

Children with special health care needs face challenges accessing information, support, and services

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Introduction

In this brief, Child Trends examines the most recently available comprehensive data on children and youth with special health care needs (CYSHCN) and their families. We find that, compared to their peers without special health care needs, CYSHCN, as a group, are more likely to experience circumstances that pose challenges to their well-being. The extent of the disparities we found suggests that CYSHCN and their families are at risk for adverse outcomes in economic, academic, and social-emotional domains—in addition to health. Moreover, racial and ethnic disparities in access to opportunities and supports exacerbate the inequities that CYSHCN and their families experience.

We used the 2016-2017 National Survey of Children's Health (NSCH) to analyze national- and state-level data on access to and quality of health care and other types of services for CYSHCN in the context of the broader literature, including NSCH findings from previous years, U.S. Department of Education data on special education services, and Medical Expenditure Panel Survey (MEPS) data. In addition to our top-level findings, our analysis of data from all 50 states and the District of Columbia illustrates widely varying outcomes for CYSHCN, depending on the state in which they live.

Key findings

- CYSHCN comprise an increasing share of the U.S. child population (currently, about 1 in 5 children), and include some whose conditions will last throughout the life course.¹
- As a group, CYSHCN—in addition to their exceptional health care needs—experience other disparities relative to their peers without special health care needs (SHCN):
 - They face greater exposure to family poverty and other adversities.
 - Their parents are more likely to have difficulties with child care arrangements that require them to change jobs.
 - They miss more school days and are more likely to repeat a grade.
- CYSHCN are slightly more likely than children and youth without SHCN to have health insurance coverage. However, despite the documented importance of a medical home^a for CYSHCN, this group is

^a A medical home is a practice model, established by the American Association of Pediatrics, to identify comprehensive and communitybased high-quality care. The criteria for a medical home include access to a personal doctor or nurse, family-centered care, effective care coordination, and accessible health care services. [American Academy of Pediatrics, Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2002). The medical home. *Pediatrics*, 110(1), 184-186].

less likely than children and youth without SHCN to have this type of coordinated care (43 versus 50 percent, respectively).

- Nationally, CYSHCN who come from wealthier families, live with two married parents, or live in homes where English is the primary language spoken are more likely to have a medical home than their CYSHCN counterparts who are less affluent, live without two married parents, or primarily speak a language other than English at home. These contrasts mirror those found for children and youth without SHCN.
- State-level data suggest disparities in access to a medical home. In no state do more than 57 percent of parents of CYSHCN report that their child has a medical home; in some states, this percentage is considerably lower. The need for improvement notwithstanding, state CYSHCN programs have made notable progress in increasing access to a medical home for the populations they serve.²
- In 8 states, at least 1 in 20 CYSHCN reportedly had no health insurance during the past year. In contrast, nationally, about 1 in 34 children without SHCN was uninsured.
- Our finding that non-Hispanic Black children are over-represented in the CYSHCN population warrants further investigation. The data could reflect the role of racism in contributing to health disparities, an identification bias, or both.

Background on CYSHCN

The CYSHCN population

The identification of CYSHCN as a distinct group dates to the last quarter of the 20th century, a period of landmark federal legislation recognizing people with disabilities. These milestones include the Developmental Disabilities Assistance and Bill of Rights Acts in 1970, the Individuals with Disabilities Education Act (IDEA; originally the Education for All Handicapped Children Act, 1975, and extended in 1986 to cover infants, toddlers, and their families); and the Americans with Disabilities Act (ADA, 1990). In the 1980s, the then-U.S. surgeon general, Charles Everett Koop. coined the term "children with special health care needs."³ Such progress reflected new attention to a historically ignored and underserved population, and the U.S. Department of Education now includes students with disabilities among the subgroups for which it requires disaggregated student achievement data. Likewise, the Department's Office for Civil Rights breaks out, by disability status, data on school attendance, discipline and safety, and educational programs and services.

Yet, labels and definitions associated with disabilities vary, potentially creating confusion about this group of children. Beginning in 1999, the U.S. Census Bureau included questions on disability in the American Community Survey. These were substantially revised in 2008 and have not changed since then.⁴ The Census questions, applying to each member of a household, ask about six types of disability: hearing, vision, cognitive, ambulatory, self-care, and independent living.

IDEA restricts eligibility for special education services to children who are diagnosed with one of 13 categories of disability.^b The National Health Interview Survey (NHIS) of the Centers for Disease Control and Prevention focuses on the concept of "activity limitation." Any such limitation is presumed to stem from an underlying condition, which is categorized as chronic, not chronic, or unknown.⁵

The federal Maternal and Child Health Bureau, which developed the measure of CYSHCN used in this brief, defines the group as "those who have or are at increased risk for a chronic physical, developmental,

^b Autism, deaf-blindness, deafness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment, including blindness. [https://www.parentcenterhub.org/categories/]

behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."⁶ The National Survey of Children's Health (NSCH) lists 18 specific health issues to which parents of children (ages 0-17) are asked to respond.^c

Health conditions do not necessarily result in disability, and disabilities are not necessarily accompanied by ongoing health problems. The contemporary understanding is that "the nature and severity of disability are not only a product of underlying medical conditions but also a function of the demands, expectations, and social roles that children assume in their daily lives."⁷ In addition, there is broad consensus that, from a human-rights perspective, people with disabilities (including those with SHCN) should not be excluded from full participation in all aspects of society.

