

Children and Youth With Special Health Care Needs: A Profile

Reem M. Ghandour, DrPH, MPA, Ashley H. Hirai, PhD, Mary Kay Kenney, PhD

abstract

BACKGROUND AND OBJECTIVES: The National Survey of Children's Health (NSCH) is the nation's primary source for data on children and youth with special health care needs (CYSHCN) and the only source for state-level estimates. We provide the latest estimates of CYSHCN in the United States, describe population characteristics, as well as the proportion that are served in a well-functioning system of care.

METHODS: Data from the 2016, 2017, 2018, and 2019 NSCH were appended, resulting in a final analytic sample of 30 301 CYSHCN. Bivariate associations between the covariates and SHCN status as well as the 6 core outcomes that comprise a well-functioning system of care were examined using χ^2 tests. Multivariable logistic regression was used to identify factors independently associated with SHCN status and a well-functioning system of care.

RESULTS: The overall prevalence of CYSHCN was 18.8% and ranged from 13.6% in Hawaii to 24% of individuals included in the NSCH in West Virginia. The most reported type of SHCN was prescription medication use (29.3%), whereas 25.9% of CYSHCN had functional limitations. Over one-third reported no daily activity impacts, whereas 18.9% reported consistent or significant daily impacts. CYSHCN were more likely than non-CYSHCN to be male, older, non-Hispanic Black, live in poverty, and have public insurance but disparities by race and ethnicity and income were no longer significant after adjustment. Only 14.9% of CYSHCN were reported to receive care in a well-organized system. Rates were substantially lower among older and more heavily affected children with adjusted rate ratios for access to a well-functioning system of care, indicating a 72% reduction for adolescents (12–17), compared with young children (0–5) and a 24% to 53% reduction for those with more than a prescription medication qualifying need.

CONCLUSIONS: CYSHCN remain a sizable and diverse population with distinct challenges in accessing well-functioning systems of care, particularly for those with the greatest needs. Our results provide a profile of the population designed to inform future surveillance, research, program, and policy priorities showcased in this Special Issue.

US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Rockville, Maryland

DOI: <https://doi.org/10.1542/peds.2021-056150D>

Accepted for publication Mar 4, 2022

Address correspondence to Reem M. Ghandour, DrPH, MPA, Director, Division of Epidemiology, Office of Epidemiology and Research, Maternal and Child Health Bureau, Health Resources and Services Administration, 5600 Fishers Ln, Rm 18N122, Rockville, MD 20857. E-mail: rghandour@hrsa.gov

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

This is an open access article distributed under the terms of the Creative Commons (CC BY-NC-ND 4.0) Attribution License which permits noncommercial distribution and reproduction in any medium, provided the original author and source are credited.

FUNDING: Funding for the publication of this article, including editorial support (review for formatting and consistency) for this article was funded by the US Department of Health and Human Services, Health Resources and Services Administration under contract number 75R60219D00014.

CONFLICT OF INTEREST DISCLOSURES: The authors have indicated they have no financial relationships relevant to this article to disclose.

WHAT'S KNOWN ON THIS SUBJECT: Children and youth with special health care needs (CYSHCN) are a sizable and diverse population with variable access to well-functioning systems of care. The National Survey of Children's Health is the nation's primary source for data on CYSHCN and the only source for state-level estimates.

WHAT THIS STUDY ADDS: From 2016 to 2019, the overall prevalence of CYSHCN was 18.8% nationally, and ranged from 13.6% to 24% by state. Only 14.9% of CYSHCN received care in a well-organized system, and rates were substantially lower among older and more severely affected children.

