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

One in five children and youth have special health care needs (CYSHCN), and access to timely care is important for this population because they can experience adverse social-emotional and health outcomes due to delayed or missed care. CYSHCN include individuals with a wide range of health care needs, including physical, mental and behavioral health conditions, and levels of limitations (Validova et al. 2023, Ghandour et al. 2022, Abdi et al. 2020, McPheeters et al. 2014).[1] Recent research about these populations shows that regardless of payer, most CYSHCN are not receiving the care, services, or support they need (McLellan et al. 2022, Schiff et al. 2022). For example, only one in five CYSHCN receive care in a well-functioning system that includes family partnership, adequate insurance, easy access to services, and preparation for transition to adult care (Ghandour et al. 2022).[2] A lack of support and transition preparation can lead to loss of coverage, discontinuity of care, problems with treatment and medication adherence, higher care costs, higher emergency department use, and excess morbidity, and mortality (Flanagan et al. 2022, White et al. 2018).

Almost half of CYSHCN are covered by Medicaid or a combination of Medicaid and private insurance. These children and youth may be eligible for Medicaid on the basis of a disability, such as through Supplemental Security Income (SSI) pathways, a low-income pathway, or a buy-in program.[3] Like all children under the age of 21 enrolled in Medicaid, CYSHCN 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.[4]

When CYSHCN age out of Medicaid child eligibility categories and pediatric care, they must transition to adult health coverage and care. These transitions are multi-step processes and involve the beneficiary, their family, and caretakers, and can begin several years prior to the child turning 18 (White et al. 2018). Research shows that beneficiaries and their families often receive little to no transition assistance or planning when transitioning to adult coverage and care, and experience barriers due to insufficient preparedness and lack of infrastructure support (e.g., care coordination, community resources, and finding adult providers and specialists). These barriers can lead to beneficiaries experiencing delays in transition, discontinuity of care, loss of coverage, medical complications, and poor health outcomes (Validova et al. 2023, Flanagan et al. 2022, Okumura et al. 2022, White et al. 2018, Gabriel et al. 2017, Sawacki et al. 2017).

In this issue brief, we used data from the 2021-2022 National Survey of Children's Health (NSCH), which surveys parents of children ages 0–17 years. We examined differences in reported health status, access to care, referrals, needed care, the cost of care, and transition preparedness between Medicaid-covered CYSHCN and those covered by private insurance, both Medicaid and private insurance, and those without insurance. Additionally, we compared transition preparedness for Medicaid-covered CYSHCN with a range of medical complexities and functional limitations. All analyses are descriptive and do not adjust for socioeconomic or other factors that may also be associated with differences, or attempt to establish the reasons for these differences.

Our findings show that Medicaid-covered CYSHCN had different experiences with accessing health care and other health-related services, as well as out-of-pocket costs compared to those with private insurance, both Medicaid and private coverage, and those who are uninsured. For example, Medicaid-covered CYSHCN were more likely to get needed care coordination compared to those with both Medicaid and private coverage. Additionally, they were more likely to report that their needs were met than those covered by private insurance

only and those covered by both Medicaid and private insurance. However, Medicaid-covered CYSHCN were less likely than those covered by private insurance only and those with both coverage types to have a personal doctor or nurse.

Our findings related to transition preparation indicate many similarities in experiences of CYSHCN across all insurance types and health conditions and limitations, with some notable differences. For example, across all insurance types, almost half of parents of CYSHCN know what health insurance their child will have as an adult. However, those with Medicaid-covered CYSHCN were less likely to know what health insurance their child will have as an adult than parents of those covered by private insurance only and those covered by both Medicaid and private insurance. Additionally, there were differences between CYSHCN with different health conditions and limitations. For example, CYSHCN with medication needs and no functional limitations were less likely to have a plan of care that addresses the transition to adult providers than CYSHCN with mental or behavioral health conditions and functional limitations.

Demographic Characteristics of Children and Youth with Special Health Care Needs

There are several demographic differences between CYSHCN and non-CYSHCN. CYSHCN are more likely to be ages 6–11 and 12–17 than non-CYSHCN (Table 1). Additionally, this population is more likely to be white, non-Hispanic, and Black, non-Hispanic than non-CYSHCN. Further, CYSHCN are more likely to be covered by Medicaid only or by both Medicaid and private insurance than non-CYSHCN. CYSHCN are also more likely to receive SSI and receive SSI because of a disability than non-CYSHCN.

