% were “somewhat or very dissatisfied.” No statistically significant differences in satisfaction with telehealth services were observed by region, eligibility category, CSHCN status, age, gender, or race. Seventy percent of respondents were “very likely” to continue using telehealth; 21% were “somewhat likely”; and 9% were “somewhat or very unlikely” to continue using it.

Table 17. Satisfaction with Telehealth Services

Domain/Item	Results		
	n	%	95% CI
<i>How satisfied are you with the care child received through telehealth?</i>			
Very satisfied	150	71%	(62% - 79%)
Somewhat satisfied	150	22%	(14% - 29%)
Somewhat dissatisfied	150	5%	(1% - 9%)
Very dissatisfied	150	2%	(0% - 5%)
<i>How likely are you to continue using telehealth?</i>			
Very likely	149	70%	(61% - 80%)
Somewhat likely	149	21%	(13% - 29%)
Somewhat unlikely	149	7%	(2% - 11%)
Very unlikely	149	2%	(0% - 5%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare

Dental Care Utilization and Unmet Need for Dental Care

The MaineCare program has long identified oral health and access to dental care as a priority area, and several questions related to dental services are included in the annual survey (Table 18). Nearly three quarters of children enrolled in MaineCare (73%) had a usual source of dental care in 2024, similar to the 72% reported in 2023. Children enrolled in MaineCare were significantly more likely ($p \leq .001$) to use a private dental office (58%) or community clinic (35%) than a school-based clinic (6%). However, usual source of dental care varied by region ($p < .05$) with the Central/West and Northern/Downeast regions more heavily reliant on community clinics. In the Southern region, 68% of children used a private dental office, 23% used a community clinic, and 9% were seen in school-based clinics. In the Central/Western region, 55% visited private offices, 40% used community clinics, and 5% used school-based clinics. Similarly, in the North/Downeast, 53% of children used private offices, 40% used community clinics, and 4% used school-based clinics. Notably, children with Title XXI eligibility were more likely than their Title XIX counterparts to have a usual source of dental care (78% vs. 72%, $p \leq .05$), as were children aged six to 12 and 13 or older compared to those aged five or younger (83% and 79% vs. 54%, $p \leq .001$). Additionally, CSHCN were more likely than non-CSHCN to have a usual source of dental care (80% vs. 68%, $p \leq .001$) (data not shown).

Survey results show that 60% of all children enrolled in MaineCare in 2024 had received dental services in the past six months, similar to the 55% reported in 2023. Children aged six to 12 and 13 or older were more likely than those aged five or younger to have received dental care (67% and 65% vs. 45%, $p \leq .001$), as were those in

Title XXI compared to Title XIX (65% vs. 58%, $p \leq .05$) and CSHCN compared to non-CSHCN (67% vs. 55%, $p \leq .01$) (data not shown).

Approximately one fifth (21%) of all children with MaineCare coverage in 2024 had dental care that was delayed or not received, similar to the 23% reported in 2023. Although this remains higher than pre-pandemic levels (which ranged from 8% to 14% between 2014 and 2019), rates of delayed dental care may be trending down slightly from a high of 26% in 2020 and 2022. Notably, CSHCN were statistically more likely than non-CSHCN to have experienced a delayed or unmet need for dental care (27% vs. 18%, $p \leq .01$) (data not shown).

Finally, among the 218 respondents who provided a reason why their child's dental care, tests, or treatments were delayed or not received, the most cited reasons were long waits to get an appointment (32%), no dentists in the area that accept MaineCare patients (31%), and scheduling issues (11%). Ten percent of respondents indicated their dental provider refused to accept MaineCare, and another 10% indicated there was some other reason for delayed or unmet need for care. These other reasons included dental providers operating at full capacity, a lack of appointments for new patients, and staffing shortages in dental offices.

Table 18. Dental Care Utilization and Prevalence of Unmet Need for Dental Care

Domain/Item	Results		
	n	%	95% CI
<i>Any Dental Care</i>			
Child received care from a dentist/dental clinic in past 6 months	980	60%	(56% - 63%)
<i>Usual source of Dental Care</i>			
Particular dentist or dental clinic child goes to for dental needs or advice (all ages)	982	73%	(69% - 76%)
Age 5 or younger	260	54%	(47% - 61%)
Age 6–12	409	83%	(79% - 88%)
Age 13 or older	313	79%	(74% - 85%)
<i>Site of Visit</i>			
Private dental office	670	58%	(54% - 63%)
Community clinic	670	35%	(31% - 40%)
School-based clinic	670	6%	(4% - 8%)
<i>Unmet Need for Dental Care</i>			
Dental care delayed or not received at some time in past 6 months	981	21%	(18% - 25%)
<i>Reasons for Unmet Need for Dental Care</i>			
Long wait to get appointment	218	32%	(24% - 40%)
No dentists in area take MaineCare patients	218	31%	(23% - 39%)
Scheduling issues	218	11%	(6% - 16%)
Dental provider refused MaineCare	218	10%	(5% - 16%)
Some other reason	218	10%	(5% - 15%)
MaineCare would not cover care	218	2%	(0% - 5%)
Could not afford care	218	2%	(0% - 4%)
Dentists too far away	218	1%	(0% - 2%)
Problems getting to dentist's office	218	1%	(0% - 2%)
Did not know where to get care	218	0%	(0% - 0%)

n=unweighted sample size; percent estimates weighted to represent entire population of children enrolled in MaineCare

Regional Differences in MaineCare Performance

To help inform targeted improvement efforts, we examined regional differences in MaineCare performance across three county-based regions of the state: the Southern region (Cumberland and York counties), the Central/Western region (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset, and Waldo counties), and the Northern/Downeast region (Aroostook, Hancock, Penobscot, Piscataquis, and Washington counties). Results show statistically significant regional differences in several key areas (Table 19).

First, the Southern region was home to a greater proportion of BIPOC members than the Central/Western and Northern/Downeast regions of the state (28% vs. 13% and 13%, $p \leq .001$). Similarly, when asked if their child was of Hispanic or Latino origin or descent, respondents in the Southern region were more likely to answer “yes” compared to those in the Central/Western and Northern/Downeast regions (8.9% vs. 2.8% and 3.9%, $p \leq .01$). Consistent with 2023 survey results, children living in the Southern region of the state were significantly more likely to receive school-based behavioral health treatment or counseling compared to those in the Central/Western or Northern/Downeast regions (80% vs. 54% and 67%, $p \leq .01$). Access to specialist appointments also varied by region with members in the Central/Western region being the least likely to secure appointments as soon as they thought they needed (43% vs. 52% in the North/Downeast and 68% in the South, $p \leq .05$). Notably, respondents in the Southern region of the state were borderline statistically significantly more likely than those in the Central/Western and Northern/Downeast regions to have received help coordinating their child’s care among different providers or services (65% vs. 51% and 44%, $p = 0.0561$).

As noted above, children’s source of dental care varied significantly by region ($p < .05$) with 68% of children in the South receiving care at a private dental office compared to 55% in the Central/Western region and 52% in the North/Downeast. Notably, the Central/Western and Northern/Downeast regions were significantly more reliant upon community clinics (both 40%) compared to the Southern region of the state (23%). Finally, school-based dental clinics were also more common in the Southern region (8%) than the Central/Western (4%) or Northern/Downeast (5%) regions of the state.

Additionally, although the number of respondents who used the MaineCare Member Services help line in 2024 was small and results should be interpreted with caution, 56% of respondents in the Southern region reported the help line provided the information or help they needed compared to 45% in the Central/Western region and just 10% in the North/Downeast ($p \leq .05$).

