

# Medicaid Access in Brief: Children and Youth with Special Health Care Needs

Almost one in five children and youth have special health care needs (CYSHCN), and ensuring access to care for them is especially important because they can have multiple and complex medical health needs (Ghandour et al. 2022).<sup>1</sup> Recent research on these populations has shown that most CYSHCN are not getting the care, services, or support they need, regardless of payer (McLellan et al. 2022; Schiff et al. 2022). Given their higher needs, they potentially face greater consequences than other children if they do not receive care or if it is delayed. In addition, coordinating multiple providers and the financial strain of the cost of care may impose a substantial burden on their families.

Medicaid provides comprehensive coverage for eligible CYSHCN with little to no out-of-pocket costs. These children and youth may be eligible for Medicaid on the basis of a disability, through a low-income pathway, or through a buy-in program.<sup>2</sup> Like all children under age 21 enrolled in Medicaid, these children are entitled to the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, which requires states to provide any medically necessary service named in the Medicaid statute—including optional services not otherwise covered by the state—without caps or other limits. For children with other coverage, such as employer-sponsored insurance, Medicaid may provide services that are unavailable through their private coverage.<sup>3</sup>

In this issue brief, we used data from the 2018 and 2019 National Survey of Children's Health (NSCH) to examine differences in health status, access to care, referrals, needed care, and the cost of care for CYSHCN covered by Medicaid with those covered by private insurance and those without insurance.

We found that across all insurance coverage types, CYSHCN experienced difficulties accessing the support, mental health care, and referred providers they needed. For example, over one fifth of families with CYSHCN reported needing additional help with coordination of their child's health care in the past 12 months. There were also differences in cost, access, and use of services between those covered by Medicaid and private insurance. CYSHCN covered by Medicaid were more likely than those covered by private insurance to report having little or no out-of-pocket costs for care and to have adequate health insurance coverage. However, those covered by Medicaid were less likely than those with private insurance to have a primary care provider and a usual source of care for preventive or other health care needs and significantly more likely than those with private insurance to have had an emergency room visit or hospitalization in the past 12 months.

## Demographic Characteristics of Children and Youth with Special Health Care Needs

Across all payors, CYSCHN had different demographic characteristics than those without special health care needs:

- More than one-third (36.6 percent) of CYSCHN are covered by Medicaid, and the percent varied by state (ranging from 24.0 percent to 55.4) (Appendix Table A-1).
- The share of white, non-Hispanic and Black, non-Hispanic CYSCHN (52.8 percent and 15.5 percent, respectively) was greater than the share of white, non-Hispanic and Black, non-Hispanic children and youth without special health care needs (49.6 percent and 12.8 percent, respectively).



- The share of Hispanic CYSHCN (21.9 percent) was smaller than Hispanic children and youth without special health care needs (26.5 percent).
- A greater proportion of CYSHCN are 6-11 years old and 12-17 years old (36.8 percent and 45.8 percent) than those without special health care needs (32.8 percent and 31.6 percent).
- A greater proportion of these children are male (58.3 percent) compared to those without special health care needs (49.4 percent).

Households with CYSHCN were more likely to have low incomes and to participate in other benefits programs compared to households without CYSHCN:

- A greater proportion of households with CYSHCN have incomes below 100 percent the federal poverty level (FPL) (22.7 percent) than those without special health care needs (18.1 percent).
- A greater proportion of households with CYSHCN received Temporary Assistance for Needy Families benefits (5.8 percent) and Supplemental Nutrition Assistance Program benefits (23.2 percent) than those without special health care needs (3.4 percent and 16.2 percent).

**TABLE 1.** Selected Demographic and Socioeconomic Characteristics of Children (Ages 0-17), 2019

| Demographic characteristics                            | Percentage of children age 0-17 |            |
|--|---------------------------------|------------|
|  | CYSHCN                          | non-CYSHCN |
| <b>Age</b>   |                                 |            |
| 0-5  | 17.4%                           | 35.5%*     |
| 6-11   | 36.8                            | 32.8*      |
| 12-17  | 45.8                            | 31.6*      |
| <b>Sex</b>   |                                 |            |
| Male   | 58.3                            | 49.4*      |
| Female   | 41.7                            | 50.6*      |
| <b>Highest education of adult in child's household</b> |                                 |            |
| Less than high school                                  | 6.4                             | 9.9*       |
| High school or GED                                     | 19.8                            | 18.7       |
| Some college or technical school                       | 25.7                            | 20.9*      |
| College degree or higher                               | 48.1                            | 50.5       |
| <b>Race and ethnicity</b>                              |                                 |            |
| Hispanic   | 21.9                            | 26.5*      |
| White, non-Hispanic                                    | 52.8                            | 49.6*      |
| Black, non-Hispanic                                    | 15.5                            | 12.8*      |
| Asian, non-Hispanic                                    | 9.7                             | 11.1       |
| <b>Primary language</b>                                |                                 |            |
| English  | 93.2                            | 84.7*      |
| Other language   | 6.8                             | 15.3*      |
| <b>Family income</b>                                   |                                 |            |
| Less than 100 percent FPL                              | 22.7                            | 18.1*      |
| Less than 138 percent FPL                              | 31.0                            | 26.2*      |
| 100-199 percent FPL                                    | 21.2                            | 21.3       |
| 200-399 percent FPL                                    | 26.8                            | 29.4*      |
| 400 percent FPL or higher                              | 29.3                            | 31.2       |