Special needs of CYSHCN

Compared to caregivers of children and youth without SHCN, caregivers of CYSHCN reported more frequent medical care for their children, as well as greater usage of specialized care or therapies, prescription medications, and medical equipment.⁸ In addition, CYSHCN are more likely to face psychosocial challenges that require specialized attention. For example, CYSHCN have higher rates of exposure to adverse childhood experiences (ACEs) than children and youth without SHCN; for some CYSCHN, this may reflect a diminished ability to defend themselves against emotional, physical, and sexual abuse, or a greater exposure to multiple caregivers and settings.⁹ In school settings, CYSHCN are at greater risk of disciplinary removal and placement in restrictive settings.^{10,11} CYSHCN face multiple barriers to school success, including higher rates of school absence exceeding 11 days annually, repeating a grade, and calls to the student's home due to problems at school–all of which can lower motivation and achievement.¹² CYSHCN also face more social challenges at school, including behavioral problems and bullying.¹³ Beyond the individual, families and caregivers of CYSHCN also face various barriers to well-being, such as financial stress, burdens related to care, and social isolation,^{14,15} which suggests the need to support them alongside their children through a comprehensive, holistic approach.¹⁶

To meet their diverse needs, CYSHCN and their families rely on a variety of services and supports. Evidence suggests that having a medical home (a model of family-centered, community-based care) is effective in improving health-related outcomes, including greater health and fewer activity limitations, as well as meeting criteria of care quality, such as timeliness and family-centeredness.¹⁷ One aspect of a medical home that may be particularly important for CYSHCN is family-centered care, which refers to the involvement of a child's family in healthcare decision making. A 2010 analysis of NSCH data found that family-centered care among CYSHCN was associated with fewer unmet service needs and less delayed health care. The same analysis found that family-centered care was also associated with reduced family financial burden, including lower out-of-pocket costs and fewer hours devoted to care coordination.¹⁸

Beyond the provision and quality of health care, various social determinants affect health outcomes. For example, poverty, housing instability, and food insecurity have all been linked with poorer health outcomes for children and caregivers, contributing to or potentially worsening conditions for CYSHCN.^{19,20} However, protective factors for CYSHCN and their families have also been identified: Supportive and stable relationships, positive parenting practices, and healthy family dynamics are characteristics of the home setting that can have a positive impact on outcomes for CYSHCN.²¹ Additionally, school and neighborhood contexts can play a large role in engaging and supporting the families of CYSHCN, in particular through their provision of physical amenities (e.g., recreation centers, playgrounds), collaboration among health providers, and coordinated systems of care. This collaboration across a variety of networks and supports is essential to addressing the multifaceted strengths and needs of CYSHCN and their families.^{22,23}

^c ADD/ADHD; anxiety problems; asthma; autism, Asperger's, ASD; behavioral problems; bone, joint, or muscle problems; brain injury; cerebral palsy; depression; developmental delay; diabetes; epilepsy; hearing problems; intellectual disability; learning disability; speech problems; Tourette Syndrome; vision problems.

Addressing access to services for CYSHCN and their families

Despite considerable documentation of their needs, the evidence indicates that many CYSHCN and their families do not receive adequate levels of support. According to a 2015 study,²⁴ only a small proportion of CYSHCN receive all attributes of a high-quality health care system. Care gaps exist especially among racial and ethnic minorities, lower-income families, households whose primary language is not English, and those most affected by their health conditions. Families of Black and Hispanic CYSHCN reported having more frequent care coordination needs that go unmet, as well as lower satisfaction with the care they receive.^{25,26}

Inequities for this population extend beyond the realm of health care. According to one study, fewer CYSHCN met criteria for optimal home, neighborhood, and school environments than children and youth without SHCN.²⁷ These disparities, even those that are relatively small, may still be meaningful for CYSHCN and their families, since they may stand to benefit most from supportive environments.

Access to high-quality care and supports can be influenced by a number of factors. Affordability of services is a significant barrier for many families of CYSHCN. While the majority of CYSHCN have access to some type of insurance coverage,²⁸ about one-third of families with CYSHCN reported that their insurance coverage was inadequate.²⁹ The insurance process is complicated for CYSHCN, considering their need for more frequent visits and more specialized care,³⁰ and some insurance plans may not cover all necessary care and coordination. Health care expenditures can be up to three times higher for CYSHCN than children and youth without SHCN, and average out-of-pocket costs for CYSHCN have been estimated to be double those of other children and youth.³¹

An additional factor associated with the care that CYSHCN receive is the state in which they reside. While numerous federal programs and policies apply to children and families nationwide, states also enact their own policies and regulations affecting the supports CYSHCN receive and, indirectly, the outcomes they experience.³² For example, 36 states and the District of Columbia have adopted and implemented policies that expand Medicaid coverage to additional populations, including those identified by disability status.³³

State policies can also affect outcomes for CYSHCN that are not directly related to health. For example, in states that require school-based case management for children with disabilities, CYSHCN were less likely to repeat a grade.³⁴ State policies can also sometimes affect states' compliance with federal regulations. For example, in 2004, Texas implemented a policy that placed a cap on the number of students receiving special education and related services, effectively denying services required under IDEA to many children with disabilities across the state.³⁵

Methodological overview

Using 2016-2017 National Survey of Children's Health data, we examined select demographic characteristics of CYSHCN and their families and made bivariate comparisons to children and youth without SHCN. We also conducted multivariate logistic regressions to assess the likelihood that CYSHCN have access to a medical home, and conducted selective analyses of data for all 50 states and District of Columbia.

For more information on our data, sample, and methodology, please refer to Appendix A on page 15. Appendix B (page 17) includes more detailed information on the national prevalence of specific health conditions among CYSHCN and state-level data for selected health conditions, and on the prevalence of special education plans for CYSHCN overall.

Findings

This section first presents data from the NSCH that are descriptive of CYSHCN and their families at the national level, and contrasts those with the characteristics of children and youth without SHCN and their

families. Next, we focus specifically on access to a medical home, again contrasting CYSHCN and their counterparts without SHCN. Last, we provide data for all 50 states and the District of Columbia, focusing on the prevalence of CYSHCN and access to a medical home.

National-level findings

Child characteristics

- Overall, the national prevalence of SHCN among children and youth is 19 percent; males account for a higher proportion of all CYSHCN (58 percent) than females (42 percent; see Table 1).
- By race and ethnicity, non-Hispanic Black children comprise 18 percent of the CYSHCN population (a significantly higher percentage than their representation in the total child population); shares of non-Hispanic White children do not differ significantly from those in the overall population. Although our analyses cannot determine causality, this disparity prompts concern that identification bias or other social determinants, including racism, may contribute to the prevalence of SHCN identified among non-Hispanic Black children^d (see Figure 1).