Parents of CYSHCN reported education and income levels that are different from those reported by parents of children without special health care needs. For example, parents of CYSHCN are less likely to have a college degree or higher than parents of non-CYSHCN. Additionally, parents of CYSHCN are significantly less likely to have income at 400 percent of the Federal Poverty Level (FPL) or higher and more likely to have income below 138 percent of the FPL than parents of children without special health care needs. Parents of CYSHCN are more likely to receive food stamps and cash assistance from the government than parents of non-CYSHCN.

TABLE 1. Selected Demographic and Socioeconomic Characteristics of Children (Ages 0–17), 2022

Demographic characteristics	CYSHCN	non-CYSHCN
Age		
0–5	17.0%	34.4%*
6–1	35.0	33.0*
12–17	48.1	32.6*
Health insurance		
Private only	50.6	59.9*
Medicaid only	37.2	28.5*
Private and Medicaid	7.6	4.3*
Uninsured	4.7	7.3*
SSI status		
Does the child receive SSI	6.4	1.3*
Does the child receive SSI because of a disability	4.6	0.1*
Sex		
Male	55.0	50.3*
Female	45.1	49.7*

Demographic characteristics	CYSHCN	non-CYSHCN
Highest education of adult in child's household		
Less than high school	7.5	8.8
High school or GED	19.7	18.3
Some college or technical school	22.5	19.4*
College degree or higher	50.4	53.5*
Race and ethnicity		
Hispanic	23.8	27.8*
White, non-Hispanic	50.4	47.2*
Black, non-Hispanic	15.3	11.8*
Asian, non-Hispanic	2.2	5.6*
Primary language		
English	90.3	83.6*
Spanish	6.9	10.9*
Other language	2.8	5.5*
Family income		
Has income less than 138 percent FPL	29.0	24.8*
Less than 100 percent FPL	21.0	17.8*
100–199 percent FPL	21.2	19.2*
200–399 percent FPL	27.3	28.7
400 percent FPL or higher	30.6	34.3*
Other benefits programs		
Family receives WIC benefits	9.4	10.4
Family receives cash assistance from government	6.0	4.3*
Family receives food stamps	25.2	17.2*

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. SSI is Supplemental Security Income. GED is General Education Development. *Difference from CYSHCN is statistically significant at the 0.05 level.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Health Characteristics of Children and Youth with Special Health Care Needs

Almost three-quarters of Medicaid-covered CYSHCN reported having very good or excellent health, but their health status differed from non-CYSHCN. For example, CYSHCN are less likely to report very good or excellent health and more likely to report fair or poor health than non-CYSHCN (Table 2). Additionally, CYSHCN oral health differed from those without special health care needs. For example, this population is more likely to report having one or more oral health problems and less likely to report that their teeth are in very good or excellent condition than non-CYSHCN.

CYSHCN experience a range of physical and behavioral health conditions and limitations, with nearly 40 percent reporting having four or more conditions that can require different levels of treatment. For example, over 30 percent of Medicaid-covered CYSHCN reported behavioral or conduct problems or having a learning disability, and 20 percent reported having depression (Appendix A-2). Further, Medicaid-covered CYSHCN were more likely

to have a behavioral or conduct problem, a developmental delay, anxiety problems, and heart condition than non-CYSHCN (Appendix A-2).

TABLE 2. Medicaid-Covered Children's Health Status, Conditions, and Limitations by Special Health Care Needs Status (Ages 0–17), 2022

Health measures	Total	CYSHCN	Non-CYSHCN
Health status			
Very good/excellent	**89.9%**	74.0%	94.1%*
Good	**8.8**	21.5	5.4*
Fair/poor	**1.3**	4.5	0.5*
Condition of children's teeth			
Excellent/very good	**77.5**	65.7	80.7*
Good	**16.9**	23.8	15.0*
Fair/poor	**5.6**	10.5	4.3*
Oral health problems			
One or more oral health problems	**14.4**	19.5	13.0*
Number of reported conditions			
No conditions	**51.6**	6.2	63.6*
1 condition	**21.9**	16.2	23.4*
2 conditions	**11.3**	22.1	8.4*
3 conditions	**5.8**	17.2	2.9*
4 or more conditions	**9.4**	38.4	1.7*

Notes: CYSHCN is children and youth with special health care needs. See Appendix A-2 for a full list of conditions.
*Difference from CYSHCN is statistically significant at the 0.05 level.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Experiences with Accessing and Using Care

In the analysis below, we compare measures of health service use, quality of care, unmet service needs, and the barriers to accessing this care in the last 12 months for CYSHCN across insurance types.