To cite: Ghandour RM, Hirai AH, Kenney MK. Children and Youth With Special Health Care Needs: A Profile. *Pediatrics*. 2022;149(s7):e2021056150D

For more than 100 years, the federal government has maintained a special responsibility to serve children, particularly those living with complex and chronic medical conditions. Over time, our understanding of this population has evolved: from the “crippled children’s programs” of the 1930s, to the establishment of the Title V Maternal and Child Health Services Block Grant¹ program in 1981 with calls to support a system of care for a broader “noncategorical” definition of children with chronic health needs.^{2,3} Finally, in 1998, the Health Resources and Services Administration’s Maternal and Child Health Bureau (HRSA MCHB) embraced a new approach, defining Children and Youth with Special Health Care Needs (CYSHCN) as “those 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.”⁴ Two years later, HRSA MCHB, in collaboration with partners and stakeholders, specified 6 “core outcomes” comprising a system of care for CYSHCN and their families.^{5,6}

These policy evolutions ultimately drove a significant shift in surveillance and, in 2001, HRSA MCHB worked with the Centers for Disease Control and Prevention’s National Center for Health Statistics (CDC NCHS) to field the first National Survey of Children with Special Health Care Needs (NS-CSHCN). Designed to produce estimates of the prevalence and impact of special health care needs (SHCN) across the nation and in each state, as well as the proportion of this population that reported receiving services in a well-functioning system of care, the NS-CSHCN was the first population-level surveillance system to employ a noncategorical definition of SHCN aligned with HRSA MCHB’s definition

of CYSHCN and capable of assessing the complex array of sociodemographic, health, healthcare, and other systems-related factors that can influence the health and well-being of this unique, yet sizable population of children.⁷ Over 2 decades later, HRSA MCHB has extended this investment through the redesigned National Survey of Children’s Health (NSCH). Today, assessment of the prevalence and impact of SHCN in the NSCH remains anchored by the CSHCN screener,^{8–10} a brief, parent-reported questionnaire that assesses the presence of 5 impacts that may be experienced as the result of a chronic condition, regardless of diagnoses. This information is complemented by robust content on healthcare access, utilization, and quality and related child-, family- and community-level factors. As a result, the NSCH remains a critical source for data on the health, wellbeing, and needs of CYSHCN and the only source for state-level estimates.

The 4 goals of this paper are: (1) to provide national and state-level estimates of the prevalence of SHCN in the United States using the latest data from the NSCH; (2) to describe sociodemographic and health status-related characteristics of CYSHCN and their families; (3) to describe the proportion of CYSHCN that are served in a “system of care;” and (4) to provide an overview of the NSCH.

METHODS

Data Source

The NSCH is funded and directed by the HRSA MCHB and conducted by the US Census Bureau. The NSCH was significantly redesigned for 2016, combining 2 previously separate quadrennial surveys, the National Survey of Children With Special Health Care Needs (NS-CSHCN) and the NSCH.¹¹ Since 2016, the survey has been conducted as an

annual, cross-sectional, address-based, self-administered survey using both web and paper-based methodologies. The survey employs a 2-phased design: (1) a screener to assess the presence, basic demographic characteristics, and SHCN status of children in the home; and (2) a detailed, age-specific questionnaire (0–5 years, 6–11 years, and 12–17 years) that collects information about the health, health care, and related family and community-level factors that can impact health for 1 randomly selected child. The 2-phased design is notable because it facilitates an 80% oversample of CYSHCN in households with both CYSHCN and non-CYSHCN present.¹²

Data are collected for approximately 9 months of the year (June–January) and released the following October. The 2016 NSCH yielded a total of 50 212 questionnaires, followed by 21 599 in 2017, 30 530 in 2018, and 29 433 in 2019. The overall weighted response rate in each year was: 40.7%, 37.4%, 43.1%, and 42.4%, respectively, and the weighted interview completion rates (reflecting the probability that a household that started the survey completed it) were 69.7%, 70.9%, 78.0%, and 79.5%. Approximately 75% of all questionnaires are completed online with the remainder completed via paper and mail. Participation in the survey is voluntary, and data are collected in English or Spanish from a parent or caregiver knowledgeable about the child’s health and health care. The design and administration have been described previously.^{12–15} NSCH data and questionnaires are publicly available.¹⁶

Variables

CYSHCN are identified using the CSHCN screener which assesses: (1) need and use of prescription medication; (2) above-routine use of medical, mental health, or

TABLE 1 Items Used in the CSHCN Screener in Years 2016 to 2019 of the National Survey of Children's Health