Source: Child Trends analysis of data from the National Survey of Children's Health, 2016-2017. * Statistical analysis of the differences in the proportions of racial and ethnic groups in the total population versus the proportions of racial and ethnic groups among those with special health care needs is significant.

• Among CYSHCN, the six most prevalent conditions are attention-deficit disorder/attention-deficit hyperactivity disorder (ADD/ADHD; 33 percent); asthma (33 percent); externalizing disorders (behavioral or conduct problems; 30 percent); internalizing disorders (anxiety/depression; 28 percent); learning disabilities, and developmental delays (each 25 percent; see Appendix B Table 3).

^d In addition to the direct effects of racial discrimination on health [Priest, N., Paradies, Y., Trenerry, B., Truong, M., Karlsen, S., & Kelly, Y. (2013). A systematic review of studies examining the relationship between reported racism and health and wellbeing for children and young people. *Social Science & Medicine*, *95*, 115-127.], Black children and their families are more likely than their White peers to experience poorer-quality health care [Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. (2003). Unequal treatment: Confronting racial and ethnic disparities in health care. Washington, DC: National Academies Press], live in housing and neighborhoods where they are exposed to toxicants and other health risks [Collins, M. B., Munoz, I., & JaJa, J. (2016). Linking 'toxic outliers' to environmental justice communities. *Environmental Research Letters*, *11*(3)] and be exposed to adversities that can result in toxic stress, which in turn is associated with social-emotional problems and learning difficulties.

- As expected, CYSHCN are more likely than children and youth without SHCN to have a special education plan; of the latter group, just 3 percent have such a plan, compared with 30 percent of CYSHCN (See Table 1). Specifically, CYSHCN with ADD/ADHD, externalizing behavioral problems, and learning disabilities are significantly more likely than their peers to have a special education plan (see Appendix B Table 4).
- The percentage of school-age CYSHCN who miss seven or more school days in a year is three times the percentage among their peers without SHCN (21 versus 6 percent). Similarly, the percentage of school-age CYSHCN who repeat a grade is twice the percentage of their peers (12 versus 5 percent; see Figure 2).

Figure 2. Percentages of children and youth who repeated a grade, and with chronic school absence, by SHCN status: 2016-17 (weighted percentages)



Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017. * The bivariate association between SHCN status and this child characteristic is statistically significant.

• Current health insurance coverage and coverage in the past 12 months are both slightly more common among CYSHCN, compared to children and youth without SHCN. However, despite the documented importance of a medical home for CYSHCN, in particular, this group is less likely than children and youth without SHCN to have this type of coordinated care (See Table 1).

Table 1. Selected child characteristics, by SHCN status (weighted percentages)

Child characteristics		CYSHCN	Children and youth without SHCN
Overall prevalence		18.8	81.3
Age	0-5*	17.9	35.6
	6-11*	38.1	32.9
	12-17*	44.0	31.5

Chil	d characteristics	CYSHCN	Children and youth without SHCN
Gender*	Male	58.0	49.5
Gender	Female	42.0	50.5
Pace/Ethnicity	White non-Hispanic	51.2	51.5
Race/Ethnicity	Black non-Hispanic*	17.8	12.0
	Hispanic*	22.2	25.3
	Asian*	2.4	5.1
	Non-Hispanic Other	6.4	6.1
Adverse	None*	38.6	58.8
Childhood	1*	26.3	24.2
Experiences	2 or more*	35.2	17.1
Education	Special education plan* ^{a, b}	29.6	3.3
Luucation	Missed days ^b		
	None*	21.6	34.2
	1–6 days	57.9	59.7
	7 or more days*	20.5	6.1
	Repeated a grade ^{* b}	11.8	5.0
Insurance	Currently covered*	96.1	93.8
mourance	Ever had insurance in the past 12 months*	92.9	91.6
	Gap in coverage in the past 12 months	4.2	3.6
	No coverage in the past 12 months*	2.9	4.8
Medical home	Care meets medical home criteria*	43.2	49.8

Source: Child Trends' analysis of data from the National Survey of Children's Health (NSCH), 2016-2017.

^a The survey question includes children who have in place an Individualized Family Service Plan or Individualized Education Plan.

^b These measures are asked for children and youth ages 6 to 17 who are attending school.

* The bivariate association between SHCN status and this child characteristic is statistically significant.

Compared to their peers without SHCN, the prevalence of ACEs among the CYSHCN population is higher. In addition to economic hardship, prevalence of the other eight ACEs listed in the NSCH is higher among CYSHCN (see Figure 3). For instance, compared to their peers, more CYSHCN have experienced each of the following:

- 1) had a parent incarcerated, 2) witnessed domestic violence, 3) been a victim of or witnessed violence in the neighborhood, 4) lived with an adult with a substance abuse or mental illness, and 5) experienced racism;
- A higher cumulative number of these adversities—for example, 35 percent of CYSHCN are reported to have had two or more, compared to 17 percent of children and youth without SHCN (See Table 1).



Figure 3. Exposure ever to adverse childhood experiences, by type, for children and youth with and without SHCN: 2016-2017 (weighted percentages)

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017. * The bivariate association between SHCN status and this child characteristic is statistically significant.

Family characteristics and other circumstances of CYSHCN

- Compared to children and youth without SHCN, CYSHCN are more likely to live with a single parent, and less likely to live with two married parents. They are more likely to live in families where the primary language spoken is English (see Table 2).
- CYSHCN are more likely than those without SHCN to be poor (26 and 20 percent, respectively, are in families below the federal poverty level). CYSHCN are more likely than their counterparts to receive assistance from several public benefit programs (cash assistance, food stamps, and reduced- price school meals, but not the Special Supplemental Nutrition Program for Women, Infants, and Children [WIC]).
- CYSHCN are slightly less likely to live in neighborhoods considered safe, and more likely to live in neighborhoods where there are two or more detracting characteristics.
- CYSHCN are more likely to receive care at least 10 hours per week from a non-parent or guardian. Furthermore, parents of CYSHCN are more likely to report a job change because of child care difficulties.