| Demographic characteristics      | Percentage of children age 0-17 |            |
|----------------------------------|---------------------------------|------------|
|                                  | CYSHCN                          | non-CYSHCN |
| <b>Other benefits programs</b>   |                                 |            |
| Family receives WIC benefits     | 10.8                            | 12.2       |
| Family receives income from TANF | 5.8                             | 3.4*       |
| Family receives SNAP             | 23.2                            | 16.2*      |
| <b>Health insurance</b>          |                                 |            |
| Private only                     | 51.6                            | 60.6*      |
| Medicaid only                    | 36.6                            | 27.7*      |
| Private and Medicaid             | 8.3                             | 4.1*       |
| Uninsured                        | 3.5                             | 7.6*       |

**Notes:** CYSHCN is children and youth with special health care needs. FPL is federal poverty level. WIC is Supplemental Nutrition Program for Women, Infants, and Children. SNAP is Supplemental Nutrition Assistance Program, formerly referred to as Food Stamps. TANF is Temporary Assistance for Needy Families.

\* Difference from CYSHCN is statistically significant at the 0.05 level.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Health Characteristics of Children and Youth with Special Health Care Needs

CYSHCN have complex health needs, and were less likely to report very good or excellent health (73.7 percent) than those without special health care needs (94.2 percent) (Table 2). About three-quarters of CYSHCN reported having two or more conditions. The most commonly reported behavioral health conditions included attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD) (35.4 percent), anxiety problems (34.5 percent), behavioral or conduct problems (30.4 percent), developmental delay (25.3 percent), and learning disabilities (25.1 percent). The most commonly reported other medical conditions included allergies (47.8 percent) and asthma (32.4 percent) (Appendix A-2).

**TABLE 2.** Children's Insurance Coverage, Health Status, and Conditions Reported by Special Health Care Needs Status, 2019

| Health measures                             | Percentage of children age 0-17 |            |
|---|---------------------------------|------------|
|   | CYSHCN                          | non-CYSHCN |
| <b>Health status</b>                        |                                 |            |
| Very good or excellent                      | 73.7%                           | 94.2%*     |
| Good  | 20.5                            | 5.3*       |
| Fair or poor                                | 5.8                             | –          |
| <b>Number of reported health conditions</b> |                                 |            |
| No conditions                               | 6.3                             | 64.7*      |
| 1 condition                                 | 17.1                            | 23.1*      |
| 2 conditions                                | 23.4                            | 8.1*       |
| 3 conditions                                | 15.6                            | 2.4*       |
| 4 or more conditions                        | 37.6                            | 1.7*       |

**Notes:** CYSHCN is children and youth with special health care needs. Full list of conditions are listed in Appendix A-2.

\* Difference from CYSHCN is statistically significant at the 0.05 level.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.



CYSHCN also reported having worse oral health than those without special health care needs (Table 3). They were more likely than those without special health care needs to report fair or poor oral health (10.1 percent compared to 3.9 percent) and to have one or more oral health problems, which includes toothaches, bleeding gums or decayed teeth or cavities (20.2 percent compared to 12.4 percent).

**TABLE 3.** Oral Health Measures Reported by Special Health Care Needs Status, 2019

| Oral health                                      | Percentage of children age 0-17 |            |
|--|---------------------------------|------------|
|  | CYSHCN                          | non-CYSHCN |
| <b>Condition of children's teeth<sup>1</sup></b> |                                 |            |
| Very good or excellent                           | 70.1%                           | 82.0%*     |
| Good   | 19.8                            | 14.1*      |
| Fair or poor                                     | 10.1                            | 3.9*       |
| <b>Oral health problems<sup>2</sup></b>          |                                 |            |
| One or more oral health problems <sup>1</sup>    | 20.2                            | 12.4*      |

**Notes:** CYSHCN is children and youth with special health care needs.

\* Difference from CYSHCN is statistically significant at the 0.05 level.

<sup>1</sup> Age 1-17.

<sup>2</sup> Includes toothaches, bleeding gums or decayed teeth or cavities.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Experiences with Accessing and Using Care by Insurance Status

Over one-third of CYSHCN are covered by Medicaid, more than half are covered by private insurance, and 8.3 percent have both private and Medicaid insurance coverage. Those covered by Medicaid were less likely to have a usual source of care and to use health care services than those covered by private insurance. However, CYSHCN covered by Medicaid and private insurance reported similar rates of unmet health care needs.