Number	Question
Question 1	Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
Follow-up 1	Is this because of any medical, behavioral, or other health condition?
Follow-up 2	Is this a condition that has lasted or is expected to last for at least 12 mo?
Question 2	Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
Follow-up 1	Is this because of any medical, behavioral, or other health condition?
Follow-up 2	Is this a condition that has lasted or is expected to last for at least 12 mo?
Question 3	Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
Follow-up 1	Is this because of any medical, behavioral, or other health condition?
Follow-up 2	Is this a condition that has lasted or is expected to last for at least 12 mo?
Question 4	Does your child need or receive special therapy, such as physical, occupational, or speech therapy?
Follow-up 1	Is this because of any medical, behavioral, or other health condition?
Follow-up 2	Is this a condition that has lasted or is expected to last for at least 12 mo?
Question 5	Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives treatment or counseling?
Follow-up 1	Has this problem lasted or is it expected to last for at least 12 mo?

Source: Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002;2(1):38-48.

educational services compared with other children of the same age; (3) functional limitations in day-to-day life; (4) need and use of specialized therapies; and (5) need and use of treatment or counseling for an emotional, behavioral, or developmental condition. Following each question, respondents confirm the presence of a related physical, mental, behavioral, or other health condition that has or is expected to last at least 12 months (Table 1).^{8,17} Type of SHCN was derived from responses to the screener items and grouped according to healthcare and functional impacts: (1) prescription medication need and use only, (2) elevated service need and use only, (3) elevated service need and use and prescription medication need and use, or (4) functional limitations.¹⁸

Sociodemographic characteristics considered include the child's sex, age (0–5, 6–11, or 12–17 years), race and ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic American Indian or Alaska Native, non-Hispanic Asian, non-Hispanic Native Hawaiian or Other Pacific Islander, or non-

Hispanic Multiple race), primary household language (English or non-English), parental nativity (parent(s) born in United States or parent(s) born outside of United States), family structure (2 parents, married; 2 parents, unmarried; single parent; or other), household income-to-poverty ratio (<100% FPL, 100% to 199% FPL, 200% to 399% FPL, or ≥400% FPL), highest education among primary caregivers in the household (less than or equal to high school or general educational development (GED), some college or associate's degree, or greater than or equal to a bachelor's degree), insurance status and type (public only, private only, combination of public and private, or uninsured), military status of primary caregivers in the household (current active duty, previous but not current active duty, active duty for training in the Reserves or National Guard, or no military service), state of residence, geographic region (Northeast, South, Midwest, or West), and urban-rural residence, defined by metropolitan statistical area (MSA) designation (MSA Principal City, MSA nonPrincipal City, or non-MSA).¹⁹

Health-related factors include: daily activity limitations (never affected; moderately affected - some of the time; or consistently affected - often or a great deal) and the presence of 1 or more physical, emotional or developmental diagnosed conditions. The NSCH assesses the presence of 27 conditions based on parent and caregiver responses to the following question: "Has a doctor or other health care provider ever told you that this child has ...;" affirmative responses are followed by condition-relevant follow-up questions.

The receipt of comprehensive, high-quality services in a well-functioning system of care is assessed using 34 separate survey items which comprise 5 to 6 core outcomes, depending on the child's age: (1) families are partners in decision-making; (2) medical home access; (3) early and continuous screening for special health care needs (operationalized through receipt of preventive health care); (4) continuous and adequate health insurance; (5) access to community-based services; and for children ages 12 to 17 years, (6) receipt of healthcare transition planning services. A full list of survey items used to assess the core outcomes is presented in Table 2.