	Family characteristics	CYSHCN	Children and youth without SHCN
Ratio of family	0-99%*	25.7	20.2
income to federal	100-199%	22.4	21.6
poverty level	200-399%*	25.1	27.4
	>400%*	26.9	30.8
Family structure	Other*	12.0	8.3
	Single mother*	22.2	13.3
	Two parents, unmarried	9.5	8.8
	Two parents, married*	56.3	69.6
Language spoken at	English*	91.0	84.3
home	Not English*	9.0	15.7
Child care	Child receives care at least 10 hours per week (not including care from a parent/guardian)*	59.9	53.2
	Job change because of child care difficulties*	18.8	7.5
Receipt of public	Cash assistance*	7.1	3.7
assistance	Food stamps*	27.5	18.4
	Reduced- price school meals *	44.8	31.3
	WIC	12.8	13.3
Neighborhood	Safety *	90.8	95.3
characteristics	Amenities ^a		
	Fewer than 2 amenities	21.9	20.6
	2 or more amenities	78.1	79.4
	Detracting Elements ^b		
	Fewer than 2 detracting elements*	87.1	91.1
	2 or more detracting elements*	13.0	8.9

Table 2. Family characteristics, by SHCN status (weighted percentages)

Source: Child Trends' analysis of data from the National Survey of Children's Health (NSCH), 2016-2017.

^a The survey asks about the following neighborhood amenities: sidewalks or walking paths; parks or playground; recreation centers, community center, or boys' and girls' club; and libraries or bookmobiles.

^b The survey asks about the following detracting elements: litter or garbage on the street or sidewalk, poorly kept or rundown housing, and vandalism such as broken windows or graffiti.

* The bivariate associations between SHCN status and each of the family variables listed here are statistically significant, except for receipt of WIC benefits and neighborhood amenities.

CYSHCN: Access to a medical home

• There are inequities in access to high-quality care, as reported by parents, among the CYSHCN population. While a child's age, sex, and race or ethnicity are not significantly associated with access to care that meets medical home criteria, family-level factors were. Children who have medical insurance, those in households with incomes at least twice the federal poverty level, and those with English as the primary language spoken at home are more likely to have a medical home than their counterparts without insurance, with incomes below the poverty level, and with a language other than English as the primary language spoken at home, respectively. Children in homes with a single mother or two unmarried parents are less likely than children living with two married parents to have a medical home (see Appendix B Table 6).

- Across the medical home components, compared to non-Hispanic White children, non-Hispanic Black children are less likely to have a personal doctor or nurse, or family-centered care. Asian children are more likely to have a personal doctor or nurse, and less likely to have problems getting needed referrals. Hispanic children are less likely to have a personal doctor or nurse, and a usual source for sick care (see Appendix B Table 7).
- Children 6 to 11 years old, in comparison to children ages 0 to 5, are less likely to have a personal doctor or nurse. Girls are more likely than boys to have problems getting needed referrals.
- Access to insurance is associated with greater likelihood of having a personal doctor or nurse, a usual source for sick care, and family-centered care. However, it is also associated with greater likelihood of problems getting needed referrals.
- Children living in families with incomes above the poverty level are more likely to have a personal doctor or nurse and a usual source for sick care. Children in families with income levels at least twice the federal poverty level are more likely to have family-centered care than children in families with income below the poverty. Notably, children in families with income levels at least four times the federal poverty level are more likely to have problems getting needed referrals.
- Children living in homes where English is the primary language are more likely to have a personal doctor or nurse and receive family-centered care.
- Finally, compared to children living in households with two married parents, those who lived in unmarried, two-parent households and those who did not live with a biological or adoptive guardian or parent were less likely to have a usual source for sick care. Children living in single-mother households were also less likely to have access to effective care coordination and family-centered care, compared to children in married, two-parent homes. Finally, children who did not live with a biological or an adoptive guardian or parent were also less likely to have access to effective care coordination and family-centered care.

State-level findings

We highlight a number of measures related to identification of SHCN and access to supports that vary greatly by state. Although states' contexts differ in numerous ways that may affect CYSHCN and their families, it is important to understand the degree to which state-specific policies may either facilitate or hinder access to appropriate supports and services. The data suggest that states' policy responses to these needs may differ, meaning that the likelihood that CYSHCN and their families will get the supports they need depends, to some degree, on where they happen to live.

• Prevalence of SHCN among children and youth varies by state, from a high of 24 percent (Kentucky, Mississippi, and West Virginia) to a low of 13 percent (Hawaii; see Figure 4 on the next page).



Figure 4. Percentage of CYSHCN, by state: 2016-2017 (weighted percentages)

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017.

• States vary widely in the proportion of CYSHCN who receive a specialized education plan. In Texas and Iowa, this is 19 percent; in New York, it is 43 percent (see Figure 5).^e



Figure 5. Percentage of CYSHCN who have a special education plan: 2016-2017 (weighted percentages)

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017. Note: (a) Among those with ADHD, behavioral problems and learning disabilities CYSHCN are significantly more likely than children without SHCN to have a special education plan.

^e The low numbers in Texas may reflect the policy implemented in 2004 that limited the number of children receiving special education and related services (U.S. Department of Education, 2018).

- Several findings emerge from among the most prevalent categories of SHCN (See Appendix Table 4):
 - The proportion diagnosed with ADD/ADHD who have a special education plan varies from 71 percent in the District of Columbia, to 24 percent in Texas and Hawaii.
 - Sixty-eight percent of children in New Jersey with externalizing disorders have a special education plan, while in Texas, 23 percent do.
 - In Alaska, 58 percent of children with internalizing disorders have a special education plan compared to 16 percent in Mississippi.
- Among the proportion of CYSHCN who have a medical home, there are wide disparities among the states. Nebraska leads at 57 percent, while Nevada is lowest at 30 percent (See Appendix B Figure 7). The proportion of those without SHCN who have a medical home ranges from 64 to 37 percent (Vermont and Nevada, respectively; See Appendix B Figure 8). In one state only (Delaware) the percentage of CYSHCN who have a medical home significantly exceeds the percentage of children and youth without SHCN who have a medical home (see Figure 6).