These findings highlight several important regional demographic differences and disparities in access to needed health care services and supports and may be useful to MaineCare administrators and staff as they develop targeted interventions to improve the experience of care among children enrolled in MaineCare and ensure the equitable deployment and distribution of MaineCare resources throughout the state.

Table 19. Regional Differences in MaineCare Performance

Characteristic/Item*	Southern Region	Central/Western Region	Northern/Downeast Region	p-value
<i>Black, Indigenous, and People of Color (% Yes)</i>	28.3%	13.0%	12.9%	<.0001
<i>Hispanic or Latino origin or descent (% Yes)</i>	8.9%	2.8%	3.9%	<.001
<i>Received school-based treatment or counseling (% Yes)†</i>	80.2%	54.3%	67.3%	<.01
<i>Received specialist appointment as soon as needed (% Always)†</i>	68.3%	43.2%	52.4%	<.05
<i>Child's regular source of dental care (% Private office, % School-based clinic, % Community clinic)</i>	68.1% 8.3% 23.0%	55.4% 4.1% 39.8%	52.7% 5.5% 40.4%	<.05
<i>MaineCare Member Services provided information or help needed (% Always)†</i>	56.4%	44.8%	9.7%	<.05
<i>MaineCare plan, doctor's office, or clinic helped coordinate child's care among different providers or services (% Yes)†</i>	65.2%	51.4%	43.8%	0.0561

* Results are weighted to represent the entire population of children enrolled in MaineCare.

† Sample size less than 100 for one or more regions. Use results with caution.

Member Experiences with MaineCare

The final question of the 2024 survey asked respondents if they had anything else to share about their experiences with MaineCare. Of the 1,015 total survey respondents in 2024, 36.7% (n=373) provided a response to this question, with feedback reflecting a mix of both positive and negative experiences and suggesting areas that could be targeted for improvement. Initially, the open-ended responses were independently reviewed and coded into broad themes by three members of the research team. Next, the team reviewed and reconciled the themes and consistently applied the final approach. A breakdown of the different themes and topic areas that emerged during analysis and coding of the open-ended responses are presented in Table 20 below, including examples of the types of comments made, the percent of respondents who provided comments by topic area, and example quotes.

Positive feedback was the most commonly recurring theme with 41% of respondents offering compliments about MaineCare services and supports. Many respondents expressed gratitude, describing the peace of mind the program brings to families including single parents, grandparents, and individuals in difficult circumstances. Others praised MaineCare's support specifically for children with special healthcare needs and its role in helping immigrant families access essential healthcare services.

While many respondents expressed appreciation for MaineCare, a number of specific challenges were also noted. Importantly, issues with dental care emerged as the most common concern by a considerable margin, with over one third (34%) of respondents reporting difficulties accessing dental services including long waitlists, dental provider shortages, being unable to find dentists who accept MaineCare patients, and the absence of orthodontic coverage. Respondents also mentioned limited access or long wait times for other essential health care services and providers including primary care (9%), mental health (6%), other types of specialty care (5%), and optometry (3%).

The second most commonly reported challenge after dental care access were administrative barriers and frustration with perceived bureaucratic inefficiencies (18%) including repetitive paperwork requests, delayed updates to insurance information, and rigid eligibility requirements that in effect compel families to remain at or below poverty level to maintain coverage. Some respondents lamented the perceived inadequacy of out-of-state coverage and highlighted communication challenges such as difficulty reaching representatives, confusion over eligibility notices, and problems using the online portal. Although many respondents who reported administrative barriers also expressed gratitude for the care their child had received, navigating the system was often described as overwhelming, time-consuming, and stressful, particularly for families advocating for children with complex needs.

A considerable number of respondents (8%) reported issues getting or refilling their child's prescription medications. This included problems and delays with prior authorization, limited cost coverage, lack of coverage for preferred brands, limited choice of pharmacy, and lack of drug coverage for specific health conditions. Some respondents (5%) also emphasized challenges with the MaineCare Member Services help line, including long phone wait times, difficulty reaching representatives, unhelpful staff, and poor communication.

Although the survey focuses on the experience of children enrolled in MaineCare, some respondents (3%) expressed dissatisfaction with adult or parental coverage, noting that income eligibility is too limited, eligibility transitions are disruptive and stressful, that it would be helpful for parental eligibility to be tied to child eligibility, and that adult dental services are too limited. Another three percent provided responses that were coded as "other" because there were so few of that type or they did not fit in an existing category including comments related to transportation services, dissatisfaction with local hospital care, and calls for universal health insurance coverage. Finally, several individuals (1%) raised concerns about perceived provider stigma against MaineCare members, including suspected differences in the quality and timeliness of care their children received, stating that MaineCare patients seem to experience longer wait times, fewer appointment options, and less comprehensive treatment compared to those with private insurance.

Overall, while many respondents expressed deep appreciation for MaineCare and the support it provides, their feedback also underscores the need to address persistent issues such as access to dental care, wait times for services, and administrative hurdles to ensure the program continues to meet the needs of its members effectively.

Table 20. Member Experiences with MaineCare (n=373)

Theme/Topic Area	Percent*	Example Quotes [†]
Positive feedback and compliments <ul style="list-style-type: none"> - general appreciation and gratitude - improved access to care - high quality coverage - good customer service 	40.5%	<i>"We've had a lot of different services and MaineCare is the best, especially with a child with so many different special health needs. It's a blessing to have."</i> <i>"As a grandparent raising grandkids, it has been a relief not to worry about their health coverage."</i>
Dental care access <ul style="list-style-type: none"> - no local dentists - no local dentists accept MaineCare - limited coverage (e.g. orthodontia) - long waitlists 	33.8%	<i>"The waitlist for a dentist is a year long and the drive is an hour."</i> <i>"Dental is absolutely horrible. Either they don't accept MaineCare, or they are not accepting new patients. We have to travel outside of our area 90 minutes to get dental care."</i>
Administrative barriers <ul style="list-style-type: none"> - restrictive eligibility guidelines - lengthy and complicated enrollment process - out of pocket costs 	18.2%	<i>"We've had issues with losing coverage unexpectedly and having to reapply. It's hard to get through when making calls, never easy. The website has a lot of issues, and then I need to call about it and it takes forever."</i>