Usual source of care and health service use in the past 12 months

In the past 12 months, across coverage types, more than 90 percent of CYSHCN had a medical visit and over 80 percent had a usual source of care, but there were several differences in accessing health care services among coverage types (Table 3). For example, Medicaid-covered CYSHCN were less likely than CYSHCN with private insurance only and those covered by both Medicaid and private insurance to have a personal doctor or nurse. Additionally, Medicaid-covered CYSHCN were less likely to visit a specialist in the past 12 months than those covered by private insurance only. Lastly, Medicaid-covered CYSHCN were more likely to go to the emergency room in the past 12 months than those with any other insurance type.

There were differences in reported access to care coordination and other health care services between Medicaid-covered CYSHCN and those with other insurance types. For example, Medicaid-covered CYSHCN were more likely to get needed care coordination than those with both Medicaid and private insurance. Medicaid-covered CYSHCN were less likely to receive care coordination, and ongoing and comprehensive care in a medical home than CYSHCN with private insurance only. Further, parents of Medicaid-covered CYSHCN were more likely to

provide at-home health care for 11 hours or more a week than parents of CYSHCN covered by private insurance only, but less likely than parents of CYSHCN with both Medicaid and private insurance.

TABLE 3. Health Care Use for Children and Youth with Special Health Care Needs (Age 0–17) by Insurance Status, 2022

Service use measures	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
Service use in the past 12 months					
Medical visit	**91.4%**	91.3%	93.9%*	93.8%	61.6%*
Preventive medical visit (at least one visit)	**87.1**	87.0	90.3*	87.4	52.5*
Specialist visit	**87.0**	82.9	90.3*	87.6	73.5
Vision test	**60.7**	61.5	61.2	62.5	47.3*
Has a doctor or nurse or health professional	**77.6**	71.6	84.4*	82.1*	44.9*
Usual source for sick care and preventive care	**80.9**	73.6	88.4*	86.7*	48.0*
Received family-centered care	**74.6**	71.3	79.7*	77.8*	41.0*
Dental/oral health visit (at least one visit)	**85.8**	81.7	90.0*	89.0*	66.6*
Preventive dental visits	**96.2**	94.1	97.5*	97.6*	94.1
ER visit	**24.4**	33.0	18.5*	25.8*	18.3*
Hospital admission	**7.1**	9.2	4.9*	12.1	—
Use of alternative health care or treatment	**10.1**	6.9	11.1*	15.4*	—
Received needed mental health treatment or counseling	**83.5**	80.6	86.1*	85.4	74.6
Care coordination					
Received needed care coordination	**65.9**	66.3	66.0	57.2*	75.6
Family needed extra help coordinating child's health care in last 12 months	**23.2**	24.5	21.0	32.2*	20.9
Other service use					
Received special services to meet developmental needs	**29.3**	33.8	24.4*	42.9*	23.6
Received coordination, ongoing, comprehensive care within a medical home	**38.3**	31.1	45.6*	34.8	22.6
Child received effective care coordination	**65.9**	66.3	66.0	57.2*	75.6
Currently received services under a special education or early intervention plan	**30.9**	33.1	28.1*	42.0*	26.2
Time spent providing at home health care for child					
Less than 1 hour per week	**13.5**	8.4	16.2*	15.2*	—
1-4 hours per week	**8.7**	8.8	8.8	11.0	—
5-10 hours per week	**3.3**	4.6	2.4*	4.4	—

Service use measures	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
11 hours or more per week	**5.6**	8.2	2.8*	13.8*	—
Child does not need health care provided on weekly basis	**68.8**	70.0	69.9	55.6*	69.0
Time spent coordinating health care for children who needed it					
Less than 1 hour per week	**20.9**	16.9	23.2*	25.3*	—
1-4 hours per week	**9.3**	10.2	8.2	15.0*	—
5-10 hours per week	**1.5**	—	0.8*	2.5	—
11 hours or more per week	**2.0**	2.9	0.7*	5.6	—
Child does not need health care provided on weekly basis	**66.3**	67.7	67.0	51.7*	70.6

Notes: CYSHCN is children and youth with special health care needs. ER is emergency room.
*Difference from Medicaid only is statistically significant at the 0.05 level.

– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Quality of care, unmet service needs, and barriers to care

Across payers, CYSHCN reported similar experiences with unmet service needs and barriers to accessing these services, but they reported differences in difficulty obtaining needed care. Over 80 percent of all parents of CYSHCN reported usually or always feeling partnered with doctors in shared decision making for their child's health (Table 4). Additionally, over half of all CYSHCN had no difficulty getting specialty care, if needed, regardless of payer. However, Medicaid-covered CYSHCN were more likely to not receive needed care in the past 12 months than those covered by private insurance only. Additionally, parents with Medicaid-covered CYSHCN were less likely to report being frustrated some of the time in their efforts to get services for their child than parents of CYSHCN who are covered by both Medicaid and private insurance and more likely than those who are uninsured.

Over half of CYSHCN, regardless of insurance type, found it somewhat or very difficult to get needed mental health care. However, Medicaid-covered CYSHCN were more likely to report no difficulties finding mental health care than CYSHCN covered by private insurance only and those covered by Medicaid and private insurance.

TABLE 4. Unmet Need and Quality of Care for Children and Youth with Special Health Care Needs (Ages 0–17) by Insurance Status, 2022

Unmet need and quality measures	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
How difficult was it to get the child's needed mental health care?[1]					
No difficulties	**41.2%**	46.3%	37.9%*	33.4%*	48.8%
Somewhat/very difficult	**54.2**	48.0	58.7*	64.3*	35.7
Not possible to obtain care	**4.6**	5.7	3.4	—	—
How much of a problem was it to get the specialist care that the child needed?[2]					
No difficulties	**61.4**	60.8	63.5	55.5	47.3
Somewhat/very difficult/not possible to obtain care	**38.6**	39.2	36.5	44.5	52.7

Unmet need and quality measures	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
Difficulties getting referrals to see any doctors or receive any services in the past 12 months					
Did not need a referral	**62.4**	59.2	64.9*	56.1	70.0
Did not have any difficulties	**26.1**	27.5	25.0	28.2	22.5
Somewhat/very difficult	**11.6**	13.4	10.0*	15.7	–
How much of a problem was it to get the referral?[3]					
No difficulties	**69.3**	67.3	71.4	64.2	75.1
Somewhat/very difficult	**30.0**	31.6	28.0	35.7	–
How often were you frustrated in efforts to get services for the child?					
Usually or always	**9.7**	10.8	7.9*	11.4	17.8
Sometimes	**34.9**	36.4	33.3	42.9*	25.7*
Never	**55.5**	52.8	58.8*	45.7*	56.5
Unmet need					
Needed, but did not receive care in last 12 months	**8.4**	9.5	7.0*	11.5	–
Which of the following contributed to the child not receiving needed services[4]					
Not eligible	**23.2**	24.2	18.1	41.7	–
Not available in area	**40.0**	39.9	40.7	51.1	–
Problems getting an appointment	**68.3**	65.9	71.7	75.6	–
Transportation/child care problems	**17.8**	21.9	9.3*	–	–
Office wasn't open when care needed	**20.3**	19.3	16.7	38.1	–
Issues related to cost	**46.8**	41.1	47.4	48.0	–
Quality of care					
Doctor spoke with child without guardian or caregiver in the room	**59.2**	57.4	60.9	55.6	57.3
Doctor asked about parental concerns about child's learning, development, or behavior (0-5 year-old child)	**59.7**	59.9	57.2	69.1	–
Family usually or always feels partnered in shared decision-making for child's health	**83.2**	83.7	83.6	85.3	56.4*
Receives care in a well-functioning system	**13.6**	15.3	13.4	15.0	–

Notes: CYSHCN is children and youth with special health care needs.
*Difference from Medicaid only is statistically significant at the 0.05 level.
– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.
[1] Among children who needed or had treatment or counseling.
[2] Among children that needed or had a specialist visit.
[3] Among children who got a referral.
[4] Among children who needed but did not receive care.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Insurance Coverage Adequacy and Cost of Care

In the past 12 months, across all payers, over 90 percent of CYSHCN were consistently insured and their current insurance coverage met their needs, but with some differences (Table 5). For example, Medicaid-covered CYSHCN were more likely to report that their current insurance allowed them to see needed providers and have their needs met than those covered by private insurance only and those covered by both Medicaid and private insurance. Additionally, parents of Medicaid-covered CYSHCN were less likely to avoid changing jobs because of concerns maintaining insurance coverage than parents of CYSHCN covered by private insurance only and those covered by both Medicaid and private insurance.

Parents of Medicaid-covered CYSHCN were more likely to have no out-of-pocket costs than those with CYSHCN covered by other payers, but they also reported challenges with paying medical bills. For example, parents of Medicaid-covered CYSHCN were more likely to report having trouble paying for their child's medical bills in the past 12 months compared to those covered by private insurance only.

