

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

Ensuring access to care for children and youth with special health care needs is especially important because they can have multiple and complex health, developmental, and behavioral health needs.¹ They potentially face greater health and developmental consequences than other children if they do not receive care or if their care is delayed. Coordinating multiple providers and the financial strain of meeting the cost of care may impose a substantial burden on their families.

Medicaid provides comprehensive coverage for eligible children and youth with special health care needs 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.² Like other children under age 21 enrolled in Medicaid, they 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.³

Using data from the 2016 National Survey of Children's Health, in this issue brief we compare the characteristics of children and youth with special health care needs to children and youth without special health care needs, and their use of services and reported barriers by type of health coverage. We find that, in 2016, children and youth with special health care needs:

- were more likely to have Medicaid coverage than children and youth without special health care needs;
- differed with regard to use of services depending on whether they had Medicaid, private coverage, or were uninsured (e.g., although most children and youth with special health care needs who had Medicaid coverage reported a medical visit in the past year, these rates were lower than those with private coverage, but higher than those who were uninsured); and
- reported higher rates of unmet need if they had Medicaid coverage than if they had private coverage, although the children with Medicaid were more likely to report that the program covered benefits and services to meet their needs compared to their privately insured counterparts.

Characteristics of Children and Youth with Special Health Care Needs

Children and youth with special health care needs were more likely than those without special health care needs to be covered by Medicaid, although their rates of Medicaid coverage varied by state (Appendix



Table A-1). They were more likely to report fair or poor health, or fair or poor condition of their teeth. They also were more likely to report having behavioral health conditions or having multiple conditions (Table 1). About three-quarters of children and youth with special health care needs reported having two or more conditions, and almost half reported having both a behavioral health and a non-behavioral health condition (Table 1). The conditions most commonly reported included allergies, asthma, attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), behavioral or conduct problems, and anxiety problems. (For additional detail on conditions reported, see Appendix Table A-2.)

TABLE 1. Children’s Insurance Coverage, Health Status, and Conditions Reported by Special Health Care Needs Status, 2016

| Characteristic | Has special health care needs | No special health care needs |
|--|-------------------------------|------------------------------|
| Insurance coverage | | |
| Medicaid only | 40.6% | 29.6%* |
| Private only | 46.5 | 58.8* |
| Medicaid and private | 7.4 | 3.5* |
| Other | 1.7 | 1.6 |
| Uninsured | 3.8 | 6.5* |
| Health status | | |
| Excellent/very good | 69.8 | 94.5* |
| Good | 23.7 | 4.8* |
| Fair/poor | 6.6 | 0.7* |
| Condition of child's teeth¹ | | |
| Excellent/very good | 65.5 | 81.6* |
| Good | 25.1 | 14.1* |
| Fair/poor | 9.5 | 4.3* |
| Number of reported conditions² | | |
| No conditions | 5.6 | 64.5* |
| One condition | 17.1 | 23.4* |
| Two conditions | 23.1 | 7.8* |
| Three conditions | 15.5 | 2.6* |
| Four or more conditions | 38.7 | 1.7* |
| Reported behavioral health condition² | | |
| Yes | 66.5 | 12.4* |
| No | 33.5 | 87.6* |
| Reported behavioral health condition plus other non-behavioral health condition² | | |
| Yes | 44.8 | 5.6* |
| No | 55.2 | 94.4* |



TABLE 1. (continued)

Notes:

* Difference from children and youth with special health care needs is statistically significant at the 0.05 level.

¹ Excludes children who do not have teeth.

² Reported conditions are based on the response to "has a doctor or other health care provider ever told you that you had..." or "does that child have any of the following...".

Source: MACPAC analysis of the 2016 National Survey of Children’s Health.

Use of Services and Barriers to Care by Insurance Status

Overall, use of services and barriers to care reported by children and youth with special health care needs with Medicaid differs from that of similar children and youth with private-only coverage in each of the four categories we measured: visits during the past 12 months, mental health treatment, usual source of care, and unmet need.