<ul style="list-style-type: none"> - redundant paperwork and mail correspondence - difficulty using online portal 		
<p>Primary care and generalist care access</p> <ul style="list-style-type: none"> - limited number of providers - providers won't accept MaineCare - long waitlists - limited coverage - insufficient preventive care 	8.6%	<p><i>"We choose to pay out of pocket for primary care due to not getting good care within MaineCare."</i></p> <p><i>"Primary care has a long wait to get appointments. We've had to use the walk-in clinic more frequently."</i></p>
<p>Prescription medicine</p> <ul style="list-style-type: none"> - problems with prior authorization - limited cost coverage - preferred brands not covered - health condition not covered - limited choice of pharmacy 	8.0%	<p><i>"Prior authorizations and routine prescriptions can be hard for providers to keep up on and it takes longer than it should."</i></p>
<p>Mental health care access</p> <ul style="list-style-type: none"> - limited number of providers - long waitlists 	5.9%	<p><i>"The wait for mental health services is incredibly long."</i></p>
<p>MaineCare Member Services Help Line issues</p> <ul style="list-style-type: none"> - hard to contact customer service - long waits for help - poor communication 	5.4%	<p><i>"Every time calling in the lines are always busy, and I can't get through."</i></p>
<p>Other specialty care access</p> <ul style="list-style-type: none"> - specialist physicians (e.g., neurology, oncology, immunology) - home and community-based services - occupational, physical, and speech therapy - special medical equipment - diagnostic services (e.g., MRI) 	5.1%	<p><i>"Our child has cancer, and it was hard to find a doctor when he had a relapse. After 3 months, we finally got in to see a neurologist. He saved our child's life. It's also been hard to schedule MRIs."</i></p> <p><i>"It's hard to get an appointment with an allergist – it took a year to get in."</i></p>
<p>Optometry access</p> <ul style="list-style-type: none"> - services too expensive - coverage too limited - limited number of providers 	2.9%	<p><i>"Finding eye doctors who take MaineCare is incredibly difficult."</i></p>
<p>Parental coverage</p> <ul style="list-style-type: none"> - eligibility transitions destabilizing and confusing - parental eligibility should be tied to child eligibility - adult dental services too limited 	2.9%	<p><i>"For children it's great, but not for me—I keep getting taken even off though I earn below the income level."</i></p>
<p>Other</p> <ul style="list-style-type: none"> - transportation services - dissatisfaction with local hospital care - desire for universal health insurance 	2.7%	<p><i>"I don't know if it goes through MaineCare, but for transportation to appointments we've had wonderful experiences with Modivcare. But another branch we have not felt safe with certain drivers. They have been distracted, talking on the phone, seatbelts not working, and driving reckless."</i></p>
<p>Perceived provider stigma against MaineCare members</p> <ul style="list-style-type: none"> - lower quality of care - delayed appointments - judgmental providers 	1.3%	<p><i>"MaineCare recipients seem to get the lowest grade of care as opposed to if you had private insurance."</i></p> <p><i>"Providers that bill through MaineCare seem to have a tendency to delay treatment simply because we have MaineCare."</i></p>

* Percents do not total 100% because respondents often addressed multiple themes in their response.

‡ Quotes have been edited slightly for clarity and conciseness.

Conclusions and Recommendations

The 2024 survey findings summarized in this report demonstrate various levels of MaineCare program performance across a wide range of CAHPS and state-added measures. Despite strong performance on a number of survey items, results also indicate areas that would benefit from targeted policy interventions and/or technical assistance to improve MaineCare services for children. In 2024, MaineCare exhibited strong performance on CAHPS items related to getting needed care, tests, or treatment; getting appointments with specialists; getting urgent and non-urgent care quickly; personal doctors explaining things clearly; personal doctors listening carefully and respecting consumer comments; personal doctors spending enough time with the child; personal doctors seeming informed and up to date about care received from other providers; ease of accessing special therapy; personal doctors talking about how the child is feeling, growing, or behaving and how the child's health conditions affect the family's day-to-day life; and doctors and providers answering questions and providing needed help contacting school or daycare. Results also suggest potential areas for improvement such as accessing special medical equipment and devices, getting needed treatment and counseling, health plan information and customer service, and coordination of care. While many respondents expressed deep appreciation for MaineCare and the support it provides, they also underscored the need to address persistent issues such as access to dental care, wait times for services, and various administrative hurdles.

We recommend continued administration of the CAHPS Child Medicaid Survey in 2025 and beyond to allow for continued monitoring of member experience within the MaineCare program. Ongoing use of the modified CAHPS survey will allow assessment of program performance changes over time and enable MaineCare to comply with federal Medicaid and CHIP reporting requirements. MaineCare administrators and staff may wish to explore strategies described in the [CAHPS Ambulatory Care Improvement Guide](#) to address areas of need identified by the 2024 survey.²⁶ The CAHPS guide is a comprehensive resource for health plans, medical groups, and other providers seeking to improve performance in patient experience domains measured by the CAHPS survey. Finally, the results of this survey can be used by the Office of MaineCare Services to support improvement efforts both within the MaineCare program and among health care providers who serve children enrolled in MaineCare. Future surveys should continue to integrate MaineCare-specific questions to gather information on key policy initiatives and priority areas for OMS.

²⁶ Agency for Healthcare Research and Quality. (created April 2016; last reviewed March 2023). The CAHPS Ambulatory Care Improvement Guide: Practical Strategies for Improving Patient Experience. <https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/improvement-guide.html>

Appendix A: Summary of MaineCare Coverage for Children

Eligibility Group	Family Income Eligibility Limits (% of Federal Poverty Level) *			Premium Payments	Funding Source
	Children Ages 0 to 1 [†]	Children Ages 1 to 5	Children Ages 6 to 19		
Medicaid	300%	300%	300%	No monthly premiums	Medicaid (Title XIX)
Medicaid Expansion (using CHIP funds)	191% - 208%	140 – 208%	132 – 208%	No monthly premiums	CHIP (Title XXI)

Note: Children up to age 18 with a disabling condition and monthly income up to 300% of the federal SSI income eligibility limit (approximately 225% FPL) are also eligible for MaineCare. These children are grouped with the “Medicaid” group for the purposes of the survey.

*Eligibility levels listed here are the highest income levels under which each age group of children is covered under MaineCare. The income levels listed under Medicaid Expansion represent the levels to which Medicaid has expanded using CHIP funds, which became available in 1997 when CHIP was created.

[†]Infants are not included in the target population for purposes of this survey.

Age Group	Family Income Eligibility Limits (% of Federal Poverty Level)	
Age 0 to 1	Traditional Medicaid 0 – 300% FPL	Medicaid Expansion 191% - 208%
Ages 1 to 5	Traditional Medicaid 0 – 300% FPL	Medicaid Expansion 140 – 208% FPL
Ages 6 to 19	Traditional Medicaid 0 – 300% FPL	Medicaid Expansion 132 – 208% FPL

Note: To be eligible for the infant category, the child has not yet reached their first birthday. To be eligible for the “1 to 5” category, the child is age one or older but has not yet reached their sixth birthday. To be eligible in the “6 through 19” category, the child is age six or older but has not yet reached their twentieth birthday.

Sources:

Staff from the Office of MaineCare Services, Maine Department of Health and Human Services.
 Medicaid and CHIP Payment and Access Commission (MACPAC). MACStats EXHIBIT 35. Medicaid and CHIP Income Eligibility Levels as a Percentage of the FPL for Children and Pregnant Women by State. Available at: <https://www.macpac.gov/publication/macstats-compiled/>

Appendix B: 2024 Survey Instrument

SURVEY QUESTIONS

Q1 Option

The Department of Health and Human Services records indicate that *[Child's name]* is now enrolled in MaineCare. Is this correct?
 [IF "NO" OR "UNSURE", PROBE: MaineCare is health insurance provided by DHHS. They give you a plastic ID card if you are eligible.]

Q1	1 YES	Q3
Q1	2 NO	Q2
Q1	3 YES, AS A SECONDARY INSURANCE	Q2
Q1	9 DON'T KNOW/ NOT APPLICABLE	Q2

Q2 Text Entry

What is the name of your child's health plan?

Q2	0 FILL-IN RESPONSE	END OF SURVEY
----	--------------------	---------------

Q3 Option

What is your child's gender?

Q3	1 MALE	NEXT
Q3	2 FEMALE	NEXT
Q3	3 NONBINARY	NEXT
Q3	4 OTHER [SPECIFY] <i>text box entry:</i> _____	NEXT
Q3	9 DECLINE TO STATE	NEXT

Q4 Option

YOUR CHILD'S HEALTH CARE IN THE LAST 6 MONTHS

These questions ask about *[Child's name]*'s health care over the last 6 months from a clinic, emergency room, or doctor's office. This includes care your child got in person, by phone, or by video. Do **not** include dental visits **or** care your child got when *he/she/they* stayed *overnight* in a hospital.

In the last 6 months, did *[Child's name]* have an illness, injury, or condition that needed care right away?