TABLE 5. Out of Pocket Costs and Covered Benefits for Children and Youth with Special Health Care Needs (Ages 0–17) by Insurance Status, 2022

Cost measures in the past 12 months	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
Health insurance coverage					
Consistently insured throughout the past year	**93.5%**	97.6%	98.3%	99.6%*	—
Currently uninsured or had periods without coverage	**6.5**	—	1.7	—	100.0%*
Current insurance coverage					
Meet child's needs	**91.0**	94.5	88.5*	90.7*	—
Allows children to see needed providers	**93.4**	94.9	92.6*	91.0*	—
Out-of-pocket expenses are reasonable	**52.4**	56.4	51.6	52.0	—
Current insurance coverage is adequate[1]	**65.4**	84.3	51.9*	62.6*	—
Avoided changing jobs because of concerns about maintaining health insurance for child	**13.2**	7.2	16.2*	25.9*	—
Problems paying for any of child's medical or health care bills	**24.1**	30.5	21.3*	28.7	50.1*
Current insurance for mental/behavioral health					
Always adequate	**51.6**	61.6	43.6*	52.6*	—
Usually adequate	**29.0**	27.5	30.5	26.6	—
Sometimes or never adequate	**19.4**	10.9	25.9*	20.8*	—
What were your out-of-pocket costs for child's medical, health, dental, and vision care in last 12 months?					
$0	**35.3**	74.8	5.3*	31.4*	54.9*
$1-$249	**16.3**	14.6	16.6	26.3*	—
$250-$499	**12.4**	4.2	18.5*	12.7*	10.6*

Cost measures in the past 12 months	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
$500-$999	**11.9**	3.7	18.3*	9.5*	—
$1,000-$5,000	**19.0**	2.1	32.6*	16.0*	10.1*
More than $5,000	**5.1**	0.6	8.6*	4.2*	—

Notes: CYSHCN is children and youth with special health care needs.
*Difference from Medicaid only is statistically significant at the 0.05 level.
– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.
[1] 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.
[2] Among those who paid for health, dental, or vision care.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Transition Preparation

In this section, we present findings on how CYSHCN experience the transition process.[5] The categories of children and youth included in this analysis are those with medication needs with and without functional limitations, complex physical conditions with and without functional limitations, and mental and behavioral conditions with and without functional limitations.[6]

Transition planning

Across all payers, although almost half of parents reported knowing how their child will be covered as an adult, there were several differences between the transition preparation experience of Medicaid-covered CYSHCN and those with other insurance types (Table 6). For example, parents of Medicaid-covered CYSHCN were less likely to know what health insurance their child will have as an adult than CYSHCN covered by private insurance only and by both Medicaid and private insurance. Medicaid-covered CYSHCN were more likely to have a health care provider actively work with them to understand their health care changes at age 18 than CYSHCN covered by private insurance only. However, Medicaid-covered CYSHCN were less likely to have health care providers create a plan of care to meet their health goals than CYSHCN covered by both Medicaid and private insurance.

TABLE 6. Transition Preparedness for Children and Youth with Special Health Care Needs (Ages 0–17) by Insurance Status, 2022

Transition measures in the last 12 months	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
Health insurance transition					
The parent knows how the child will be covered as an adult	**47.7%**	30.5%	59.9%*	52.1%*	32.0%
Someone has discussed with the parent how to keep the child's health insurance when they become an adult	**5.7**	4.8	6.2	—	—
Transition planning					
Child receives services need for transition to adult health care[1]	**23.1**	24.6	23.4	20.3	—

Transition measures in the last 12 months	Total CYSHCN	Medicaid only	Private only	Medicaid and private	Uninsured
Child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs	**40.4**	42.0	39.0	52.9*	29.4
You and this child have access to this plan of care	**94.5**	92.8	95.1	97.3*	96.0
Someone has talked with you about when this child will need to see doctors or other health care providers who treat adults	**23.9**	23.2	24.3	21.6	—
Child's health care provider actively worked with this child to understand the changes in health care that happen at age 18	**44.5**	51.2	40.2*	45.1	42.4
Does this plan of care address transition to doctors and other health care providers who treat adults?[2]					
Yes	**31.6**	36.3	28.8	32.0	—
No	**54.9**	50.5	56.7	58.2	64.2
No, this child has already seen providers who treat adults	**13.4**	13.2	14.5	9.8	—
Children with special health care needs who receive care in a well-functioning system	**13.6**	15.3	13.4	15.0	—