Visits during the past 12 months

Most children and youth with special health care needs who have Medicaid had a medical visit in the last year. These rates were higher than those who were uninsured, but not as high as those with private coverage or those who had both Medicaid and private coverage (Figure 1). Although the majority of Medicaid-covered children and youth with special health care needs reported having a dental visit in the past 12 months, they were also less likely to have had a dental visit than those with private coverage. Medicaid-covered children and youth with special health care needs were more likely than those with private coverage to have two or more emergency room visits; almost 16 percent reported having two or more visits to the emergency room, compared to 5 percent of those with private-only coverage.

FIGURE 1. CYSHCN Visits with Health Care Providers in Past Twelve Months, by Insurance Status, 2016

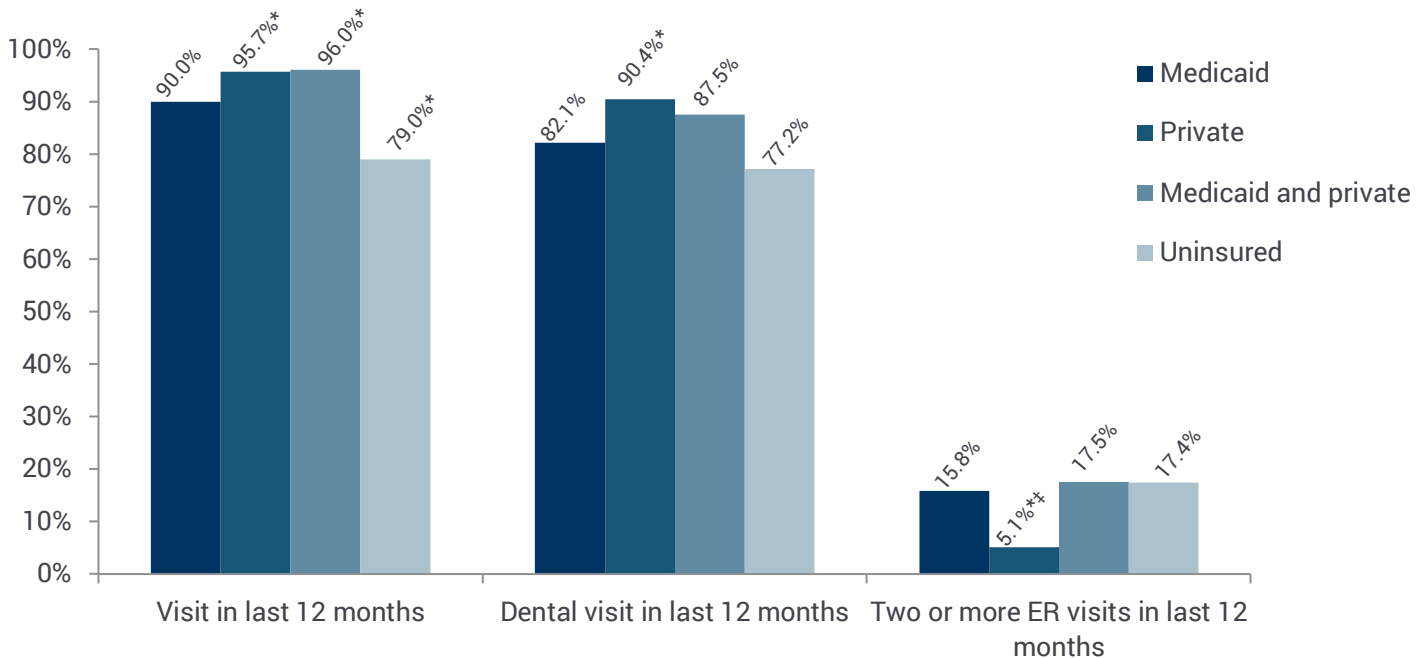


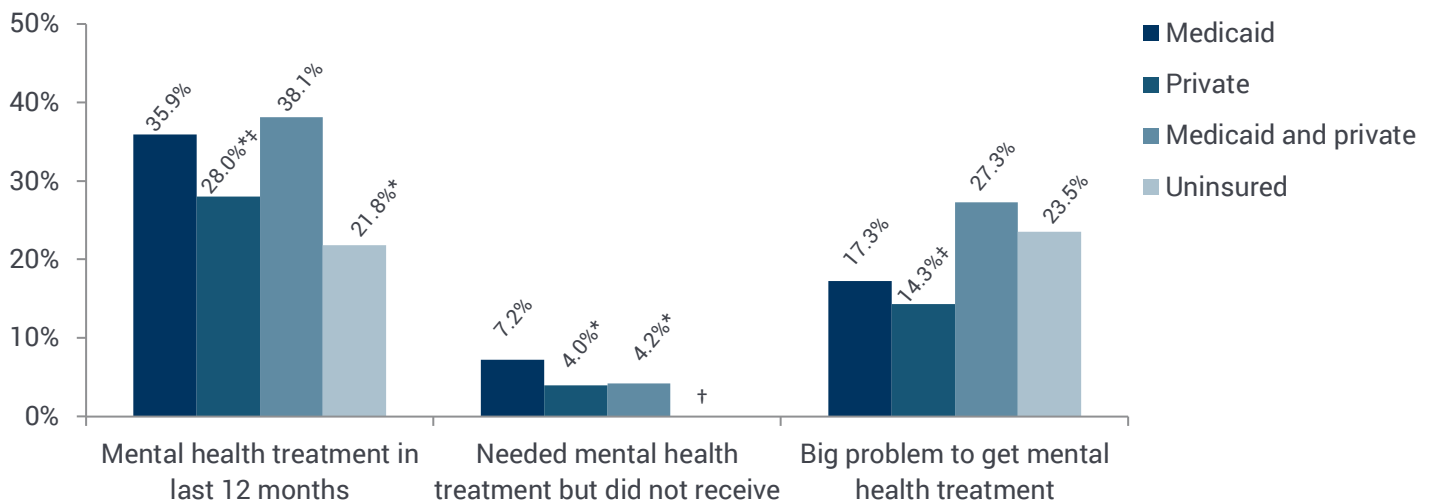
FIGURE 1. (continued)

Notes: CYSHCN is children and youth with special health care needs. ER is emergency room.
 * Difference from Medicaid is statistically significant at the 0.05 level.
 ‡ Difference from Medicaid and private is statistically significant at the 0.05 level.
Source: MACPAC analysis of the 2016 National Survey of Children’s Health.

Mental health treatment

Children and youth with special health care needs with Medicaid were more likely to have mental health treatment in the past 12 months than those who had private coverage or were uninsured (Figure 2). However, those with Medicaid were more likely those with private-only or Medicaid and private coverage to report needing mental health treatment but not receiving it. Children and youth with special health care needs with Medicaid and private coverage were more likely to report that it was a big problem to obtain the mental health services needed when compared to those with private coverage only.

FIGURE 2. CYSHCN Visits for and Problems Getting Mental Health Treatment, by Insurance Status, FY 2016