Q4	1 YES
Q4	2 NO
Q4	9 DON'T KNOW/ NOT APPLICABLE

Q5 Option

In the last 6 months, when *[Child's name]* needed care right away, how often did *he/she/they* get care as soon as *he/she/they* needed?

Q5	1 Never	NEXT
Q5	2 Sometimes	NEXT
Q5	3 Usually	NEXT
Q5	4 Always	NEXT
Q5	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q6 Option

In the last 6 months, did you make any in person, phone, or video appointments for a check-up or routine care for *[Child's name]*?

Q6	1 YES	NEXT
Q6	2 NO	Q8
Q6	9 DON'T KNOW/ NOT APPLICABLE	Q8

Q7 Option

In the last 6 months, how often did you get an appointment for a *check-up or routine care* for *[Child's name]* as soon as *he/she/they* needed?
 [INTERVIEWER NOTE: AT A DOCTOR'S OFFICE OR CLINIC]

Q7	1 Never	NEXT
Q7	2 Sometimes	NEXT
Q7	3 Usually	NEXT
Q7	4 Always	NEXT
Q7	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q8 Option

In the last 6 months, not counting the times [Child's name] went to an emergency room, how many times did he/she/they get healthcare in person, by phone, or by video?

Q8	1 1	NEXT
Q8	2 2	NEXT
Q8	3 3	NEXT
Q8	4 4	NEXT
Q8	5 5 TO 9	NEXT
Q8	6 10 OR MORE	NEXT
Q8	0 NONE	Q12
Q8	9 DON'T KNOW/ NOT APPLICABLE	Q11

Q9 Option

In the last 6 months, how often did you have your questions answered by your child's doctors or other health providers?

Q9	1 Never	NEXT
Q9	2 Sometimes	NEXT
Q9	3 Usually	NEXT
Q9	4 Always	NEXT
Q9	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q10 Option

Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all [Child's name]'s health care in the last 6 months?

Q10	00 0 Worst health care possible	NEXT
Q10	01 1	NEXT
Q10	02 2	NEXT
Q10	03 3	NEXT
Q10	04 4	NEXT
Q10	05 5	NEXT
Q10	06 6	NEXT
Q10	07 7	NEXT
Q10	08 8	NEXT
Q10	09 9	NEXT
Q10	10 10 Best health care possible	NEXT
Q10	99 DON'T KNOW/ NOT APPLICABLE	NEXT

Q11 Option

In the last 6 months, how often was it easy to get the care, tests, or treatment [Child's name] needed?

Q11	1 Never	NEXT
Q11	2 Sometimes	NEXT
Q11	3 Usually	NEXT
Q11	4 Always	NEXT
Q11	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q12 Option

Is your child now enrolled in any kind of school or daycare?

Q12	1 YES	NEXT
Q12	2 NO	Q15
Q12	9 DON'T KNOW/ NOT APPLICABLE	Q15

Q13 Option

In the last 6 months, did you need [Child's name]'s doctors or other health providers to contact a school or daycare center about his/her/their health or health care?

Q13	1 YES	NEXT
Q13	2 NO	Q15
Q13	9 DON'T KNOW/ NOT APPLICABLE	Q15

Q14 Option

In the last 6 months, did you get the help you needed from [Child's name]'s doctors or other health providers in contacting his/her/their school or daycare?

Q14	1 YES	NEXT
Q14	2 NO	NEXT
Q14	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q15 Option

SPECIALIZED SERVICES

Special medical equipment or devices include a walker, wheelchair, nebulizer, feeding tubes, or oxygen equipment.
 In the last 6 months, did you get or try to get any special medical equipment or devices for *[Child's name]*?

Q15	1 YES	NEXT
Q15	2 NO	Q18
Q15	9 DON'T KNOW/ NOT APPLICABLE	Q18

Q16 Option

In the last 6 months, how *often* was it easy to get special medical equipment or devices for your child?

Q16	1 Never	NEXT
Q16	2 Sometimes	NEXT
Q16	3 Usually	NEXT
Q16	4 Always	NEXT
Q16	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q17 Option

Did anyone from *[Child's name]*'s MaineCare plan, doctor's office, or clinic help you get special medical equipment or devices for your child?

Q17	1 YES	NEXT
Q17	2 NO	NEXT
Q17	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q18 Option

In the last 6 months, did you get or try to get special therapy such as physical, occupational, or speech therapy for *[Child's name]*?

Q18	1 YES	NEXT
Q18	2 NO	Q21
Q18	9 DON'T KNOW/ NOT APPLICABLE	Q21

Q19 Option

In the last 6 months, how *often* was it easy to get this therapy for *him/her/them*?

Q19	1 Never	NEXT
Q19	2 Sometimes	NEXT
Q19	3 Usually	NEXT
Q19	4 Always	NEXT
Q19	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q20 Option

Did anyone from *[Child's name]*'s MaineCare plan, doctor's office, or clinic help you get this therapy for your child?

Q20	1 YES	NEXT
Q20	2 NO	NEXT
Q20	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q21 Option

In the last 6 months, did you get or try to get treatment or counseling for *[Child's name]* for an emotional, developmental, or behavioral problem?

Q21	1 YES	NEXT
Q21	2 NO	Q24
Q21	9 DON'T KNOW/ NOT APPLICABLE	Q24

Q22 Option

In the last 6 months, how *often* was it easy to get this treatment or counseling for your child?

Q22	1 Never	NEXT
Q22	2 Sometimes	NEXT
Q22	3 Usually	NEXT
Q22	4 Always	NEXT
Q22	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q23 Option

Did anyone from *[Child's name]*'s MaineCare plan, doctor's office, or clinic help you get this treatment or counseling for *him/her/them*?

Q23	1 YES	NEXT
Q23	2 NO	NEXT
Q23	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q24 Option Skip if Q8=0 or Q8=9

In the last 6 months, did [Child's name] get care from more than one kind of health care provider or use more than one kind of health care service?

- Q24 1 YES NEXT
- Q24 2 NO Q26
- Q24 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q25 Option Skip if Q8=0 or Q8=9

In the last 6 months, did anyone from [Child's name]'s MaineCare plan, doctor's office, or clinic help coordinate your child's care among these different providers or services?

- Q25 1 YES NEXT
- Q25 2 NO NEXT
- Q25 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q26 Option

YOUR CHILD'S PERSONAL DOCTOR

A personal doctor is the one your child would see if *he/she/they* need(s) a check-up, has a health problem, or gets sick or hurt.

Does [Child's name] have a personal doctor?

- Q26 1 YES NEXT
- Q26 2 NO Q41
- Q26 9 DON'T KNOW/ NOT APPLICABLE Q41

Q27 Option

In the last 6 months, how many times did [Child's name] have an in-person, phone, or video visit with *his/her/their* personal doctor?

- Q27 1 1 NEXT
- Q27 2 2 NEXT
- Q27 3 3 NEXT
- Q27 4 4 NEXT
- Q27 5 5 to 9 NEXT
- Q27 6 10 or more NEXT
- Q27 0 NONE Q37
- Q27 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q28 Option

In the last 6 months, how often did *his/her/their* personal doctor explain things in a way that was easy to understand?

- Q28 1 Never NEXT
- Q28 2 Sometimes NEXT
- Q28 3 Usually NEXT
- Q28 4 Always NEXT
- Q28 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q29 Option

In the last 6 months, how often did [Child's name]'s personal doctor listen carefully to you?

- Q29 1 Never NEXT
- Q29 2 Sometimes NEXT
- Q29 3 Usually NEXT
- Q29 4 Always NEXT
- Q29 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q30 Option

In the last 6 months, how often did *his/her/their* personal doctor show respect for what you had to say?