Analyses

Public Use Data files for 2016, 2017, 2018, and 2019 were appended to obtain the largest possible sample of CYSHCN for a final analytic sample of 131 774 children ages 0 to 17 years old, including 30 301 CYSHCN. Bivariate associations between the covariates and SHCN status as well as the 6 core outcomes were examined using χ^2 tests (Tables 3 and 4). Multivariable logistic regression was used to identify factors independently associated with SHCN status and receipt of care in a well-functioning system (Table 5). State-

TABLE 2 Survey Items Used in Composite Measures for a Well-Functioning System of Care in Years 2016 to 2019 of the National Survey of Children's Health

Measure or Component	Survey Item
Core outcome 1: family partnership in decision making (when relevant)	
Doctors always or usually discuss range of options	During the past 12 months, how often did this child's doctors or other health care providers discuss with you the range of options to consider for his or her health care or treatment?
Doctors always or usually make it easy to raise concerns or disagree	During the past 12 months, how often did this child's doctors or other health care providers make it easy for you to raise concerns or disagree with recommendations for this child's health care?
Doctors always or usually work with family to make decisions	During the past 12 months, how often did this child's doctors or other health care providers work with you to decide together which health care and treatment choices would be best for this child?
Core outcome 2: medical home	
Usual source of care	Is there a place that this child usually goes when he or she is sick or you or another caregiver needs advice about his or her health?
Personal doctor or nurse	Do you have 1 or more persons you think of as this child's personal doctor or nurse? A personal doctor or nurse is a health professional who knows this child well and is familiar with this child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant.
No problems getting referrals (when relevant)	During the past 12 months, did this child need a referral to see any doctors or receive any services? → If yes, how much of a problem was it to get referrals?
Care coordination (when relevant)	During the past 12 months, have you felt that you could have used extra help arranging or coordinating this child's care among the different health care providers or services? → If yes, during the past 12 months, how often did you get as much help as you wanted with arranging or coordinating this child's health care? Overall, how satisfied are you with the communication among this child's doctors and other health care providers? During the past 12 months, did this child's health care provider communicate with the child's school, child care provider, or special education program? → If yes, overall, how satisfied are you with the health care provider's communication with the school, child care provider, or special education program?
Family-centered care	During the past 12 months, how often did this child's doctors or other health care providers spend enough time with this child? During the past 12 months, how often did this child's doctors or other health care providers listen carefully to you? During the past 12 months, how often did this child's doctors or other health care providers show sensitivity to your family's values and customs? During the past 12 months, how often did this child's doctors or other health care providers provide the specific information you needed concerning this child? During the past 12 months, how often did this child's doctors or other health care providers help you feel like a partner in this child's care?
Core outcome 3: early and continuous screening for special health care needs	
Preventive medical care visit	During the past 12 months, did this child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations, or any other kind of medical care? → If yes, during the past 12 months, how many times did this child visit a doctor, nurse, or other health care professional to receive a preventative check-up? A preventative check-up is when this child was not sick or injured, such as an annual or sports physical, or well-child visit.
Preventive dental care visit	During the past 12 months, did this child see a dentist or other oral health care provider for any kind of dental or oral health care? → If yes, during the past 12 months, did this child see a dentist or other oral health care provider for preventive dental care, such as check-ups, dental cleanings, dental sealants, or fluoride treatments?
Core outcome 4: continuous and adequate health insurance	
Current insurance coverage	Is this child currently covered by any kind of health insurance or health coverage plan?
No gaps in insurance coverage in past year	During the past 12 months, was this child ever covered by any kind of health insurance or health coverage plan?

TABLE 2 Continued

Measure or Component	Survey Item
Insurance always or usually meets needs for services	How often does this child's health insurance offer benefits or cover services that meet this child's needs?
Insurance always or usually meets needs for providers	How often does this child's health insurance allow him or her to see the health care providers he or she needs?
Out-of-pocket costs always or usually reasonable	Including copays and amounts from Health Savings Accounts and Flexible Spending Accounts, how much money did you pay for this child's medical, health, dental, and vision care during the past 12 months? Do not include health insurance premiums or costs that were or will be reimbursed by insurance or another source. How often are these costs reasonable?
Core outcome 5: access to community-based services Needs for health care are met	During the past 12 months, was there any time when this child needed health care, but it was not received? By health care, we mean medical care as well as other kinds of care like dental care, vision care, and mental health services.
Never or sometimes frustrated in trying to get services	During the past 12 months, how often were you frustrated in your efforts to get services for this child?
Core outcome 6: healthcare transition planning services Health care provider discussed the shift to a provider who treats adults (when relevant, among youth who see providers who treat only children)	Do any of this child's doctors or other health care providers treat only children? → If yes, have they talked with you about having this child eventually see doctors or other health care providers who treat adults?
Health care provider actively worked to help youth gain self-care skills or understand changes in health care	Has this child's doctor or other health care provider actively worked with this child to gain skills to manage his or her health and health care? For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he or she may need? Has this child's doctor or other health care provider actively worked with this child to understand the changes in health care that happen at age 18? For example, by understanding changes in privacy, consent, access to information, or decision-making?
Youth had time alone with health care provider at last preventive visit	At his or her last preventive check-up, did this child have a chance to speak with a doctor or other health care provider privately, without you or another adult in the room? (Note: youth with no preventive check-up in the past 12 mo are coded as No.)