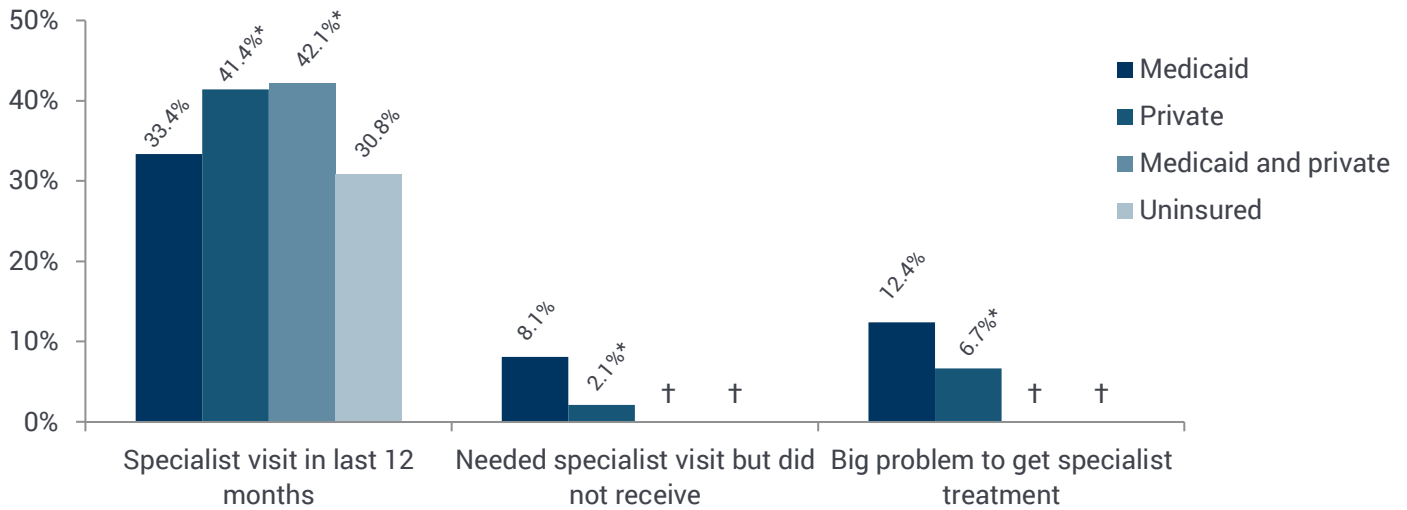
Notes: CYSHCN is children and youth with special health care needs.
 * Difference from Medicaid is statistically significant at the 0.05 level.
 ‡ Difference from Medicaid and private is statistically significant at the 0.05 level.
 † Estimate is unreliable because it has a relative standard error greater than or equal to 30 percent.
Source: MACPAC analysis of the 2016 National Survey of Children’s Health.

Specialty care

Children and youth with special health care needs with Medicaid coverage were less likely than their counterparts with either private-only coverage or private and Medicaid coverage to have seen a specialist in the past 12 months (Figure 3). These children and youth were also more likely to report needing such a

visit but not receiving one and that getting specialist treatment was a big problem compared to similar children and youth with private-only coverage.

FIGURE 3. CYSHCN Visits to and Problems Getting Treatment from a Specialist, by Insurance Status, FY 2016



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

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

† Estimate is unreliable because it has a relative standard error greater than or equal to 30 percent.

Source: MACPAC analysis of the 2016 National Survey of Children’s Health.

Usual source of care

More children and youth with special health care needs with Medicaid reported a usual source of care for both preventive and sick care than those who are uninsured (Table 2). However, those with private coverage reported higher rates of a usual source of care. While children and youth with special health care needs with Medicaid were more likely than those with private coverage to report that someone helped coordinate their care in order to connect them to the services and providers they needed, they also reported that they could use extra help in care coordination.

TABLE 2. Usual Source of Care and Care Coordination among CYSHCN, by Insurance Status, 2016

| Measure | Medicaid only | Private only | Medicaid and private | Uninsured |
|--|---------------|--------------|----------------------|-----------|
| Usual source of care¹ | | | | |
| Preventive care | 92.0% | 97.2%* | 96.1%* | 77.3%* |
| Sick care | 77.2 | 89.3*† | 79.7 | 64.9* |
| Care coordination | | | | |
| Someone helps coordinate care ² | 20.8 | 15.2* | 19.1 | † |



TABLE 2. (continued)

| Measure | Medicaid only | Private only | Medicaid and private | Uninsured |
|---|---------------|--------------|----------------------|-----------|
| Could use extra help coordinating care ³ | 21.8 | 14.6*† | 26.1 | 16.4 |
| Usually got as much help as wanted | 19.5 | 21.8 | 23.5 | † |

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

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

‡ Difference from Medicaid and private is statistically significant at the 0.05 level..

† Estimate is unreliable because it has a relative standard error greater than or equal to 30 percent.

¹ Does not include those who reported the emergency department as their usual source of care for sick care or for preventive care if preventive care location was the same as for medical care.

² Among children with a medical visit.

³ Among children who saw more than one provider.

Source: MACPAC analysis of the 2016 National Survey of Children's Health.