Figure 6. Difference in percentage of access to medical home between children and youth without SHCN and CYSHCN 2016-2017 (weighted percentages)



Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017

+ In these states, the percentage of CYSHCN with access to a medical home is greater than the percentage for children and youth without SHCN, but the difference is not statistically significant.

*In these states, the difference between the two populations is statistically significant.

 Insurance coverage rates over the past 12 months for CYSHCN, by state, range from 87 percent (Arkansas and Florida) to 99 percent (California). Up to 10 percent of CYSHCN (Arkansas) experienced a gap in coverage during the past 12 months, and as many as 9 percent (Alabama) had no coverage. None of these figures, in any state, were as high for children and youth without SHCN, except for the uninsured percentage in Texas, which was higher among children and youth with SHCN (See Appendix Table 5).

Conclusion

The findings in this brief make clear that CYSHCN, as a group, encounter numerous barriers to their wellbeing that are not shared to the same extent by their peers without SHCN. CYSHCN encounter challenges associated with family, neighborhood, and school circumstances, and in accessing appropriate, comprehensive, coordinated health care. These barriers may reflect, in part, the consequences of racial prejudice, since circumstantial evidence shows that Black non-Hispanic children and youth are overrepresented among CYSHCN.

Further, the experiences of CYSHCN appear to differ markedly, depending on the state where they live. Not only does the reported prevalence of SHCN vary among states, but health insurance coverage, access to appropriate care (as measured by a child's having a medical home), and access to special education plans for this group also vary widely from state to state. State-level data may be helpful to advocates, policymakers, and researchers seeking to identify both the causes and the consequences of this variability and to set reasonable goals for improving conditions for CYSHCN.

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Appendix A: Methodology

We examined selected demographic characteristics of CYSHCN and their families and made bivariate comparisons of these variables between CYSHCN and children and youth without SHCN. Next, controlling for the child's age, sex, race or ethnicity, current health insurance coverage, family income, family structure, and the language spoken at home, we used multivariate logistic regression to examine the joint association of several child and family characteristics with the likelihood that a child with SHCN has a medical home, as well as each of its components (access to a personal doctor or nurse, family-centered care, effective care coordination, usual source of sick care, and getting referrals when needed).

Data

The data used in this brief come from the combined 2016-2017 National Survey of Children's Health (NSCH). As of 2016, the NSCH was consolidated with the National Survey of Children with Special Health Care Needs. This survey was conducted in all 50 states and the District of Columbia by the U.S. Census Bureau, with funding from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. This survey provides data on various aspects of children's lives, including health, access to high-quality health care, and family, neighborhood, and social contexts.

Sample

Prior to the survey, households were randomly sampled to complete a screener, used to identify households with at least one child under age 18. In households meeting this criterion, surveys were adminstered using a secure web-based platform or a mailed, paper version. The responding adult was asked to answer regarding a single focal child. Children ages 0 to 5 were oversampled. For the analyses in this brief, the total sample is 71,811. This combined sample includes data collected in 2016 (50,212) and 2017 (21,599). Our analyses are weighted to be statistically representative of children at the national and state levels.

Measures

In order to understand the population of interest for these analyses, we first compared CYHSCN and those without SHCN on a number of child- and family-level demographic characteristics (e.g., race, gender, income, family structure, receipt of public assistance, and neighborhood characteristics). Second, we examined access to a medical home, including its individual components.

Child characteristics

The NSCH's screener asks about the focal child's sex, age, race, and ethnicity. The screener also includes a series of health questions to determine whether the focal child has had a medical, behavioral, developmental, or emotional health condition lasting at least 12 months, or one expected to last more than 12 months. These children are considered to have SHCN. For children ages 6 to 17, the NSCH also gathers information on school-related experiences, such as whether the child ever received a special education plan (Individualized Family Service Plan or Individualized Education Plan), the number of school days missed in the past year, and whether the child ever repeated a grade.

Because they are related to child health, we also examined survey items indicating health insurance coverage at the time of the survey, coverage in the past 12 months, and whether there was a gap in coverage during that time.

Finally, we included information on adverse childhood experiences. The NSCH asks the following questions of the responding adult:

• Since this child was born, how often has it been very hard to get by on your family's income—hard to cover the basics like food or housing?

- To the best of your knowledge, has this child EVER experienced any of the following?
 - Parent or guardian divorced or separated
 - Parent or guardian died
 - Parent or guardian served time in jail
 - o Saw or heard parents or adults slap, hit, kick, or punch one another in the home
 - Was a victim of violence or witnessed violence in neighborhood
 - o Lived with anyone who was mentally ill, suicidal, or severely depressed
 - Lived with anyone who had a problem with alcohol or drugs
 - Was judged unfairly because of his or her race or ethnic group

Response options for the first ACE question were "Never," "Rarely," "Somewhat often," or "Very Often." Responses of "Somewhat often" or "Very Often" were recoded as "Yes"; responses of "Never" or "Rarely" were recoded as "No." Responses to the each part of the second question were "Yes" or "No." We examined the prevalence ACEs individually, as well as the cumulative number of ACEs reported.

Family characteristics

Family demographics included in the analysis are income (as a percentage of the federal poverty level), receipt of selected public assistance programs, family structure, language spoken at home, and selected neighborhood characteristics. In addition, we included an item on the family's difficulty accessing child care.

Medical home

In the 2016-2017 NSCH, the medical home measure is a composite of responses to five items:

- 1. Personal doctor or nurse: Do you have one or more persons you think of as this child's personal doctor or nurse?
- 2. Usual source for sick care: Does this child have a place that he or she usually goes to first when he or she is sick or needs a caregiver's advice about his or her health?
- 3. Family-centered care: If this child received care during the past 12 months, did he/she receive family-centered care?
- 4. Problems getting needed referrals: Did this child have problems getting referrals when needed during the past 12 months?
- 5. Effective care coordination when needed: Did this child receive effective care coordination?