Reproduced in part with permission from the authors.²¹

level estimates were compared with the national estimate using *t* tests for overlapping groups (Fig 1 and Supplemental Table 6). Urban-rural estimates were calculated using the restricted access file and approved for release by the US Census Bureau (disclosure avoidance approval number CBDRB-FY21-POP001-0179).

Sample weights are developed by the US Census Bureau annually to account for differences in the probability of household selection and differential nonresponse. Missing data for child sex, race, and ethnicity were imputed using hotdeck methods (missing <1%). Two additional variables were multiply imputed using sequential regression methods: federal poverty ratio (missing: 18.6% in 2016, 16.0% in 2017, 15.3% in 2018, and 17.6% in 2019) and respondent's

educational attainment (missing: 3.0% in 2016, 2.0% in 2017, 2.0% in 2018, and 2.4% in 2019). The application of these weights to analyses allow for the production of estimates that are representative of all noninstitutionalized children ages 0 to 17 residing in housing units at both the national and state levels. All analyses accounted for the complex survey design using SAS-callable SUDAAN, version 11.0.1. (Research Triangle Institute).

RESULTS

Nearly 14 million, or 18.8% of US children, were reported to have a SHCN from 2016 to 2019. As illustrated in Table 3, the sociodemographic profile of the SHCN population differed from the population without such needs. For example, although the child population without SHCN was

roughly evenly split by sex and age, CYSHCN were more likely to be male (58.0% versus 49.5%) and older than 5 (88.2% versus 64.5%). With respect to race and ethnicity, CYSHCN were more likely than non-CYSHCN to be non-Hispanic Black (17.0% versus 12.4%), but less likely to be Hispanic (21.7% versus 26.1%) or non-Hispanic Asian (2.6% versus 5.1%). CYSHCN were less likely to live in a household where English was not the primary language (8.1% compared with 15.9%) or both parents were born outside of the United States (19.4% compared with 29.9%). CYSHCN were more likely to live in poverty (23.9% versus 19.4%) or have any public health insurance coverage (46.7% versus 32.9%) and less likely to live in a household where at least 1 adult had attained a college degree (46.6% versus 50.0%) or

TABLE 3 Sociodemographic Characteristics of US Children and Youth Ages 0 to 17 Years by Special Health Care Need Status, National Survey of Children's Health 2016 to 2019