### Usual source of care

CYSHCN with Medicaid were less likely than those covered by private insurance to report having a health care provider (78.1 percent compared to 83.3 percent) (Table 4). Across all insurance coverage types, families reported similar rates of receiving the needed care coordination for their child's health care in the past 12 months.

**TABLE 4.** Usual Source of Care and Care Coordination among Children and Youth with Special Health Care Needs (Ages 0-17), by Insurance Status, 2019

| Usual care and care coordination                     | Percentage of CYSHCN age 0-17 |         |                      |           |
|--|-------------------------------|---------|----------------------|-----------|
|  | Medicaid                      | Private | Medicaid and private | Uninsured |
| <b>Usual source of care</b>                          |                               |         |                      |           |
| Has a health care provider                           | 78.1%                         | 83.3%*  | 75.6%                | 73.5%     |
| Has a usual source for sick care and preventive care | 72.3                          | 89.6*   | 75.0                 | 68.0      |
| <b>Care coordination</b>                             |                               |         |                      |           |
| Received needed care coordination                    | 65.7                          | 69.4    | 64.0                 | 62.8      |



**Notes:** CYSHCN is children and youth with special health care needs.

\* Difference from Medicaid is statistically significant at the 0.05 level

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Health service use in the past 12 months

The majority of CYSHCN covered by Medicaid, private insurance, or both had a medical visit, at least one preventative medical visit, and a specialist visit in the past year. However, some health service use differed between those covered by Medicaid and those with private insurance coverage.

- CYSHCN covered by Medicaid were more likely than those covered by private insurance to receive special services to meet developmental needs (32.2 percent compared to 20.8 percent), receive comprehensive care within a medical home (53.9 percent compared to 34.5 percent), and receive services under a special education or early intervention plan (38.4 percent compared to 25.8 percent).
- CYSHCN covered by Medicaid reported higher rates of emergency room (ER) visits (36.9 percent) and hospital admissions (9.8 percent) compared to those covered by private insurance (20.9 percent and 6.7 percent, respectively).
- CYSHCN covered by Medicaid were less likely than those covered by private insurance to have had at least one dental visit (85.0 percent compared to 90.7 percent).

There are also differences in time spent by family members coordinating health care and providing home health care by health insurance coverage type (Table 5).

- Family members of CYSHCN covered by Medicaid were more likely to spend over 11 hours providing home health care than those covered by private insurance only (9.4 percent compared to 2.6 percent).

**TABLE 5.** Health Care Use for Children and Youth with Special Health Care Needs (Age 0-17) by Insurance Status, 2019

| Health care services                        | Percentage of CYSHCN age 0-17 |               |              |                      |           |
|---|-------------------------------|---------------|--------------|----------------------|-----------|
|   | Total                         | Medicaid only | Private only | Medicaid and private | Uninsured |
| <b>Health care use</b>                      |                               |               |              |                      |           |
| Preventive dental visits                    | 96.9%                         | 95.3%         | 98.3%*       | 96.7%                | 91.3%     |
| Medical visit                               | 94.5                          | 94.1          | 95.7         | 92.4                 | 85.4*     |
| At least one preventative medical visit     | 90.0                          | 89.0          | 91.6         | 87.8                 | 82.8      |
| Specialist visit                            | 86.7                          | 88.6          | 86.5         | 83.4                 | 80.1      |
| Vision test                                 | 77.0                          | 76.8          | 79.3         | 75.1                 | 49.9*     |
| At least one dental or oral health visit    | 88.4                          | 85.0          | 90.7*        | 92.1*                | 80.6      |
| ER visit                                    | 28.8                          | 36.9          | 20.9*        | 37.4                 | 39.3      |
| Hospital admission                          | 8.6                           | 9.8           | 6.7*         | 14.7                 | –         |
| Use of alternative health care or treatment | 13.4                          | 10.7          | 15.0*        | 15.2                 | –         |
| Received family-centered care               | 79.9                          | 76.2          | 84.2*        | 73.9                 | 69.4      |