To be considered as having a medical home, a child must receive care that meets the criteria for the first three components. Additionally, any child needing referrals or care coordination must meet the criteria for the other two components. Finally, family-centered care is a measure of a parent's reported care experiences, such as whether the medical staff spent enough time with the child, listened carefully, were sensitive to the family's values and needs, and/or provided information, and whether the parent felt like a partner in the medical planning. If there were positive response to any one of the five components, and the remainder of responses were missing or legitimately skipped, the child was identified as having a medical home.

For this analysis, we used data recoded as "Care met medical home criteria" or "Care did not meet medical home criteria." In addition, we examined the five separate components of a medical home. Regarding the specific health conditions identified in the survey, we followed common practice^f in grouping "depression" and "anxiety problems" together as "internalizing disorders"; likewise, we refer to "behavioral or conduct problems" as "externalizing disorders."

^f Carney, R., Stratford, B., Moore, K. A., Rojas, A., & Daneri, P. (2015). What works for reducing problem behaviors in early childhood: Lessons from experimental evaluations. Bethesda, MD: Child Trends. Retrieved from <u>https://www.childtrends.org/wp-content/uploads/2015/08/2015-32WhatWorksProblemBehaviors.pdf</u>

¹⁵ Children with special health care needs face challenges accessing information, support, and services

Appendix B: Figures and Tables

Table 3. Most prevalent conditions among CYSHCN: 2016-2017 (weighted percentages)

Conditions	Percentage of children with special health care needs
ADD/ADHD	33.5
Asthma	33.0
Externalizing disorders (behavioral or conduct problems)	30.4
Internalizing disorders (anxiety or depression)	28.2
Learning Disability	25.3
Developmental Delay	24.9
Speech Disorder	22.5
Autism (ASD)	12.3
Genetic Condition	11.7
Brain Injury	6.2
Intellectual Disability	5.4
Epilepsy	3.7
Diabetes	2.1
Blood Disorder	1.6
Cerebral Palsy	1.3
Down Syndrome	0.8
Tourette Syndrome	0.7
Cystic Fibrosis	0.1

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017. Note: Percentages sum to more than 100 percent because parents may report a child has more than one condition.

Table 4. CYSHCN who have a special education plan, by selected health conditions, by state: 2016-2017(weighted percentages)

State	ADD/ADHD	Externalizing disorders	Internalizing disorders	Learning disability	Speech & language disability	Intellectual disability	Autism
United States	43.1	46.2	37.9	71.8	64.8	83.4	75.9
Alabama	30.9	40.5	19.7	62.8	75.5	92.1	68.7
Alaska	52.5	58.2	57.6	84.0	77.3	100.0	81.9
Arizona	44.3	56.9	44.9	68.1	63.4	67.9	82.5
Arkansas	37.3	34.1	32.4	51.1	47.7	48.5	67.7
California	46.1	55.0	36.0	79.6	75.4	82.8	88.9
Colorado	51.3	41.6	51.1	86.2	75.7	74.3	84.2
Connecticut	54.3	59.7	42.8	80.3	58.7	100.0	79.9
Delaware	49.9	50.2	40.7	81.8	75.2	100.0	70.2
District of Columbia	70.7	60.2	44.9	75.2	67.0	66.6	86.4
Florida	40.0	45.4	38.4	63.2	50.2	42.5	64.7
Georgia	42.9	41.6	37.9	63.5	52.7	93.7	77.1
Hawaii	23.7	36.8	35.3	63.2	48.5	81.7	62.5
Idaho	40.6	45.0	30.9	72.9	69.7	100.0	70.6
Illinois	56.7	59.4	44.0	78.4	72.6	93.5	96.5

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State	ADD/ADHD	Externalizing disorders	Internalizing disorders	Learning disability	Speech & language disability	Intellectual disability	Autism
Indiana	43.6	42.4	42.0	70.3	60.0	78.1	64.4
lowa	30.3	29.0	24.2	63.8	65.7	100.0	64.9
Kansas	50.5	51.7	38.9	78.1	62.4	79.0	62.1
Kentucky	55.1	53.9	46.3	65.3	64.9	70.4	67.2
Louisiana	33.6	32.4	22.2	59.5	39.9	69.3	54.0
Maine	55.4	53.8	40.9	74.0	61.6	86.1	63.5
Maryland	51.5	54.5	52.3	83.3	74.3	91.0	72.3
Massachusetts	55.0	54.0	55.4	79.6	79.5	100.0	87.6
Michigan	39.7	31.5	26.7	63.7	68.2	47.5	62.3
Minnesota	46.1	54.3	30.0	80.8	62.1	60.4	76.5
Mississippi	33.1	30.1	15.7	66.4	45.1	91.7	53.3
Missouri	41.5	47.6	22.5	70.5	59.3	100.0	65.5
Montana	33.5	33.8	36.1	55.8	61.7	87.7	92.8
Nebraska	54.7	58.4	39.1	82.2	65.4	47.8	88.2
Nevada	47.4	50.7	38.0	85.3	62.2	95.3	90.0
New Hampshire	46.5	52.1	32.9	62.9	72.7	81.8	71.5
New Jersey	68.6	68.4	56.6	79.9	66.0	96.2	79.2
New Mexico	41.9	44.1	48.4	83.5	65.7	98.8	84.4
New York	49.6	59.7	50.8	85.1	83.8	96.9	78.3
North Carolina	40.7	46.7	31.8	74.8	61.5	69.8	79.4
North Dakota	56.9	52.7	42.4	71.1	60.7	100.0	83.5
Ohio	42.2	49.7	42.4	83.3	66.4	95.0	94.1
Oklahoma	45.7	47.8	37.4	76.3	70.4	82.8	80.6
Oregon	45.9	49.7	40.4	66.1	63.2	94.6	72.4
Pennsylvania	48.0	49.9	41.9	84.1	69.9	93.6	75.3
Rhode Island	46.1	49.7	40.7	69.1	63.3	100.0	75.8
South Carolina	40.8	45.6	34.4	74.7	64.7	100.0	78.3
South Dakota	38.3	36.5	25.2	72.8	62.7	88.7	56.4
Tennessee	47.6	43.1	42.8	69.1	54.9	53.4	57.9
Texas	23.6	22.8	29.5	49.5	57.4	69.9	32.0
Utah	36.8	41.4	31.7	66.5	76.7	68.9	75.4
Vermont	50.3	52.6	47.2	72.1	54.4	88.4	83.7
Virginia	50.7	54.6	40.7	83.4	63.8	100.0	86.8
Washington	52.8	51.1	36.3	67.8	52.6	91.6	73.4
West Virginia	38.5	40.9	30.3	58.7	44.7	77.7	41.8
Wisconsin	38.9	48.5	24.3	77.4	70.1	89.5	91.4
Wyoming	48.4	44.9	31.6	72.8	76.1	68.3	69.9

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017.