Notes: CYSHCN is children and youth with special health care needs.
*Difference from Medicaid only is statistically significant at the 0.05 level.
– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.
[1] Age 12–17.
[2] Among those who have a transition plan.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Medicaid-covered CYSHCN health conditions and functional limitations

Across all health conditions and functional limitations, less than 25 percent of Medicaid-covered CYSHCN received needed transition services, but there were some reported differences in received services between these groups (Table 7). For example, parents of CYSHCN with medication needs and no limitations were more likely to have a doctor talk to them about when their child will need to see adult providers than parents of CYSHCN with mental or behavioral health conditions and no limitations. Additionally, CYSHCN with medication needs and no limitations were less likely to have a plan of care that addresses transition to adult providers than CYSHCN with mental or behavioral health conditions and limitations.

TABLE 7. Transition Preparedness for Medicaid-Covered Children and Youth with Special Health Care Needs (Ages 0–17) by Conditions and Limitations, 2022

Transition measures in the past 12 months	Children with ongoing medication needs, no limitations	Children with complex physical conditions, no limitations	Children with mental or behavioral conditions, no limitations	Children with complex physical conditions and limitations	Children with mental or behavioral conditions and limitations
Health insurance transition					
The parent knows how the child will be covered as an adult	26.5%	25.6%	29.3%	32.3%	31.6%
Transition planning					
Child received services needed for transition to adult health care[1]	23.1	23.2	24.3	—	20.9
Child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs	38.5	47.2	41.4	47.3	43.3
You and this child have access to this plan of care	98.5	91.8	94.3	—	86.1*
Someone has talked with you about when this child will need to see doctors or other health care providers who treat adults	33.8	18.5	16.9*	—	21.0
Child's health care provider actively worked with this child to understand the changes in health care that happen at age 18	59.1	50.4	49.7	34.7*	38.2*
Children with special health care needs who receive care in a well-functioning system	16.0	16.1	16.4	14.7	12.5
Does this plan of care address transition to doctors and other health care providers who treat adults?[2]					
Yes	44.5	32.5	31.6	—	30.4
No	39.0	53.9	52.0	—	60.4*
No, this child has already seen providers who treat adults	16.6	13.6	16.4	—	—

Notes: CYSHCN is children and youth with special health care needs.
*Difference from children with ongoing medication needs and no limitations is statistically significant at the 0.05 level.
– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.
[1] Age 12–17.
[2] Among those who have a transition plan.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

Methodology

The NSCH is funded and directed by the Maternal and Child Health Bureau (MCHB) of the Health Resources & Services Administration in the U.S. Department of Health and Human Services. Respondents are the parents or guardians 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 MCHB'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 (CAHMI 2024). Medicaid coverage was defined as those reporting 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.

Identifying children and youth with medical complexities and functional limitations

Our analyses used categories related to the children and youth's specific medical needs and functional limitations that were developed by a team at the PolicyLab at the Children's Hospital of Philadelphia. They developed six population categories based on medical complexity for physical and behavioral health conditions and functional limitations using questions about the child's needs from the NSCH children with special health care needs screener. These categories allow analyses to differentiate between children with less complex needs and those with significant limitations that require more intensive care (Validova et al. 2023).[7]

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] The National Survey of Children's Health defines a well-functioning system with five measures for children age 0-11 years, and six measures for children age 12-17 years. Those five measures for children age 0-11 years include: the family feels like a partner in their child's care, child has a medical home, child receives medical and dental preventive care, child has adequate and continuous insurance, and child has no unmet need or barriers to access services. For adolescents age 12-17 years, preparation for transition to adult healthcare is included in addition to the five measures for younger children (NSCH 2024)

[3] 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)). Children with

disabilities can also be covered under the Katie Beckett option or through a buy-in program. 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/.

[4] 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.

[5] Transitions are a multi-step process of moving from a pediatric to an adult model of health care and are the purposeful, planned shift from child-centered to adult-oriented providers, settings, and content of visits to provide comprehensive, age-appropriate care (Flanagan et al. 2022).

[6] A child has functional limitations if they are prevented, in any way, in their ability to do things most children of the same age can do. The methods used to determine these categories were developed by the PolicyLab at the Children's Hospital of Philadelphia (Validova et al. 2023).