| Health care services  | Percentage of CYSHCN age 0-17 |               |              |                      |           |
|---|-------------------------------|---------------|--------------|----------------------|-----------|
|   | Total                         | Medicaid only | Private only | Medicaid and private | Uninsured |
| <b>Other service use</b>  |                               |               |              |                      |           |
| Received needed mental health treatment or counseling <sup>1</sup>                | 87.5                          | 86.7          | 87.9         | 92.3                 | 75.0      |
| Received special services to meet developmental needs                             | 26.4                          | 32.2          | 20.8*        | 40.5                 | 14.9*     |
| Received care coordination, and ongoing, comprehensive care within a medical home | 43.6                          | 53.9          | 34.5*        | 50.6                 | 51.9      |
| Child received effective care coordination  | 67.4                          | 65.7          | 69.4         | 64.0                 | 62.8      |
| Child received services need for transition to adult health care <sup>2</sup>     | 24.9                          | 24.7          | 25.2         | 27.1                 | –         |
| Received services under a special education or early intervention plan            | 32.2                          | 38.4          | 25.8*        | 49.5*                | 20.8*     |
| <b>Time spent providing at home health care for child</b>                         |                               |               |              |                      |           |
| Less than 1 hour per week   | 15.6                          | 12.4          | 18.9*        | 22.8*                | –         |
| 1-4 hours per week  | 9.4                           | 10.5          | 8.4          | 11.9                 | –         |
| 5-10 hours per week   | 3.8                           | 3.9           | –            | 6.4                  | –         |
| 11 hours or more per week   | 6.3                           | 9.4           | 2.6*         | –                    | –         |
| Child does not need weekly health care services                                   | 64.9                          | 63.9          | 66.8         | 53.0*                | 75.7*     |
| <b>Time spent coordinating health care for children who needed it</b>             |                               |               |              |                      |           |
| Less than 1 hour per week   | 20.6                          | 20.4          | 21.3         | 21.0                 | 13.0      |
| 1-4 hours per week  | 11.1                          | 12.0          | 9.1          | 22.3                 | –         |
| 5-10 hours per week   | 1.4                           | –             | –            | –                    | –         |
| 11 hours or more per week   | 2.0                           | 3.3           | –            | –                    | –         |
| Child does not need weekly health care services                                   | 64.9                          | 63.1          | 67.9         | 49.8*                | 74.0      |

**Notes:** CYSHCN is children and youth with special health care needs.

\* Difference from Medicaid is statistically significant at the 0.05 level.

<sup>1</sup> Denominator only includes those who needed treatment.

<sup>2</sup> Ages 12-17.

– Estimate not reported due to too small of a sample size or is unreliable because it has a relative standard error greater than or equal to 30 percent.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Quality of care

Across insurance coverage sources, CYSHCN reported similar rates of having a doctor speak to the child privately and ask about parental concerns (Table 6). However, fewer of those covered by Medicaid reported that they felt like there was shared decision making for the child's health (34.7 percent) compared to those with private insurance (47.5 percent). Further, about one in five reported receiving care in a well-functioning system.



**TABLE 6.** Selected Quality of Care Measures for Children and Youth with Special Health Care Needs (Age 0-17) by Insurance Status, 2019

| Quality of care   | Percentage of CYSHCN age 0-17 |         |                      |
|---|-------------------------------|---------|----------------------|
|   | Medicaid                      | Private | Medicaid and private |
| Doctor spoke with child without guardian or caregiver in the room <sup>1</sup>        | 58.4%                         | 59.5%   | 54.3%                |
| Doctor asked about parental concerns <sup>2</sup>                                     | 39.6                          | 50.7    | 55.6                 |
| Family usually or always feels partnered in shared decision-making for child's health | 34.7                          | 47.5*   | 43.5                 |
| Receives care in a well-functioning system <sup>3</sup>                               | 20.3                          | 16.7    | 16.8                 |

**Notes:** CYSHCN is children and youth with special health care needs. Uninsured is not included in this figure because estimates could not be reported for these measures. This is due to a small of a sample size or unreliable results with a relative standard error greater than or equal to 30 percent.

\* Difference from Medicaid is statistically significant at the 0.05 level.

<sup>1</sup> Age 12-17.

<sup>2</sup> Age 0-5.

<sup>3</sup> This measure was constructed with 50 survey questions related to shared decision-making, care in the medical home, care coordination, health insurance coverage, access to medical and dental preventive care, transition to adulthood, and system of care.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Unmet service needs and barriers to accessing needed care

CYSHCN covered by Medicaid or private insurance reported similar difficulties with accessing mental health treatment and specialist care and with getting a referral for needed care (Table 7). For example, for those covered by Medicaid, 17.6 percent reported not being able to get the mental health treatment or counseling that the child needed. Additionally, for those who needed a referral, 10.5 percent of those with Medicaid reported it as somewhat or very difficult to get a referral. Of those covered by Medicaid who received referrals, about one quarter found it somewhat difficult to receive the care, and fewer than 5 percent were unable to receive the care needed from the referral.