Note: Among all children and youth with ADD/ADHD, externalizing disorders, and learning disabilities, CYSHCN are significantly more likely than children and youth without SHCN to have a special education plan. For children and youth with a speech and language disability, autism, or intellectual disability, the relative likelihood of a special education plan could not be determined, because in some states the number of children with these conditions is either small or not identified.



Figure 7. CYSHCN with a medical home, by state: 2016-2017 (weighted percentages)

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017





Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017

Table 5. Health insurance coverage among CYSHCN and children and youth without SHCN, by state: 2016-2017 (weighted percentages)

State	Ever had ins the pa	surance coverage in 12 months	Gap in cov 12	verage in the past 2 months	No coverage in the past 12 months	
	CYSHCN	Children and youth without SHCN	CYSHCN	Children and youth without SHCN	CYSHCN	Children and youth without SHCN
United States	92.9	91.6	4.2	3.6	2.9	4.8
Alabama	90.2	96.1	1.2	1.2	8.6	2.7
Alaska	96.2	89.8	3.7	4.5	0.2	5.7
Arizona	93.2	88.2	3.0	4.4	3.7	7.5
Arkansas	86.7	90.1	10.1	5.2	3.2	4.7
California	98.7	93.3	1.0	2.5	0.3	4.2
Colorado	89.5	91.9	7.0	4.3	3.4	3.9
Connecticut	96.9	97.0	1.6	1.3	1.6	1.7
Delaware	95.6	92.0	3.0	3.4	1.4	4.6
District of Columbia	91.6	94.2	4.0	2.1	4.4	3.7
Florida	87.2	85.7	7.1	7.7	5.8	6.6
Georgia	89.3	87.1	8.0	8.0	2.7	4.9
Hawaii	97.8	98.0	1.3	0.9	0.9	1.2
Idaho	92.7	93.3	3.3	2.3	4.0	4.4
Illinois	93.7	94.8	2.4	3.2	3.8	2.0
Indiana	96.9	92.1	2.3	3.1	0.8	4.9
lowa	91.5	92.9	3.7	2.2	4.9	4.9
Kansas	91.3	90.5	6.7	6.5	2.0	3.1
Kentucky	96.0	89.7	1.6	3.5	2.4	6.8
Louisiana	93.9	93.7	3.0	1.9	3.1	4.4
Maine	94.5	93.8	1.6	3.2	3.9	3.0
Maryland	95.0	94.1	1.5	2.8	3.5	3.2
Massachusetts	96.2	97.2	2.2	0.4	1.6	2.4
Michigan	90.6	95.0	3.7	2.1	5.7	3.0
Minnesota	94.1	93.7	5.5	3.9	0.5	2.3
Mississippi	91.3	93.0	3.7	3.1	5.0	3.9
Missouri	90.8	93.0	1.8	2.0	7.4	5.0
Montana	96.1	94.7	2.1	2.7	1.9	2.6
Nebraska	88.3	93.5	8.6	3.4	3.1	3.2
Nevada	93.9	87.7	4.4	6.0	1.7	6.3
New Hampshire	97.7	95.9	0.9	2.8	1.5	1.3
New Jersey	91.4	93.6	6.3	2.6	2.3	3.8
New Mexico	95.5	90.4	1.7	3.7	2.8	5.9
New York	90.4	95.8	8.2	1.3	1.4	2.8
North Carolina	91.9	89.7	3.0	4.0	5.1	6.3
North Dakota	93.7	93.2	4.5	3.9	1.9	2.9
Ohio	93.8	93.3	5.0	2.3	1.2	4.4
Oklahoma	89.6	91.1	4.6	2.5	5.9	6.4
Oregon	93.0	92.0	5.2	5.5	1.7	2.5
Pennsylvania	94.8	92.3	4.3	1.1	0.8	6.6
Rhode Island	96.4	93.7	0.8	3.6	2.9	2.8
South Carolina	91.0	90.5	4.3	3.0	4.8	6.5
South Dakota	94.8	95.2	2.2	2.6	3.0	2.1

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State	Ever had ins the pa	r had insurance coverage in the past 12 months		Gap in coverage in the past 12 months		age in the past 12 months
Tennessee	97.0	93.8	2.5	2.3	0.5	3.9
Texas	90.0	82.9	7.1	7.6	2.9	9.5
Utah	93.2	91.3	4.4	4.8	2.4	4.0
Vermont	97.2	97.9	1.0	0.8	1.8	1.3
Virginia	95.5	93.0	3.1	2.3	1.4	4.7
Washington	94.8	97.5	2.4	0.9	2.8	1.6
West Virginia	91.9	94.1	1.7	2.5	6.3	3.4
Wisconsin	97.5	94.3	1.6	2.3	0.9	3.4
Wyoming	94.1	90.8	3.7	4.1	2.2	5.1

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017

Table 6. Among CYSHCN and their families, effects of selected characteristics on the likelihood of care that meets criteria for a medical home