Unmet need

In general, children and youth with special health care needs with Medicaid reported needing care, but not receiving it, at higher rates than those with private-only coverage (Table 3). They were more likely to report that the contributing factors to this unmet need included that the child was not eligible for the services (although under Medicaid's EPSDT requirements, they are entitled to all medically necessary, Medicaid-covered services even if not covered by the state plan). Children and youth with special health care needs with Medicaid-only coverage were more likely to report that the services were not available in their area and that there were problems getting an appointment. In contrast, children and youth with special health care needs who had private coverage were more likely to report that there were issues related to cost.

TABLE 3. Unmet Need and Barriers to Care among CYSHCN, by Insurance Status, 2016

| Measure | Medicaid only | Private only | Medicaid and private | Uninsured |
|--|---------------|--------------|----------------------|-----------|
| Needed, but did not receive care in the last 12 months ¹ | 10.2% | 4.6%* | 6.9% | 15.9% |
| Contributing factors to the child not receiving needed services ² | | | | |
| Not eligible | 55.1 | 21.7* | † | † |
| Not available in area | 50.0 | 24.3* | 35.8 | † |
| Problems getting an appointment | 69.6 | 45.0*‡ | 76.4 | 53.9 |
| Issues related to cost | 43.8 | 70.9* | 56.1 | 65.4 |

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

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

‡ Difference from Medicaid and private is statistically significant at the 0.05 level.

† Estimate is unreliable because it has a relative standard error greater than or equal to 30 percent.

¹ Among all children, not just those who reported that they needed but did not receive care.

² Among children who reported that they needed but did not receive care.

Source: MACPAC analysis of the 2016 National Survey of Children's Health.



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Covered Benefits and Cost of Care, by Insurance Status

Compared to their privately insured counterparts, Medicaid-covered children and youth with special health care needs were more likely to report that the program offered benefits or covered services that met their needs (Table 4). Specifically, children and youth with special health care needs with Medicaid only were more likely than those with private coverage only or Medicaid and private coverage to report that their insurance always offered benefits—including behavioral health benefits—to meet their needs, and allowed them to see the provider they need. Children and youth with special health care needs with Medicaid only were also more likely to report that the costs of services was always reasonable compared to those with private-only coverage and those with Medicaid and private coverage.

TABLE 4. Covered Benefits and Costs among CYSHCN, by Insurance Status, 2016

| Measure | Medicaid only | Private only | Medicaid and private | Uninsured |
|--|---------------|--------------|----------------------|-----------|
| Insurance always offers benefits or covers services that meet child's needs ¹ | 63.9% | 53.8%* | 50.8%* | N/A |
| Insurance always allows child to see provider child needs ¹ | 76.8 | 70.9* | 68.3* | N/A |
| Insurance always offers behavioral health benefits that meet child's needs ² | 63.7 | 40.7* | 49.9* | N/A |
| These costs were always reasonable ³ | 36.8 | 15.8* | 15.8* | † |
| Problems paying medical bills in last 12 months ⁴ | 20.1 | 24.0‡ | 35.8* | 40.0* |

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

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

‡ Difference from Medicaid and private is statistically significant at the 0.05 level.

† Estimate is unreliable because it has a relative standard error greater than or equal to 30 percent.

¹ Among currently insured children.

² Among children who use behavioral health services and are currently insured.

³ Among children who paid for health, dental, or vision care.

⁴ Among children with medical expenses.

Source: MACPAC analysis of the 2016 National Survey of Children's Health.

These data are useful in describing service use by children and youth with special health care needs with Medicaid. They also highlight areas in which these children and youth who have Medicaid coverage have unmet needs and face barriers to accessing services, in particular, mental health treatment and specialty services. Further exploration of these areas could be helpful for identifying opportunities for addressing them. The data also suggest other areas where additional investigation may be warranted, such as why children and youth with special health care needs with Medicaid coverage report lack of eligibility for services or issues related to cost as barriers to care, particularly given the comprehensive coverage and no or low-cost services that Medicaid requires for children.



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Methodology

The National Survey of Children’s Health (NSCH) is funded and directed by the Maternal and Child Health Bureau, Health Resources & Services Administration in the U.S. Department of Health and Human Services. 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>.