- Q30 1 Never NEXT
- Q30 2 Sometimes NEXT
- Q30 3 Usually NEXT
- Q30 4 Always NEXT
- Q30 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q31 Option

Is [Child's name] able to talk with doctors about *his/her/their* health care?

- Q31 1 YES NEXT
- Q31 2 NO Q33
- Q31 9 DON'T KNOW/ NOT APPLICABLE Q33

Q32

Option

In the last 6 months, how often did [Child's name]'s personal doctor explain things in a way that was easy for him/her/them to understand?

- Q32 1 Never NEXT
- Q32 2 Sometimes NEXT
- Q32 3 Usually NEXT
- Q32 4 Always NEXT
- Q32 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q33

Option

In the last 6 months, how often did [Child's name]'s personal doctor spend enough time with him/her/them?

- Q33 1 Never NEXT
- Q33 2 Sometimes NEXT
- Q33 3 Usually NEXT
- Q33 4 Always NEXT
- Q33 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q34

Option

In the last 6 months, did [Child's name]'s personal doctor talk with you about how [Child's name] is feeling, growing, or behaving?

- Q34 1 YES NEXT
- Q34 2 NO NEXT
- Q34 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q35

Option

In the last 6 months, did [Child's name] get care from a doctor or other health provider besides his/her/their personal doctor?

- Q35 1 YES NEXT
- Q35 2 NO Q37
- Q35 9 DON'T KNOW/ NOT APPLICABLE Q37

Q36

Option

In the last 6 months, how often did [Child's name]'s personal doctor seem informed and up-to-date about the care your child got from these doctors or other health providers?

- Q36 1 Never NEXT
- Q36 2 Sometimes NEXT
- Q36 3 Usually NEXT
- Q36 4 Always NEXT
- Q36 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q37

Option

Using any number from 0 to 10, where 0 is the worst personal doctor possible and 10 is the best personal doctor possible, what number would you use to rate [Child's name]'s personal doctor?

- Q37 00 0 Worst personal doctor possible NEXT
- Q37 01 1 NEXT
- Q37 02 2 NEXT
- Q37 03 3 NEXT
- Q37 04 4 NEXT
- Q37 05 5 NEXT
- Q37 06 6 NEXT
- Q37 07 7 NEXT
- Q37 08 8 NEXT
- Q37 09 9 NEXT
- Q37 10 10 Best personal doctor possible NEXT
- Q37 99 DON'T KNOW/ NOT APPLICABLE NEXT

Q38

Option

Does [Child's name] have any medical, behavioral, or other health conditions that have lasted for more than 3 months?

- Q38 1 YES NEXT
- Q38 2 NO Q41
- Q38 9 DON'T KNOW/ NOT APPLICABLE Q41

Q39 Option

Does [Child's name]'s personal doctor understand how these medical, behavioral, or other health conditions affect [Child's name]'s day-to-day life?

- Q39 1 YES NEXT
- Q39 2 NO NEXT
- Q39 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q40 Option

Does [Child's name]'s personal doctor understand how these medical, behavioral, or other health conditions affect your family's day-to-day life?

- Q40 1 YES NEXT
- Q40 2 NO NEXT
- Q40 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q41 Option

GETTING HEALTH CARE FROM SPECIALISTS

When you answer the next questions, include the care your child got in person, by phone, or by video. Do not include dental visits or care your child got when *he/she/they* stayed overnight in a hospital.

Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the last 6 months, did you make any appointments for [Child's name] with a specialist?

- Q41 1 YES NEXT
- Q41 2 NO Q45
- Q41 9 DON'T KNOW/ NOT APPLICABLE Q45

Q42 Option

In the last 6 months, how often did you get appointments for [Child's name] with a specialist as soon as *he/she/they* needed?

- Q42 1 Never NEXT
- Q42 2 Sometimes NEXT
- Q42 3 Usually NEXT
- Q42 4 Always NEXT
- Q42 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q43 Option

How many specialists has your child seen in the last 6 months?

- Q43 1 1 NEXT
- Q43 2 2 NEXT
- Q43 3 3 NEXT
- Q43 4 4 NEXT
- Q43 5 5 OR MORE NEXT
- Q43 0 NONE Q45
- Q43 9 DON'T KNOW/ NOT APPLICABLE Q45

Q44 Option

We want to know your rating of the specialist [Child's name] has seen most often in the last 6 months. Using any number from 0 to 10, where 0 is the worst specialist possible and 10 is the best specialist possible, what number would you use to rate that specialist?

- Q44 00 0 Worst specialist possible NEXT
- Q44 01 1 NEXT
- Q44 02 2 NEXT
- Q44 03 3 NEXT
- Q44 04 4 NEXT
- Q44 05 5 NEXT
- Q44 06 6 NEXT
- Q44 07 7 NEXT
- Q44 08 8 NEXT
- Q44 09 9 NEXT
- Q44 10 10 Best specialist possible NEXT
- Q44 99 DON'T KNOW/ NOT APPLICABLE NEXT

Q45 Option
YOUR CHILD'S HEALTH PLAN

The following questions ask about your experience with the MaineCare Member Services Help Line. They are responsible for helping you understand your coverage and assisting you with provider identification and referral; **they do not deal with eligibility issues.**

In the last 6 months, did you get information or help for *[Child's name]* from the MaineCare Member Services telephone Help Line?

Q45	1 YES	NEXT
Q45	2 NO	Q52
Q45	9 DON'T KNOW/ NOT APPLICABLE	Q52

Q46 Option

In the last 6 months, how *often* did MaineCare Member Services staff give you the information or help you needed?

Q46	1 Never	NEXT
Q46	2 Sometimes	NEXT
Q46	3 Usually	NEXT
Q46	4 Always	Q48
Q46	9 DON'T KNOW/ NOT APPLICABLE	Q48

Q47 Multiple Check Entry

Please tell me if any of the following are reasons why you did not get the information or help you needed when you called the MaineCare Member Services Help Line? [CHECK ALL THAT APPLY]

Q47	1 They were unable to answer your questions	NEXT
Q47	2 You were never able to get through	Q51
Q47	3 You had to call several times before you could speak with someone	NEXT
Q47	4 You had to wait too long to speak with someone	NEXT
Q47	5 The information you were given was wrong	NEXT
Q47	6 Member Services did not have the information you needed	NEXT
Q47	7 The information they gave you was hard to understand	NEXT
Q47	8 You could not talk to someone in the language you prefer	NEXT
Q47	9 Some other reason [PLEASE DESCRIBE] <i>text box entry:</i> _____	NEXT
Q47	99 DON'T KNOW/ NOT APPLICABLE	NEXT

Q48 Option

In the last 6 months, how *often* was it easy to understand the information you got when you called MaineCare Member Services staff for *[Child's name]*?

Q48	1 Never	NEXT
Q48	2 Sometimes	NEXT
Q48	3 Usually	NEXT
Q48	4 Always	NEXT
Q48	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q49 Option *Skip if Q46>3*

In the last 6 months, if MaineCare Member Services could not address your issue, how *often* did Member Services direct you to the correct MaineCare department?

Q49	1 Never	NEXT
Q49	2 Sometimes	NEXT
Q49	3 Usually	NEXT
Q49	4 Always	NEXT
Q49	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q50 Option

In the last 6 months, how *often* did MaineCare Member Services staff treat you with courtesy and respect?

Q50	1 Never	NEXT
Q50	2 Sometimes	NEXT
Q50	3 Usually	NEXT
Q50	4 Always	NEXT
Q50	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q51 Option

We want to know your rating of the MaineCare Members Services Help Line. Using a scale from 0 to 10 where 0 is the worst customer service possible and 10 is the best customer service possible, what number would you use to rate MaineCare Member Services Help Line?