Child and Family Ch	Adjusted odds ratios, (95- percent confidence intervals)			
Child age	6-11	0.9		
(Reference group: ages 0-5)		(0.8-1.2)		
	12-17	1.1		
		(0.9-1.3)		
Child sex	Female	1.0		
(Reference group: male)		(0.9-1.2)		
Child race and othnicity	Black pon-Hispanic	0.9		
(Reference group: White Non-Hispanic)	Black Holl-I lispanic	(0.7-1.2)		
(Reference group, white Norr Hispanic)	Hispanis (Any raca)	0.8		
	Hispanic (Any race)	(0.6-1.1)		
	Asian	1.3		
		(0.8-2.1)		
	Other non-Hispanic	0.9		
		(0.7-1.1)		
Current insurance coverage	Covered	1.7**		
(Reference group: no coverage)	Covered	(1.1-2.7)		
Patio of family income to federal	100-199%	1.1		
noverty level	100-17776	(0.8-1.4)		
(Reference group: 0-99% FPI)	200-299%	1.3**		
(200-37778	(1.0-1.6)		
	>400%	1.7***		
	2400%	(1.4-2.2)		
Family structure	Two parants upmarried	0.7*		
(Reference group: two parents married)	Two parents, unmarried	(0.5-1.1)		
(Reference group, two parents, married)	Single methor	0.8**		
	Single mother	(0.6-1.0)		
	Other	0.8*		
		(0.6-1.0)		
Language spoken at home	Fnglish	1.7**		
(Reference: Other (non-English)		(1.1-2.6)		

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017.

Significant difference at $p \le 0.1$, $p \le 0.05$, $p \le 0.01$. Note: Outcomes are based on weighted analysis. Interpretation: Odds ratios indicate whether, compared to the reference group, a given group is more or less likely to have care that meets the criteria for a medical home or components of a medical home. Values greater than 1 indicate greater likelihood; values less than 1 indicate smaller likelihood. For example, compared to the reference group, children with health insurance coverage are more likely to meet the medical home criteria.

Table 7. Among CYSHCN and their families, effects of selected characteristics on the likelihood of care that meets criteria for individual components of a medical home: 2016-17 (values are odds ratios, followed by 95-percent confidence intervals)

Child and Family Characteristics		Personal doctor or nurse	Usual source for sick care	Problems getting needed referrals	Effective care coordination	Family-centered care
Childago	4 1 1	0.8*	0.9	1.0	1.0	0.9
(Reference group:	0-11	(0.6 - 1.0)	(0.6 - 1.2)	(0.7 - 1.5)	(0.8 - 1.2)	(0.7 - 1.3)
ages 0-5)	12-17	0.8	0.8	0.9	1.1	0.9
		(0.6 - 1.1)	(0.6 - 1.1)	(0.6 - 1.3)	(0.9 - 1.4)	(0.7 - 1.3)
Child sex	Female	1.0	1.0	1.3**	0.9	0.9
(Reference group: male)		(0.8 - 1.3)	(0.8 - 1.2)	(1.0 - 1.7)	(0.8 - 1.1)	(0.7 - 1.2)
Child race and	Black pop-	0.7***	0.9	0.9	1.1	0.7**
ethnicity	Hispanic	(0.5 - 0.9)	(0.6 - 1.2)	(0.6 - 1.4)	(0.8 - 1.5)	(0.5 - 0.9)
(Reference group: White Non-	Hispanic	0.7**	0.7**	0.8	1.1	0.8
Hispanic)	(Any race)	(0.5 - 0.9)	(0.5 - 1.0)	(0.5 - 1.2)	(0.9 - 1.4)	(0.6 - 1.1)
	Asian	2.2**	1.2	0.5*	1.3	1.3
	Asian	(1.2 - 4.0)	(0.7 - 2.2)	(0.3 - 1.0)	(0.9 - 1.9)	(0.6 - 2.5)
	Other non-	0.9	0.8	0.7	1.0	1.1
	Hispanic	(0.7 - 1.3)	(0.6 - 1.1)	(0.5 - 1.2)	(0.7 - 1.3)	(0.8 - 1.6)
Current insurance	Covered	1.9***	2.4***	3.1***	0.7	1.6**
coverage (Reference group: no coverage)	covered	(1.2 - 3.0)	(1.6 - 3.7)	(1.4 - 7.0)	(0.4 - 1.2)	(0.9 – 2.7)
Patio of family	100-199%	1.4**	1.3*	1.0	0.8	1.0
income to federal	100 17770	(1.0 - 2.0)	(1.0 - 1.9)	(0.6 - 1.5)	(0.6 - 1.1)	(0.7 – 1.5)
poverty level	200-399%	1.4*	1.8***	1.1	1.0	1.5**
(Reference group:		(1.0 - 1.9)	(1.3 - 2.4)	(0.7 - 1.5)	(0.7 - 1.2)	(1.1 - 2.0)
0-99% FPL)	>400%	2.2***	2.7***	1.6**	1.1	2.4***
		(1.6 - 3.1)	(2.0 - 3.7)	(1.1 - 2.4)	(0.8 - 1.4)	(1.7 - 3.2)
Family structure	Two narents	0.8	0.7**	0.9	0.9	0.8
(Reference group:	unmarried	(0.5 - 1.2)	(0.5 - 1.0)	(0.5 - 1.5)	(0.6 - 1.2)	(0.5 - 1.2)
two parents,	Single	1.2	0.8	1.1	0.8**	0.7**
marneu	mother	(0.9 - 1.6)	(0.6 - 1.1)	(0.7 - 1.5)	(0.6 - 1.0)	(0.6 - 1.0)
	Other	1.0	0.6***	1.1	0.9	0.6***
		(0.7 - 1.4)	(0.4 - 0.9)	(0.6 - 1.8)	(0.6 - 1.2)	(0.4 - 0.9)
l anguage spoken	English	1.9**	1.4	1.0	1.2	2.1***
at home (Reference: Other (non-English)		(1.1 - 3.0)	(0.9 - 2.3)	(0.5 - 1.8)	(0.8 - 2.0)	(1.3 - 3.4)

Source: Child Trends' analysis of data from the National Survey of Children's Health, 2016-2017.

Significant difference at *p \leq 0.1, ** p \leq 0.05, *** p \leq 0.01

Note: Effects are based on weighted analysis.

Interpretation: compared to the reference group, who is more likely to have care that meets the criteria for a medical home or components of a medical home. Values greater than 1 indicate greater likelihood; values less than 1 indicate smaller likelihood. For example, compared to the reference group, Hispanic children are more likely than non-Hispanic White children to have a personal doctor or nurse.

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