**TABLE 7.** Difficulties Getting Referrals for Children and Youth with Special Health Care Needs (Age 0-17) by Insurance Status, 2019

| Referrals  | Percentage of CYSHCN age 0-17 |         |                      |           |
|--|-------------------------------|---------|----------------------|-----------|
|  | Medicaid                      | Private | Medicaid and private | Uninsured |
| <b>Difficulties with accessing mental health treatment or counseling that the child needed<sup>1</sup></b> |                               |         |                      |           |
| No difficulties  | 53.9%                         | 53.7%   | 40.4%*               | 48.8%     |
| Somewhat difficult   | 28.5                          | 30.8    | 34.5                 | 30.6      |
| Not possible to obtain care  | 17.6                          | 15.4    | 25.1                 | 20.6      |
| <b>Difficulties with accessing specialist care that the child needed<sup>2</sup></b>                       |                               |         |                      |           |
| No difficulties  | 70.4                          | 72.9    | 54.8*                | 64.3      |
| Somewhat difficult   | 18.9                          | 20.5    | 26.1                 | –         |
| Not possible to obtain care  | 10.7                          | 6.7     | 19.1                 | –         |
| <b>Difficulties getting referrals to see any doctors or receive any services in the past 12 months</b>     |                               |         |                      |           |
| Did not need a referral  | 62.3                          | 64.3    | 51.7*                | 65.2      |





| Referrals   | Percentage of CYSHCN age 0-17 |         |                      |           |
|---|-------------------------------|---------|----------------------|-----------|
|   | Medicaid                      | Private | Medicaid and private | Uninsured |
| Did not have any difficulties                                       | 27.2                          | 27.7    | 36.2                 | 18.9      |
| Somewhat difficult to get a referral                                | 9.1                           | 6.1     | 10.4                 | –         |
| Very difficult to get a referral                                    | 1.4                           | 2.0     | –                    | –         |
| <b>How much of a problem was it to get the referral<sup>3</sup></b> |                               |         |                      |           |
| No difficulties   | 72.2                          | 77.5    | 74.9                 | 54.3      |
| Somewhat difficult  | 24.2                          | 17.0    | 21.4                 | –         |
| Not possible to obtain care   | 3.7                           | 5.5     | –                    | –         |

**Notes:** CYSHCN is children and youth with special health care needs.

\* Difference from Medicaid is statistically significant at the 0.05 level.

– Estimate not reported due to too small of a sample size or is unreliable because it has a relative standard error greater than or equal to 30 percent.

<sup>1</sup> Denominator only includes children who needed or had treatment or counseling.

<sup>2</sup> Denominator only includes children that needed or had a specialist visit.

<sup>3</sup> Denominator only includes children who got a referral.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

Fewer than 10 percent of Medicaid-covered CYSHCN reported not receiving needed care in the past 12 months, and over 20 percent reported that the family needed extra help coordinating the child's health care in the past 12 months. Further, almost one quarter of families with Medicaid-covered CYSHCN that needed extra help reported never receiving extra help when they needed it (Table 8). In addition, a higher rate of those with Medicaid reported being usually or always frustrated in efforts to get services for their children than those covered by private insurance (10.0 percent compared to 6.5 percent). Of those who reported not receiving needed services, similar rates of those covered by Medicaid and private insurance reported that services were not available in their area, problems with getting an appointment, and that children were ineligible for services as contributing factors. However, those covered by Medicaid were less likely than those covered by private insurance to report cost being a barrier to receiving services (35.9 percent compared to 61.2 percent).

**TABLE 8. Unmet Services for Children and Youth with Special Health Care Needs (Age 0-17) by Insurance Status, 2019**

| Unmet service need  | Percentage of CYSHCN age 0-17 |         |                      |           |
|---|-------------------------------|---------|----------------------|-----------|
|   | Medicaid                      | Private | Medicaid and private | Uninsured |
| <b>Unmet need</b>   |                               |         |                      |           |
| Needed, but did not receive care in last 12 months  | 7.6                           | 8.0     | 9.7                  | 21.1*     |
| Family needed extra help coordinating child's health care in last 12 months                             | 21.8                          | 18.8    | 29.0                 | –         |
| <b>If you could have used extra help, how often did you get as much help as you wanted?<sup>1</sup></b> |                               |         |                      |           |
| Usually   | 24.3                          | 10.5*   | –                    | –         |
| Sometimes   | 52.7                          | 54.7    | 62.9                 | –         |
| Never   | 23.1                          | 34.8    | –                    | –         |
| <b>How often were you frustrated in efforts to get services for the child?</b>                          |                               |         |                      |           |
| Usually or always frustrated  | 10.0                          | 6.5*    | 15.8                 | 19.8      |
| Sometimes frustrated  | 29.5                          | 26.7    | 33.4                 | 42.3      |
| Never frustrated  | 60.5                          | 66.8*   | 50.8                 | 37.9*     |





| Unmet service need   | Percentage of CYSHCN age 0-17 |         |                      |           |
|--|-------------------------------|---------|----------------------|-----------|
|  | Medicaid                      | Private | Medicaid and private | Uninsured |
| <b>Which of the following contributed to the child not receiving needed services<sup>2</sup></b> |                               |         |                      |           |
| Not eligible   | 37.5                          | 35.0    | –                    | –         |
| Not available in area  | 36.8                          | 27.4    | –                    | –         |
| Problems getting an appointment  | 35.9                          | 42.0    | –                    | –         |
| Issues related to cost   | 35.9                          | 61.2*   | –                    | –         |

**Notes:** CYSHCN is children and youth with special health care needs.

\* Difference from Medicaid is statistically significant at the 0.05 level.