Q51	00 0 Worst customer service possible	NEXT
Q51	01 1	NEXT
Q51	02 2	NEXT
Q51	03 3	NEXT
Q51	04 4	NEXT
Q51	05 5	NEXT
Q51	06 6	NEXT
Q51	07 7	NEXT
Q51	08 8	NEXT
Q51	09 9	NEXT
Q51	10 10 Best customer service possible	NEXT
Q51	99 DON'T KNOW/ NOT APPLICABLE	NEXT

Q52 Option

In the last 6 months, did MaineCare give you any forms to fill out?

Q52	1 YES	NEXT
Q52	2 NO	Q54
Q52	9 DON'T KNOW/ NOT APPLICABLE	Q54

Q53 Option

In the last 6 months, how *often* were the forms from MaineCare easy to fill out?

Q53	1 Never	NEXT
Q53	2 Sometimes	NEXT
Q53	3 Usually	NEXT
Q53	4 Always	NEXT
Q53	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q54 Text Entry

Using any number from 0 to 10, where 0 is the worst health plan possible and 10 is the best health plan possible, what number would you use to rate *[Child's name]'s* MaineCare?

Q54	00 0 Worst health plan possible
Q54	01 1
Q54	02 2
Q54	03 3
Q54	04 4
Q54	05 5
Q54	06 6
Q54	07 7
Q54	08 8
Q54	09 9
Q54	10 10 Best health plan possible
Q54	99 DON'T KNOW/ NOT APPLICABLE

Q55 Option

PRESCRIPTION MEDICINES

In the last 6 months, did you get or refill any prescription medicines for *[Child's name]*?

Q55	1 YES	NEXT
Q55	2 NO	Q58
Q55	9 DON'T KNOW/ NOT APPLICABLE	Q58

Q56 Option

In the last 6 months, how *often* was it easy to get prescription medicines for *[Child's name]* through MaineCare?

Q56	1 Never	NEXT
Q56	2 Sometimes	NEXT
Q56	3 Usually	NEXT
Q56	4 Always	NEXT
Q56	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q57 Option

Did anyone from [Child's name]'s MaineCare plan, doctor's office, or clinic help you get his/her/their prescription medicines?

- Q57 1 YES NEXT
- Q57 2 NO NEXT
- Q57 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q58 Option

ABOUT YOUR CHILD'S HEALTH

In general, how would you rate [Child's name]'s overall health?

- Q58 1 Excellent NEXT
- Q58 2 Very Good NEXT
- Q58 3 Good NEXT
- Q58 4 Fair NEXT
- Q58 5 Poor NEXT
- Q58 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q59 Option

In general, how would you rate [Child's name]'s overall mental or emotional health?

- Q59 1 Excellent NEXT
- Q59 2 Very Good NEXT
- Q59 3 Good NEXT
- Q59 4 Fair NEXT
- Q59 5 Poor NEXT
- Q59 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q60 Option

Does [Child's name] currently need or use medicine prescribed by a doctor (other than vitamins)?

[INTERVIEWER NOTE: PROMPT IF NECESSARY - Do they need a prescription from a doctor to get it?]

- Q60 1 YES NEXT
- Q60 2 NO Q63
- Q60 9 DON'T KNOW/ NOT APPLICABLE Q63

Q61 Option

Is this because of any medical, behavioral, or other health condition?

- Q61 1 YES NEXT
- Q61 2 NO Q63
- Q61 9 DON'T KNOW/ NOT APPLICABLE Q63

Q62 Option

Is this a condition that has lasted or is expected to last for at least 12 months?

- Q62 1 YES NEXT
- Q62 2 NO NEXT
- Q62 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q63 Option

Does [Child's name] need or use more medical care, more mental health services, or more educational services than is usual for most children of the same age?

- Q63 1 YES NEXT
- Q63 2 NO Q66
- Q63 9 DON'T KNOW/ NOT APPLICABLE Q66

Q64 Option

Is this because of any medical, behavioral, or other health condition?

- Q64 1 YES NEXT
- Q64 2 NO Q66
- Q64 9 DON'T KNOW/ NOT APPLICABLE Q66

Q65 Option

Is this a condition that has lasted or is expected to last for at least 12 months?

- Q65 1 YES NEXT
- Q65 2 NO NEXT
- Q65 9 DON'T KNOW/ NOT APPLICABLE NEXT

Q66			Option
Is [Child's name] limited or prevented in any way in his/her/their ability to do the things most children of the same age can do?			
Q66	1 YES		NEXT
Q66	2 NO		Q69
Q66	9 DON'T KNOW/ NOT APPLICABLE		Q69
Q67			Option
Is this because of any medical, behavioral, or other health condition?			
Q67	1 YES		NEXT
Q67	2 NO		Q69
Q67	9 DON'T KNOW/ NOT APPLICABLE		Q69
Q68			Option
Is this a condition that has lasted or is expected to last for at least 12 months?			
Q68	1 YES		NEXT
Q68	2 NO		NEXT
Q68	9 DON'T KNOW/ NOT APPLICABLE		NEXT
Q69			Option
Does [Child's name] need or get special therapy such as physical, occupational, or speech therapy?			
Q69	1 YES		NEXT
Q69	2 NO		Q72
Q69	9 DON'T KNOW/ NOT APPLICABLE		Q72
Q70			Option
Is this because of any medical, behavioral, or other health condition?			
Q70	1 YES		NEXT
Q70	2 NO		Q72
Q70	9 DON'T KNOW/ NOT APPLICABLE		Q72
Q71			Option
Is this a condition that has lasted or is expected to last for at least 12 months?			
Q71	1 YES		NEXT
Q71	2 NO		NEXT
Q71	9 DON'T KNOW/ NOT APPLICABLE		NEXT
Q72			Option
Does [Child's name] have any kind of emotional, developmental, or behavioral problem for which he/she/they needs or gets treatment or counseling?			
Q72	1 YES		NEXT
Q72	2 NO		Q77
Q72	9 DON'T KNOW/ NOT APPLICABLE		Q77
Q73			Option
Has this problem lasted or is it expected to last for at least 12 months?			
Q73	1 YES		NEXT
Q73	2 NO		NEXT
Q73	9 DON'T KNOW/ NOT APPLICABLE		NEXT
Q74			Option
During the past 6 months, did [Child's name] receive the needed treatment or counseling?			
Q74	1 YES		NEXT
Q74	2 NO		Q76
Q74	9 DON'T KNOW/ NOT APPLICABLE		NEXT

Q75 Multiple Check Entry

Which types of treatment or counseling did [Child’s name] receive?

[CHECK ALL THAT APPLY]

Q75	1 Office-based treatment or counseling	NEXT
Q75	2 School-based treatment or counseling	NEXT
Q75	3 Home and/or community-based treatment or counseling	NEXT
Q75	4 Inpatient or residential treatment or counseling	NEXT
Q75	5 OTHER [Please describe]: <i>text box entry:</i> _____	NEXT
Q75	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q76 Option

How often was it easy to get this treatment or counseling?

Q76	1 Never	NEXT
Q76	2 Sometimes	NEXT
Q76	3 Usually	NEXT
Q76	4 Always	NEXT
Q76	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q77 Option

TELEHEALTH MEDICINE

These questions ask about getting any health care for your child using video by computer or mobile phone (for example, Zoom, Facetime), or a scheduled phone call with sound only (that is, no video). We refer to these services as telehealth services.

In the last 6 months, was a telehealth appointment offered for your child instead of an in-person appointment?