The 2016 NSCH combines two periodic surveys, the NSCH and the National Survey of Children with Special Health Care Needs (NS-CSHCN), into a single annual survey. Data from the earlier iteration of the NSCH were collected in 2003, 2007, and 2011–2012; the NS-CSHCN was conducted in 2011, 2005–2006, and 2009–2010. The 2016 NSCH was designed to maintain as many of the original items from both surveys as possible, including the CSHCN Screener (MCHB 2017).

Identifying children and youth with special health care needs

Children and youth were identified as having special health care needs by using the CSHCN Screener. Specifically, a child must report service use associated with a health condition that is expected to last 12 months or longer.

Identifying coverage source

MACPAC typically uses a hierarchy to assign individuals with multiple coverage sources to a primary source; however, a different approach was used with this analysis. Specifically, the NSCH has a considerable Medicaid undercount, and utilizing the hierarchy would exacerbate the undercount. Additionally, after further analysis of their characteristics (e.g., health status and service use), it is not clear whether the children reporting both Medicaid and private coverage are more similar to those reporting one source of coverage (either Medicaid or private coverage). As such, they are reported as a separate group, “Medicaid and private”, instead of as either Medicaid or private.

Defining behavioral health condition

When examining behavioral health conditions among children, this analysis includes the following reported conditions: Tourette syndrome, anxiety problems, depression, other genetic or inherited condition, behavioral or conduct problems, substance abuse, developmental delay, intellectual disability, speech/other language disorder, learning disability, other mental health condition, autism/autism spectrum disorder, and ADD/ADHD.



Endnotes

¹ 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.

² 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/>.

³ 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

Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, U.S. Department of Health and Human Services. 2017. Frequently asked questions: 2016 National Survey of Children’s Health. <https://mchb.hrsa.gov/data/national-surveys/data-user>.

McPherson, M., P. Arrango, H. Fox, et al. 1998. A new definition of children with special health care needs, *Pediatrics* 102: 137–140. <http://pediatrics.aappublications.org/content/102/1/137>



Appendix

TABLE A-1. Coverage Source for Children and Youth with Special Health Care Needs, by State, 2016¹

| State | Total children and youth with special health care needs | Medicaid only | Private only |
|----------------------|---|---------------|--------------|
| United States | 19.4% | 40.6% | 46.5% |
| Alabama | 21.2 | 52.0* | 40.5 |
| Alaska | 15.5* | 37.9 | 49.9 |
| Arizona | 19.7 | 49.5 | 34.9* |
| Arkansas | 23.1 | 60.0* | 28.1* |
| California | 15.6* | 47.6 | 46.4 |
| Colorado | 17.7 | 33.4 | 50.1 |
| Connecticut | 20.4 | 37.1 | 57.1* |
| Delaware | 22.9 | 33.3 | 50.4 |
| District of Columbia | 18.6 | 45.5 | 38.5 |
| Florida | 22.0 | 50.2* | 38.3* |
| Georgia | 19.9 | 51.0 | 35.0* |
| Hawaii | 13.7* | 16.4* | 72.2* |
| Idaho | 17.4 | 33.7 | 47.0 |
| Illinois | 19.7 | 33.4 | 56.8* |
| Indiana | 22.7 | 43.2 | 45.7 |
| Iowa | 17.7 | 34.7 | 47.5 |
| Kansas | 20.5 | 34.8 | 52.3 |
| Kentucky | 25.4* | 51.5* | 40.5 |
| Louisiana | 23.8* | 50.0 | 36.7* |
| Maine | 23.0* | 40.9 | 44.9 |
| Maryland | 18.6 | 32.5 | 57.4* |
| Massachusetts | 20.8 | 24.8* | 58.5* |
| Michigan | 20.2 | 29.4* | 53.1 |
| Minnesota | 17.9 | 30.7* | 54.9 |
| Mississippi | 24.5* | 57.3* | 24.7* |
| Missouri | 22.8 | 30.2* | 52.9 |
| Montana | 18.6 | 54.2* | 34.7* |
| Nebraska | 16.8 | 26.9* | 58.3* |
| Nevada | 15.3* | 38.3 | 44.2 |
| New Hampshire | 19.9 | 25.3* | 58.0* |
| New Jersey | 17.4 | 28.3* | 65.6* |
| New Mexico | 19.9 | 48.2 | 38.4 |
| New York | 18.5 | 36.8 | 44.3 |
| North Carolina | 21.4 | 44.1 | 40.6 |