– Estimate not reported due to too small of a sample size or is unreliable because it has a relative standard error greater than or equal to 30 percent.

<sup>1</sup> Denominator only includes children that needed extra help with care coordination.

<sup>2</sup> Denominator only includes children who needed but did not receive care.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Covered Benefits and Cost of Care

Almost all CYSHCN were consistently insured in the past 12 months. About five percent of those covered by Medicaid experienced gaps in coverage, and the majority experienced gaps in coverage related to household employment changes (47.4 percent) or Medicaid renewal or application processes (55.0 percent).

Households with Medicaid-covered CYSHCN were more likely than those covered by private insurance to report that the insurance coverage met the child's needs (92.5 percent compared to 89.1 percent), had reasonable out-of-pocket costs (65.0 percent compared to 52.6 percent), and that the insurance always met their mental and behavioral health care service needs (56.7 percent compared to 40.9 percent). Further, households with CYSHCN needs covered by private insurance were more likely than households with Medicaid-covered CYSHCN to report avoiding changing jobs due to concerns related to their health insurance (19.1 percent compared to 5.6 percent).

**TABLE 9.** Selected Insurance Measures for Children and Youth with Special Health Care Needs (Ages 0-17), 2019

| Health insurance in the past 12 months              | Percentage of CYSHCN age 0-17 |              |
|---|-------------------------------|--------------|
|   | Medicaid only                 | Private only |
| <b>Health insurance consistency</b>                 |                               |              |
| Consistently insured throughout the past year       | 94.8%                         | 98.6%*       |
| Currently uninsured or had periods without coverage | 5.2                           | –            |
| Gap related to employment change                    | 47.4                          | –            |
| Gap related to renewal or application process       | 55.0                          | –            |
| <b>Current insurance coverage</b>                   |                               |              |
| Current insurance coverage is adequate <sup>1</sup> | 83.7                          | 53.1*        |
| Meet child's needs                                  | 92.5                          | 89.1*        |
| Allows children to see needed providers             | 94.5                          | 94.1         |
| Out-of-pocket expenses are reasonable               | 65.0                          | 52.6*        |

| Health insurance in the past 12 months  | Percentage of CYSHCN age 0-17 |              |
|---|-------------------------------|--------------|
|   | Medicaid only                 | Private only |
| <b>Current insurance covers needed mental/behavioral health care services<sup>2</sup></b> |                               |              |
| Always  | 56.7                          | 40.9*        |
| Usually   | 23.5                          | 29.6         |
| Sometimes or never  | 19.9                          | 29.5*        |
| <b>Other insurance measures</b>   |                               |              |
| Avoided changing jobs because of concerns about maintaining health insurance for child    | 5.6                           | 19.1*        |
| Problems paying for any of child's medical or health care bills                           | 26.4                          | 25.4         |
| <b>Out-of-pocket costs for child's medical, health, and dental</b>                        |                               |              |
| \$0   | 73.5                          | 4.4*         |
| \$1-\$249   | 15.8                          | 17.8         |
| \$250-\$499   | 5.5                           | 18.9*        |
| \$500-\$999   | 2.3                           | 20.5*        |
| \$1,000-\$5,000   | 2.3                           | 30.3*        |
| More than \$5,000   | –                             | 8.0*         |

**Notes:** CYSHCN is children and youth with special health care needs.

\* Difference from CYSHCN is statistically significant at the 0.05 level.

<sup>1</sup> Adequate insurance is defined as children meeting all of these criteria: child currently has health insurance coverage, benefits usually or always meet child's needs, usually or always allow child to see needed providers, and either no out-of-pocket expenses or out-of-pocket expenses are usually or always reasonable.

<sup>2</sup> Age 3-17.

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

## Methodology

The NSCH is funded and directed by the Maternal and Child Health Bureau (MCHB), Health Resources & Services Administration in the U.S. Department of Health and Human Services. Respondents are the parents or guardian of randomly selected children from all 50 states and the District of Columbia. The survey provides national and state-level estimates on measures related to the health of children ages 0–17. For more information on the NSCH, see <https://mchb.hrsa.gov/data/national-surveys>.

## Identifying children and youth with special health care needs

Children and youth were identified as having special health care needs by using the [children with special health care needs \(CSHCN\) Screener](#). The screener includes five questions that were developed based on the federal Maternal and Child Health Bureau's definition of children with special health care needs. The screener is used to identify children with one or more chronic health conditions that are expected to last 12 months or longer.

## Identifying coverage source

Our analyses used the constructed insurance variable in the NSCH codebook. Medicaid coverage was defined as those who reported having "Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability." Private insurance coverage was defined as insurance provided through an employer or purchased directly from an insurance company. Individuals were defined as uninsured if they did not report having any insurance or if they had only Indian Health Service coverage.