Q77	1 YES	NEXT
Q77	2 NO	Q82
Q77	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q78 Option

In the last 6 months, how many times did you have a telehealth visit to get care, tests, or treatment for your child?

Q78	0 None	Q82
Q78	1 1	NEXT
Q78	2 2	NEXT
Q78	3 3	NEXT
Q78	4 4	NEXT
Q78	5 5 to 9	NEXT
Q78	6 10 OR MORE TIMES	NEXT
Q78	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q79 Multiple Check Entry

In the last 6 months, which of the following types of telehealth services did your child receive? [READ, CHECK ALL THAT APPLY]

Q79	1 Primary care services (for example, check-ups, well-child visits, sick visits)	NEXT
Q79	2 Mental health services	NEXT
Q79	3 Therapy for school-related learning needs (for example, physical therapy, occupational therapy, speech therapy)	NEXT
Q79	4 Some other type of specialty care [Please describe] <i>text box entry:</i> _____	NEXT
Q79	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q80 Option

Compared to in-person healthcare visits, how satisfied are you with the care your child received through telehealth?

Are you...

Q80	1 Very satisfied	NEXT
Q80	2 Somewhat satisfied	NEXT
Q80	3 Somewhat dissatisfied	NEXT
Q80	4 Very dissatisfied	NEXT
Q80	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q81		Option	
How likely are you to continue using telehealth?			
Q81	1 Very likely		NEXT
Q81	2 Somewhat likely		NEXT
Q81	3 Somewhat unlikely		NEXT
Q81	4 Very unlikely		NEXT
Q81	9 DON'T KNOW/ NOT APPLICABLE		NEXT

Q82 Option
DENTAL CARE

The next questions are about your child's dental care.
 Is there a particular dentist or dental clinic that *[Child's name]* usually goes to if *he/she/they* needs dental care or dental advice, for example, a provider who *[Child's name]* sees for regular non-emergency dental care?

Q82	1 YES		NEXT
Q82	2 NO		Q84
Q82	9 DON'T KNOW/ NOT APPLICABLE		Q84

Q83		Option	
Is your child's regular source of dental care a:			
Q83	1 Private dental office		NEXT
Q83	2 School clinic		NEXT
Q83	3 Community clinic or		NEXT
Q83	4 Another source? [Please describe] <i>text box entry:</i> _____		NEXT
Q83	9 DON'T KNOW/ NOT APPLICABLE		NEXT

Q84		Option	
In the last 6 months, did <i>[Child's name]</i> get care from a dentist's office or dental clinic?			
Q84	1 YES		NEXT
Q84	2 NO		NEXT
Q84	9 DON'T KNOW/ NOT APPLICABLE		NEXT

Q85		Option	
During the past 6 months, was there any time when <i>[Child's name]</i> needed dental care but it was delayed or not received?			
Q85	1 YES		NEXT
Q85	2 NO		Q87
Q85	9 DON'T KNOW/ NOT APPLICABLE		Q87

Q86		Option	
Which of the following <i>best describes</i> the main reason <i>[Child's name]</i> was delayed in getting dental care, tests, or treatments you or a dentist believed necessary? I'll read you a list of possible reasons.			
Q86	1 Couldn't afford care		NEXT
Q86	2 MaineCare wouldn't approve, cover, or pay for care		NEXT
Q86	3 Dentists are too far away		NEXT
Q86	4 Dental provider refused to accept MaineCare		NEXT
Q86	5 Nobody in area takes MaineCare patients		NEXT
Q86	6 Long wait to get an appointment		NEXT
Q86	7 Scheduling issues		NEXT
Q86	8 Problems getting to dental provider's office		NEXT
Q86	9 Didn't know where to go to get care, or		NEXT
Q86	10 Some other reason [Please describe] <i>text box entry:</i> _____		NEXT
Q86	99 DON'T KNOW/ NOT APPLICABLE		NEXT

Q87 Text Entry

CHILD DEMOGRAPHICS

What is your child's age?			
Q87	0 FILL-IN RESPONSE		NEXT

Q88 Option *Display if age > 3 years*

Does your child identify as transgender?			
Q88	1 YES		NEXT
Q88	2 NO		NEXT
Q88	9 DON'T KNOW/ NOT APPLICABLE		NEXT

Q89	Option	
Is your child of Hispanic, Latino/a or Spanish origin?		
Q89	1 YES, HISPANIC, LATINO/A, OR SPANISH	NEXT
Q89	2 NO, NOT HISPANIC, LATINO/A, OR SPANISH	Q91
Q89	9 DON'T KNOW/ NOT APPLICABLE	Q91
Q90	Option	
Which group best describes your child? You may select more than one. [CHECK ALL THAT APPLY]		
Q90	1 Mexican, Mexican American, or Chicano	NEXT
Q90	2 Puerto Rican	NEXT
Q90	3 Cuban	NEXT
Q90	4 Another Hispanic, Latino/a or Spanish origin [SPECIFY:] <i>text box entry</i> _____	NEXT
Q90	9 DON'T KNOW/ NOT APPLICABLE	NEXT
Q91	Multiple Check Entry	
What is your child's race? You may select one or more categories. [CHECK ALL THAT APPLY]		
Q91	1 White	Q94
Q91	2 Black or African American	NEXT
Q91	3 Asian	Q93
Q91	4 American Indian or Alaska Native	Q94
Q91	5 Native Hawaiian or Other Pacific Islander	Q94
Q91	6 Other [Please specify] <i>text box entry</i> : _____	Q94
Q91	9 DON'T KNOW/ NOT APPLICABLE	Q94
Q92	Multiple Check Entry	<i>Display if 2 is selected on Q89</i>
Which group best describes your child? You may select more than one. [CHECK ALL THAT APPLY]		
Q92	1 Black	NEXT OR Q94
Q92	2 African American	NEXT OR Q94
Q92	3 African	NEXT OR Q94
Q92	4 West Indian	NEXT OR Q94
Q92	5 Other [SPECIFY:] <i>text box entry</i> : _____	NEXT OR Q94
Q92	9 DON'T KNOW/ NOT APPLICABLE	NEXT OR Q94
Q93	Multiple Check Entry	<i>Display if 3 is selected on Q89</i>
Which group best describes your child? You may select more than one. [CHECK ALL THAT APPLY]		
Q93	1 Asian Indian	NEXT
Q93	2 Chinese	NEXT
Q93	3 Filipino	NEXT
Q93	4 Japanese	NEXT
Q93	5 Korean	NEXT
Q93	6 Vietnamese	NEXT
Q93	7 Cambodian	NEXT
Q93	8 Other [Please specify] <i>text box entry</i> : _____	NEXT
Q93	9 DON'T KNOW/ NOT APPLICABLE	NEXT
Q94	Multiple Check Entry	
Is your child a member of a federally recognized tribe? If so, which ones? You may indicate more than one. [CHECK ALL THAT APPLY]		
Q94	1 NO	NEXT
Q94	2 HOULTON BAND OF MALISEET INDIANS	NEXT
Q94	3 PASSAMAQUODDY TRIBE AT INDIAN TOWNSHIP - MOTAHKOMIKUK	NEXT
Q94	4 PASSAMAQUODDY TRIBE AT PLEASANT POINT – SIPAYIK	NEXT
Q94	5 PENOBSCOT INDIAN NATION	NEXT
Q94	6 AROOSTOOK BAND OF MICMAC INDIANS	NEXT
Q94	7 A DIFFERENT TRIBE [Please specify]: <i>text box entry</i> : _____	NEXT
Q94	9 DON'T KNOW/ NOT APPLICABLE	NEXT
Q95	Option	
Is English your child's primary language, meaning the language that they speak most often?		
Q95	1 YES	Q97
Q95	2 NO	NEXT
Q95	9 DON'T KNOW/ NOT APPLICABLE	NEXT

Q96

Option

What is your child’s primary language, meaning the language that your child speaks most often?