[7] The following survey questions were used to define a child's health care needs status: (1) Does this child currently need or use medicine prescribed by a doctor, other than vitamins? (2) Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age? (3) Does this child need or get special therapy, such as physical, occupational, or speech therapy? (4) Does this child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling? (5) Is this child limited or prevented in any way in their ability to do the things most children of the same age can do? (Validova et al. 2023)

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APPENDIX A

TABLE A-1. Coverage Source for Children and Youth with Special Health Care Needs (0–17), by State, 2021-2022[1]

State	Total CYSHCN	Medicaid only	Private only	Medicaid and private
All States	**20.2%**	**37.9%**	**50.5%**	**7.2%**
Alabama	**22.6**	42.6	44.7	8.0
Alaska	**18.6**	22.4*	52.0	15.9*
Arizona	**20.4**	38.8	48.0	9.7
Arkansas	**25.5**	53.0*	32.1*	8.3
California	**15.9**	35.2	53.2	6.8
Colorado	**21.2**	32.0*	56.5*	8.1
Connecticut	**24.1**	33.5	58.0*	—
Delaware	**22.4**	36.3	49.1	9.8
District of Columbia	**19.6**	41.4	51.5	—
Florida	**23.5**	41.5	46.4	4.2*
Georgia	**21.1**	41.6	45.2	6.5
Hawaii	**14.5**	31.0	60.0*	6.3
Idaho	**18.7**	36.8	49.6	11.4
Illinois	**18.5**	28.5*	63.8*	—
Indiana	**23.0**	41.9	44.6	9.7
Iowa	**19.3**	40.2	48.4	9.8
Kansas	**22.0**	30.6*	58.6*	9.4
Kentucky	**23.6**	47.7*	45.7	5.5
Louisiana	**25.0**	49.1*	37.2*	8.7
Maine	**24.3**	38.8	48.9	10.1
Maryland	**18.6**	32.3	60.7*	—
Massachusetts	**24.1**	33.4	59.7*	6.0
Michigan	**20.5**	33.9	51.5	13.2*
Minnesota	**19.3**	25.8*	62.2*	9.3
Mississippi	**22.9**	48.3*	39.3*	8.8
Missouri	**21.0**	37.5	51.8	—
Montana	**23.5**	48.9*	41.0*	7.1
Nebraska	**17.5**	26.6*	60.9*	8.1
Nevada	**16.8**	33.8	55.8	7.3
New Hampshire	**24.6**	27.5*	62.9*	8.2
New Jersey	**17.6**	26.9*	65.8*	—
New Mexico	**21.6**	50.4*	37.3*	7.6
New York	**18.6**	45.0*	48.5	4.2*
North Carolina	**22.7**	45.2*	48.0	5.1
North Dakota	**20.9**	25.5*	56.2	12.4
Ohio	**22.1**	40.8	47.8	7.3
Oklahoma	**23.0**	46.5*	40.6*	8.3

State	Total CYSHCN	Medicaid only	Private only	Medicaid and private
Oregon	**20.6**	35.4	54.0	8.5
Pennsylvania	**22.3**	38.1	43.8*	16.9*
Rhode Island	**21.3**	34.2	54.1	8.4
South Carolina	**22.9**	48.7*	36.6*	12.0*
South Dakota	**20.1**	30.6*	53.1	9.3
Tennessee	**21.1**	40.3	43.9*	10.2
Texas	**18.3**	38.7	48.0	—
Utah	**16.7**	12.1*	71.6*	9.4
Vermont	**25.1**	41.7	45.6	9.4
Virginia	**20.7**	32.9	60.7*	4.1*
Washington	**20.5**	23.2*	65.1*	9.3
West Virginia	**24.4**	46.9*	38.5*	10.4
Wisconsin	**19.3**	36.8	45.2	16.1*
Wyoming	**20.1**	30.1*	54.6	8.6

Notes: CYSHCN is children and youth with special health care needs. In most states, the estimates of CYSHCN who 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 does not display estimates for other coverage.

Source: MACPAC, 2024, analysis of the 2021-2022 National Survey of Children's Health.

TABLE A-2. Conditions Reported by Special Health Care Needs Status (Ages 0–17), 2022

Conditions	Total CYSHCN	CYSHCN	non-CYSHCN
Reported conditions			
Deafness/problems with hearing	**1.2%**	3.7%	0.5%*
Blindness/problems with seeing	**1.8**	4.3	1.2*
Allergies	**27.1**	46.0	22.1*
Autoimmune disease	**0.9**	3.4	0.2*
Asthma	**10.1**	24.7	6.3*
Blood disorders	**0.6**	1.5	0.3*
Brain injury, concussion, head injury[1]	**2.9**	5.8	2.1*
Cerebral palsy	**0.3**	1.0	—
Diabetes	**0.2**	0.6	—
Down Syndrome	**0.3**	1.2	—
Epilepsy or seizure disorder	**1.0**	3.4	0.4*
Heart condition	**2.6**	6.3	1.6*