TABLE A-1. (continued)

| State | Total children and youth with special health care needs | Medicaid only | Private only |
|----------------|---|---------------|--------------|
| North Dakota | 18.0 | 16.8* | 68.5* |
| Ohio | 22.9 | 38.8 | 48.6 |
| Oklahoma | 21.8 | 37.3 | 43.3 |
| Oregon | 18.5 | 32.3 | 52.9 |
| Pennsylvania | 19.1 | 42.7 | 44.7 |
| Rhode Island | 21.5 | 40.2 | 45.3 |
| South Carolina | 20.0 | 51.3* | 32.0* |
| South Dakota | 15.8* | 31.7 | 52.4 |
| Tennessee | 19.0 | 52.9* | 40.8 |
| Texas | 18.4 | 40.2 | 42.4 |
| Utah | 16.5* | 21.2* | 68.2* |
| Vermont | 21.1 | 57.6* | 32.4* |
| Virginia | 21.1 | 28.7* | 64.1* |
| Washington | 18.6 | 36.6 | 49.9 |
| West Virginia | 24.0* | 45.0 | 38.6 |
| Wisconsin | 19.2 | 30.7* | 56.1* |
| Wyoming | 20.3 | 29.7* | 54.2 |

Notes: In most states, the estimates of children and youth with special health care needs 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.

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

Source: MACPAC analysis of the 2016 National Survey of Children's Health.



TABLE A-2. Conditions Reported by Special Health Care Needs Status, 2016

| Condition | Children and youth with special health care needs | Children and youth without special health care needs* |
|---------------------------------------|---|---|
| Allergies | 47.6% | 19.6% |
| Asthma | 34.7 | 7.0 |
| ADD/ADHD | 33.6 | 2.4 |
| Behavioral or conduct problems | 31.3 | 2.5 |
| Anxiety problems | 24.7 | 2.9 |
| Learning disability | 24.0 | 1.9 |
| Developmental delay | 23.3 | 1.8 |
| Speech/other language disorder | 20.6 | 4.1 |
| Other mental health condition | 20.4 | 1.0 |
| Depression | 14.1 | 1.0 |
| Other genetic or inherited condition | 12.0 | 1.0 |
| Autism/Autism spectrum disorder | 11.0 | 0.4 |
| Frequent/severe headaches | 10.0 | 2.8 |
| Brain injury, concussion, head injury | 6.7 | 2.3 |
| Heart condition | 6.2 | 1.4 |
| Deafness/problems with hearing | 4.6 | 0.6 |
| Intellectual disability | 4.6 | † |
| Blindness/problems with seeing | 4.1 | 1.0 |
| Epilepsy or seizure disorder | 3.6 | 0.3 |
| Blood disorders | 2.1 | 0.5 |
| Diabetes | 1.8 | † |
| Cerebral palsy | 1.5 | † |
| Arthritis | 1.1 | 0.2 |
| Down syndrome | 0.7 | † |
| Substance abuse | 0.7 | † |
| Tourette syndrome | 0.6 | 0.1 |
| Cystic fibrosis | 0.1 | † |

Notes: ADD is attention-deficit disorder. ADHD is attention-deficit hyperactivity disorder. Deafness and blindness are based on the response to "does that child have any of the following..." All other reported conditions are based on the response to "has a doctor or other health care provider ever told you that you had...". The question regarding substance abuse is only asked of 6- to 17-year-olds. * Difference between all conditions with reliable estimates and children and youth with special health care needs are statistically significant from at the 0.05 level.

† Estimate is unreliable because it has a relative standard error greater than or equal to 30 percent.

Source: MACPAC analysis of the 2016 National Survey of Children's Health.