## Endnotes

<sup>1</sup> The term children and youth with special health care needs is defined by the federal Maternal and Child Health Bureau as a group of children who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al. 1998). The definition encompasses children with disabilities, as well as children with mild to severe chronic conditions, such as asthma, juvenile diabetes, and sickle cell anemia.

<sup>2</sup> For children under age 18 to be determined disabled under Supplemental Security Income rules, the child must have at least one medically determinable physical or mental impairment that causes marked and severe functional limitations and that can be expected to cause death or last at least 12 months (§ 1614(a)(3)(C)(i) of the Social Security Act (the Act)).

States have two options available to cover children with disabilities receiving services in the community. Under the Katie Beckett option, states can cover children under age 19 who are disabled while living at home and would be eligible for Medicaid if they were in an institution (§ 1902(e)(3) of the Act). The Family Opportunity Act allows children with disabilities and family incomes below 300 percent of the federal poverty level (FPL) to buy into Medicaid (§§ 1902(a)(10)(A)(ii)(XIX) and 1902(cc) of the Act). More information about eligibility pathways for children with special health care needs can be found at <https://www.macpac.gov/subtopic/children/>.

<sup>3</sup> Medicaid coordinates benefits with other insurers as a secondary payer to all other payers. This means that if an insurer and Medicaid both provide coverage of a given benefit, the other payer is first responsible for making payment and Medicaid is responsible only for any balance covered under Medicaid payment rules. Medicaid is also responsible for payment of services not covered by other insurers.

## References

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# APPENDIX A

**TABLE A-1.** Coverage Source for Children and Youth with Special Health Care Needs, by State, 2018-2019<sup>1</sup>

| States               | Percentage of CYSHCN age 0-17 |               |              |                      |
|----------------------|-------------------------------|---------------|--------------|----------------------|
|                      | Total population              | Medicaid only | Private only | Medicaid and private |
| <b>United States</b> | <b>18.9%</b>                  | 37.8%         | 50.9%        | 7.6%                 |
| Alabama              | 21.8                          | 44.2          | 42.0*        | 8.9                  |
| Alaska               | 18.3                          | 33.0          | 49.5         | 11.9                 |
| Arizona              | 19.3                          | 44.0          | 46.8         | 4.4*                 |
| Arkansas             | 22.3                          | 52.7*         | 33.6*        | 8.8                  |
| California           | 14.0                          | 29.2          | 59.6         | –                    |
| Colorado             | 18.6                          | 28.7*         | 56.5         | 11.1                 |
| Connecticut          | 20.3                          | 32.8          | 57.1         | –                    |
| Delaware             | 21.5                          | 38.3          | 50.6         | 9.1                  |
| District of Columbia | 19.6                          | 46.4          | 37.1*        | –                    |
| Florida              | 18.3                          | 55.4*         | 40.6*        | –                    |
| Georgia              | 19.4                          | 40.2          | 43.9         | 8.3                  |
| Hawaii               | 13.8                          | 24.0*         | 67.9*        | –                    |
| Idaho                | 18.6                          | 39.1          | 46.1         | 8.8                  |
| Illinois             | 19.4                          | 34.1          | 54.4         | –                    |
| Indiana              | 20.5                          | 43.1          | 46.5         | 6.4                  |
| Iowa                 | 19.8                          | 35.7          | 49.7         | 12.4                 |
| Kansas               | 20.5                          | 34.0          | 53.7         | –                    |
| Kentucky             | 22.8                          | 43.9          | 48.5         | 6.2                  |
| Louisiana            | 24.2                          | 51.5*         | 33.6*        | 6.4                  |
| Maine                | 23.0                          | 33.7          | 56.9         | 6.4                  |
| Maryland             | 19.4                          | 34.4          | 60.7*        | –                    |
| Massachusetts        | 21.1                          | 25.4*         | 64.8*        | 8.9                  |
| Michigan             | 20.7                          | 33.0          | 53.2         | 13.0                 |
| Minnesota            | 17.2                          | 24.7*         | 64.3*        | –                    |
| Mississippi          | 22.6                          | 46.5*         | 34.8*        | 11.9                 |
| Missouri             | 21.9                          | 33.4          | 53.9         | 10.7                 |
| Montana              | 19.6                          | 46.8*         | 41.0*        | –                    |
| Nebraska             | 18.8                          | 31.3          | 63.3*        | –                    |
| Nevada               | 15.5                          | 27.1*         | 53.4         | –                    |
| New Hampshire        | 23.7                          | 30.8          | 58.3         | 7.7                  |
| New Jersey           | 17.0                          | 33.6          | 59.4         | –                    |
| New Mexico           | 18.8                          | 49.5*         | 35.5*        | –                    |
| New York             | 18.4                          | 37.7          | 52.7         | 7.4                  |
| North Carolina       | 21.7                          | 40.9          | 51.3         | –                    |
| North Dakota         | 17.5                          | 24.8*         | 53.9         | 13.1*                |
| Ohio                 | 20.9                          | 36.8          | 50.8         | 10.1                 |
| Oklahoma             | 22.9                          | 48.6*         | 34.0*        | 9.3                  |
| Oregon               | 20.0                          | 36.7          | 55.2         | 6.8                  |
| Pennsylvania         | 20.8                          | 48.3*         | 36.7*        | 12.3*                |
| Rhode Island         | 20.7                          | 36.6          | 52.8         | 7.1                  |
| South Carolina       | 21.3                          | 53.1*         | 33.4*        | 9.4                  |