Conditions	Total CYSHCN	CYSHCN	non-CYSHCN
Frequent/severe headaches	**3.7**	8.8	2.2*
Tourette syndrome	**0.2**	0.7	0.1*
Anxiety problems	**11.9**	37.2	4.4*
Depression	**5.7**	20.0	1.4*
Other genetic or inherited condition	**4.5**	15.0	1.8*
Behavioral or conduct problems	**8.9**	31.1	2.3*
Developmental delay	**7.7**	25.8	2.2*
Intellectual disability	**1.3**	5.2	0.1*
Speech/other language disorder	**9.4**	23.7	5.1*
Learning disability	**8.5**	27.0	2.9*
Autism/Autism Spectrum Disorder	**3.8**	14.2	0.7*
ADD/ADHD	**11.4**	37.2	3.7*

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.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

APPENDIX B

TABLE B-1. Transition Preparedness for Medicaid-Covered Children and Youth with Special Health Care Needs (Ages 0–17) by Intellectual Disabilities and Developmental Disabilities, 2022

Transition measures in the past 12 months	Total CYSHCN	ID/DD
Health insurance transition		
The parent knows how the child will be covered as an adult	**30.5%**	44.9%*
Someone has discussed with the parent how to keep the child's health insurance when they become an adult	**4.8**	—
Transition planning		
Child received services needed for transition to adult health care[1]	**24.6**	17.3
Child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs	**42.0**	49.9
You and this child have access to this plan of care	**92.8**	90.1
Someone talked with you about when this child will need to see doctors or other health care providers who treat adults	**23.2**	22.2
Child's health care provider actively worked with this child to understand the changes in health care that happen at age 18	**51.2**	35.9*
Does this plan of care address transition to doctors and other health care providers who treat adults? [2]		
Yes	**36.3**	35.2
No	**50.5**	53.4
No, this child has already seen providers who treat adults	**13.2**	—
Children with special health care needs who receive care in a well-functioning system	**15.3**	15.0

Notes: CYSHCN is children and youth with special health care needs. ID/DD is intellectual disabilities and developmental disabilities. Intellectual disability is defined by a yes response to the K2Q60B variable and developmental disability is defined by a yes response to the K2Q36B variable.
*Difference from CYSHCN without ID/DD is statistically significant at the 0.05 level.
– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.
[1] Age 12–17.
[2] Among those who have a transition plan.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.

TABLE B-2. Transition Preparedness for Medicaid-Covered Children and Youth with Special Health Care Needs (Ages 0–17) by Race and Ethnicity, 2022

Transition measures in the past 12 months	Total CYSHCN	White non-Hispanic	Black non-Hispanic	Hispanic
Health insurance transition				
The parent knows how the child will be covered as an adult	**30.5%**	30.8%	36.9%	27.3%
Someone has discussed with the parent how to keep the child's health insurance when they become an adult	**4.8**	6.6	—	—
Transition planning				
Child received services need for transition to adult health care[1]	**24.6**	23.0	25.1	25.4
Child's with special health care needs who received services necessary to make transitions to adult health care	**24.6**	23.0	25.1	25.4
Child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs	**42.0**	48.9	46.6	29.1*
You and this child have access to this plan of care	**92.8**	94.4	94.8	89.4
Someone talked with you about when this child will need to see doctors or other health care providers who treat adults	**23.2**	20.7	29.5	18.6
Child's health care provider actively worked with this child to understand the changes in health care that happen at age 18	**51.2**	47.4	62.2*	47.2
Does this plan of care address transition to doctors and other health care providers who treat adults?[2]				
Yes	**36.3**	32.9	51.1*	27.7
No	**50.5**	52.2	40.1	61.9
No, this child has already seen providers who treat adults	**13.2**	14.9	—	—
Children with special health care needs who receive care in a well-functioning system	**15.3**	17.6	10.8*	13.9

Notes: CYSHCN is children and youth with special health care needs. Race is defined as follows: White-only, non-Hispanic; Black-only, non-Hispanic; US Census Bureau does not recommend using national population estimates for any other race categories.
*Difference from white, non-Hispanic Medicaid-covered CYSHCN is statistically significant at the 0.05 level.
– Estimate not reported due to small sample size or unreliable data with a relative standard error greater than or equal to 30 percent.
[1] Age 12–17.
[2] Among those who have a transition plan.

Source: MACPAC, 2024, analysis of the 2022 National Survey of Children's Health.