Q96	1 ARABIC	NEXT
Q96	2 FRENCH	NEXT
Q96	3 HAITIAN	NEXT
Q96	4 KHMER	NEXT
Q96	5 KINYARWANDA	NEXT
Q96	6 KIRUNDI	NEXT
Q96	7 LINGALA	NEXT
Q96	8 PORTUGUESE	NEXT
Q96	9 SOMALI	NEXT
Q96	10 SPANISH	NEXT
Q96	11 VIETNAMESE	NEXT
Q96	12 OTHER [Please specify] <i>text box entry:</i> _____	NEXT
Q96	99 DECLINE TO STATE	NEXT

Q97

Option

ABOUT YOU

What is your age?

Q97	0 Under 18	NEXT
Q97	1 18 to 24	NEXT
Q97	2 25 to 34	NEXT
Q97	3 35 to 44	NEXT
Q97	4 45 to 54	NEXT
Q97	5 55 to 64	NEXT
Q97	6 65 to 74	NEXT
Q97	7 75 or older	NEXT
Q97	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q98

Option

What is your gender?

Q98	1 MALE	NEXT
Q98	2 FEMALE	NEXT
Q98	3 NONBINARY	NEXT
Q98	4 OTHER [Please specify] <i>text box entry:</i> _____	NEXT
Q98	9 DECLINE TO STATE	NEXT

Q99

Option

What is the highest grade or level of school that you have completed?

Q99	1 8TH GRADE OR LESS	NEXT
Q99	2 SOME HIGH SCHOOL, BUT DID NOT GRADUATE	NEXT
Q99	3 HIGH SCHOOL GRADUATE OR GED	NEXT
Q99	4 SOME COLLEGE OR 2-YEAR DEGREE	NEXT
Q99	5 4-YEAR COLLEGE GRADUATE	NEXT
Q99	6 MORE THAN A 4-YEAR COLLEGE DEGREE	NEXT
Q99	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q100

Option

How are you related to *[Child’s name]*?

Q100	1 MOTHER OR FATHER	NEXT
Q100	2 GRANDPARENT	NEXT
Q100	3 AUNT OR UNCLE	NEXT
Q100	4 OLDER BROTHER OR SISTER	NEXT
Q100	5 OTHER RELATIVE	NEXT
Q100	6 LEGAL GUARDIAN	NEXT
Q100	7 SOMEONE ELSE [Please specify] <i>text box entry:</i> _____	NEXT
Q100	9 DON’T KNOW/ NOT APPLICABLE	NEXT

Q101

Text Entry

In a few words, is there anything else you would like to share about your experiences with MaineCare, specifically?

Q101	0 RESPONSE	Q102 OR Q103
------	------------	--------------

Q102

Statement

Skip if Q85>1 or if Q86≠1, 3, 4, 5, or 9

Earlier, you mentioned you were having trouble finding a dentist for *[Child's name]*. If you have access to a computer, you can go to www.insurekidsnow.gov or you can call Member Services at 1-800-977-6740.

Those are all the questions we have. Thank you very much for your time. Please click the right arrow to submit your survey responses.

Q102

END OF SURVEY

Q103

Statement

Those are all the questions we have. Thank you very much for your time. Please click the right arrow to submit your survey responses.

Q103

END OF SURVEY

Appendix C: 2024 Survey Weights and Estimation Procedures

Constructing Weights. The purposes of survey weights are to remove bias from the sample and to allow for generalization of the findings to the whole population rather than just to those who completed interviews. Weights adjust for differences in the likelihood that a member of the target population is selected for an interview (design effects) and differences between respondents and non-respondents (nonresponse bias).

We constructed weights for the analysis of the 2024 survey using standard procedures, outlined in Table C-1. The first step is to compute the probability that a child within each stratum of the population was selected as a target child for an interview (column C). There were a total of 8 strata defined based on (1) MaineCare eligibility category (Medicaid Expansion CHIP – Title XXI or traditional Medicaid – Title XIX), (2) presence of a chronic condition diagnosis in the MaineCare claims data (yes or no), and (3) number of children enrolled in MaineCare who live in the household (one or multiple). The design weight, which adjusts for differences in the probability of selection, is computed as the inverse (column D). Because the Title XXI eligibility and children with a chronic condition diagnosis categories were oversampled in the sampling process – meaning that children enrolled in Title XXI and those with a chronic condition diagnosis had a higher probability of selection – the design weights for strata that include these categories are smaller.

Next, we adjusted for differences in non-response using a method suggested by Little and Vartivarian (2003).²⁷ We ran a logistic regression model predicting the likelihood that a given sample member completed an interview using age, gender, minority status and region of residence as predictors and controlling for eligibility category, chronic condition status, and number of children in the household. The nonresponse weight was computed as the inverse of the probability of response for each child generated from these regression models. Column E lists the sum of the product of the design and nonresponse weights.

The final step was to compute a poststratification weight, designed to rebalance the response data to reflect the distribution of the population. Because we know the number of children in each stratum in the original population (listed in column A), we do not need to rely on an external source of population data to compute the poststratification weight. We simply divided the population size (column A) by the combined non-response and design weight results in column E. The final weight, incorporating all of the previous adjustments, is the product of the design, nonresponse, and poststratification weights (column G).

Estimation Procedures. Unless otherwise specified in the report, all results presented are based on weighted data, correcting for the stratified random sampling design used in the study. All statistical tests were calculated using SAS version 9.4 with survey procedures that use the Taylor series linearization approach to account for the sample design and yield valid standard errors for the weighted data.

²⁷ Little R, Vartivarian S. On weighting the rates in non-response weights. *Statistics in Medicine*. 2003; 22:1589-1599

Table C-1. 2024 Survey Weight Construction

Eligibility Category	Chronic Condition*	Children in Household	Children in Stratum (A)	Number in Sample (B)	Pr (being sampled) (C)=B/A	Design Weight (D)=1/C	Sum of Design x Non-response Weights (E)	Post-stratification Weight (F)=A/E	Sum of Final Weights (G)=(A)
Title XXI	No	One	2,575	190	0.074	13.553	2,333.81	1.1034	2,575
Title XXI	No	Multiple	8,722	797	0.091	10.944	9,448.64	0.9231	8,722
Title XXI	Yes	One	2,203	192	0.087	11.474	2,391.11	0.9213	2,203
Title XXI	Yes	Multiple	5,420	612	0.113	8.856	4,483.83	1.1190	5,420
Title XIX	No	One	15,263	288	0.019	52.997	14,594.62	1.0458	15,263
Title XIX	No	Multiple	37,958	636	0.017	59.682	35,729.96	1.0624	37,958
Title XIX	Yes	One	13,918	458	0.033	30.389	14,177.09	0.9817	13,918
Title XIX	Yes	Multiple	24,100	672	0.028	35.863	25,579.58	0.9422	24,100
Total			110,159	3,845			109,098.64		110,159

Note: Non-response weights were estimated using logistic regression models on sample members predicting response based on age, gender, minority status, and region of residence, and controlling for eligibility category, chronic condition status in claims data, and household density. The non-response weight is equal to the inverse of the predicted probability of response for a given set of characteristics.

*Presence of chronic condition based on diagnosis codes in MaineCare claims.

$$\text{Final Weight} = \text{Design Weight} \times \text{Non-response Weight} \times \text{Post-stratification Weight}$$