| States        | Percentage of CYSHCN age 0-17 |               |              |                      |
|---------------|-------------------------------|---------------|--------------|----------------------|
|               | Total population              | Medicaid only | Private only | Medicaid and private |
| South Dakota  | 17.2                          | 28.3          | 53.3         | 15.6*                |
| Tennessee     | 21.6                          | 40.6          | 49.9         | 6.0                  |
| Texas         | 17.4                          | 34.2          | 53.6         | –                    |
| Utah          | 16.2                          | 24.6*         | 64.8*        | –                    |
| Vermont       | 20.7                          | 45.2          | 44.0         | –                    |
| Virginia      | 19.3                          | 32.3          | 61.6*        | –                    |
| Washington    | 19.6                          | 34.8          | 55.4         | 6.5                  |
| West Virginia | 24.0                          | 54.8*         | 28.6*        | 11.5                 |
| Wisconsin     | 19.5                          | 25.5*         | 53.4         | 15.7*                |
| Wyoming       | 18.1                          | 34.0          | 56.4         | –                    |

**Notes:** CYSHCN is children and youth with special health care needs. In most states, the estimates of CYSHCN who had both Medicaid and private coverage or were uninsured were not reliable because the relative standard error was greater than or equal to 30 percent. Thus, those estimates are not reported here.

\* State difference from the U.S. is statistically significant at the 0.05 level to account for the dependent relationship between state and national estimates.

<sup>1</sup> Coverage types do not sum to the total, because the table doesn't display estimates for other coverage.

**Source:** MACPAC analysis of the 2018-2019 National Survey of Children's Health.

**TABLE A-2.** Conditions Reported by Special Health Care Needs Status, 2019

| Health conditions                               | Percentage of children age 0-17 |            |
|---|---------------------------------|------------|
|   | CYSHCN                          | non-CYSHCN |
| <b>Reported behavioral health conditions</b>    |                                 |            |
| Anxiety problems <sup>1</sup>                   | 34.5%                           | 4.4%*      |
| ADD or ADHD <sup>1</sup>                        | 35.4                            | 2.7*       |
| Autism or Autism Spectrum Disorder <sup>1</sup> | 14.1                            | 0.4*       |
| Behavioral or conduct problems <sup>1</sup>     | 30.4                            | 2.5*       |
| Depression <sup>1</sup>                         | 17.8                            | 1.4*       |
| Developmental delay <sup>1</sup>                | 25.3                            | 2.3*       |
| Intellectual disability <sup>1</sup>            | 4.3                             | –          |
| Learning disability <sup>1</sup>                | 25.1                            | 2.5*       |
| Other genetic or inherited condition            | 13.0                            | 1.5*       |
| Substance abuse <sup>2</sup>                    | 0.7                             | –          |
| Speech/other language disorder <sup>1</sup>     | 22.6                            | 5.0*       |
| <b>Other reported conditions</b>                |                                 |            |
| Deafness or problems with hearing               | 3.7                             | 1.0*       |
| Blindness or problems with seeing               | 4.8                             | 1.1*       |
| Allergies                                       | 47.8                            | 20.0*      |
| Arthritis                                       | 1.0                             | 0.1*       |
| Asthma  | 32.4                            | 6.8*       |
| Blood disorders                                 | 1.4                             | 0.3*       |
| Brain injury, concussion, head injury           | 5.9                             | 2.3*       |
| Cerebral palsy                                  | 1.2                             | –          |
| Cystic fibrosis                                 | 0.2                             | –          |
| Diabetes  | 1.7                             | –          |

| Health conditions                         | Percentage of children age 0-17 |            |
|---|---------------------------------|------------|
|   | CYSHCN                          | non-CYSHCN |
| Down syndrome                             | 0.5                             | –          |
| Epilepsy or seizure disorder              | 3.9                             | 0.2*       |
| Frequent or severe headaches <sup>1</sup> | 11.7                            | 3.1*       |
| Heart condition                           | 5.4                             | 1.2*       |

**Notes:** CYSHCN is children and youth with special health care needs. ADD is attention deficit disorder. ADHD is attention deficit hyperactivity disorder.

\* Difference from CYSHCN is statistically significant at the 0.05 level.

<sup>1</sup> Age 3-17

<sup>2</sup> Age 6-17

**Source:** MACPAC analysis of the 2019 National Survey of Children's Health.