	Children and Youth With Special Health Care Needs					Children and Youth Without Special Health Care Needs			
	Sample <i>n</i>	Weighted <i>N</i>	(%)	(95% CI)		Sample <i>n</i>	Weighted <i>N</i>	(%)	(95% CI)
Total	30 301	13 816 795	18.8	18.4	19.3	101 473	59 518 364	81.2	80.7–81.6
Sex									
Male	17 190	8 015 836	58.0	56.8	59.3	50 910	29 466 071	49.5	48.8–50.2
Female	13 111	5 800 959	42.0	40.7	43.2	50 563	30 052 293	50.5	49.8–51.2
Age, y									
0–5	4445	2 462 484	17.8	16.9	18.8	32 960	21 155 486	35.5	34.9–36.2
6–11	10 237	5 230 405	37.9	36.6	39.1	29 698	19 536 912	32.8	32.2–33.5
12–17	15 619	6 123 906	44.3	43.1	45.6	38 815	18 825 967	31.6	31.0–32.3
Race and ethnicity									
White, non-Hispanic	21 411	7 214 879	52.4	51.2	53.7	70 284	30 106 261	50.9	5.2–51.6
Black, non-Hispanic	2258	2 337 824	17.0	15.9	18.1	5841	7 338 499	12.4	11.9–12.9
Hispanic	3263	2 984 956	21.7	20.4	23.1	11 885	15 412 612	26.1	25.3–26.8
American Indian and Alaska Native, non-Hispanic	217	57 106	0.4	0.3	0.5	538	220 220	0.4	0.3–0.4
Asian, non-Hispanic	894	362 620	2.6	2.3	3.1	5765	3 018 723	5.1	4.8–5.4
Native Hawaiian or Other Pacific Islander, non-Hispanic	57	17 491	0.1	0.1	0.2	257	85 584	0.1	0.1–0.2
Multiple race, non-Hispanic	2064	782 974	5.7	5.2	6.2	6256	2 979 665	5.0	4.8–5.3
Primary household language									
English	29 096	12 592 197	91.9	90.9	92.8	93 412	49 595 133	84.1	83.4–84.8
Non-English	1029	1 112 595	8.1	7.2	9.1	7429	9 363 995	15.9	15.2–16.6
Nativity of parents and caregivers									
Parents born in the US	24 487	9 923 110	80.6	79.3	81.9	77 027	38 160 325	70.2	69.4–70.9
≥Parents born outside of US	3390	2 384 515	19.4	18.1	20.7	18 464	16 236 250	29.9	29.1–30.6
Family structure ^a									
2 parents, married	19 621	7 559 523	56.1	54.9	57.4	74 089	39 094 609	67.7	67.0–68.4
2 parents, unmarried	1915	1 176 851	8.7	8.0	9.6	6635	5 083 248	8.8	8.4–9.3
Single mother	6016	3 427 022	25.5	24.3	26.6	14 293	10 087 817	17.5	16.9–18.0
Other	2271	1 301 604	9.7	8.8	10.6	4568	3 506 074	6.1	5.7–6.5
Household income-to-poverty ratio, % FPL ^d									
<100% FPL	4042	3 298 531	23.9	22.5	25.3	10 615	11 539 341	19.4	18.7–20.1
100% to 199% FPL	5300	3 112 178	22.5	21.3	23.7	15 988	12 862 871	21.6	20.8–22.4
200% to 399% FPL	9012	3 527 820	25.5	24.4	26.7	31 507	16 551 422	27.8	27.2–28.5
≥400% FPL	11 947	3 878 266	28.1	27.0	29.1	43 364	18 564 730	31.2	30.6–31.8
Household educational attainment									
<High school or GED test	649	1 093 407	8.0	7.0	9.1	2392	5 629 556	9.5	8.9–10.2
High School or GED test	4022	2 843 498	20.8	19.6	21.9	12 541	11 183 406	19.0	18.4–19.6

TABLE 3 Continued

	Children and Youth With Special Health Care Needs					Children and Youth Without Special Health Care Needs			
	Sample <i>n</i>	Weighted <i>N</i>	(%)	(95% CI)		Sample <i>n</i>	Weighted <i>N</i>	(%)	(95% CI)
Some college or associate's degree	7649	3 384 402	24.7	23.7	25.8	22 539	12 707 854	21.5	21.0–22.1
≥Bachelor's degree	17 721	6 378 177	46.6	45.3	47.8	63 064	29 467 096	50.0	49.3–50.7
Insurance status and type									
Public only	7817	5 272 288	38.9	37.6	40.2	17 651	16 935 392	29.1	28.3–29.8
Private only	19 058	6 697 154	49.4	48.1	50.7	75 077	35 012 649	60.1	59.3–60.8
Public and private combined	2103	1 051 399	7.8	7.1	8.5	2739	2 238 476	3.8	3.5–4.2
Not insured	939	536 476	4.0	3.4	4.5	4446	4 104 362	7.0	6.6–7.5
Household military status ^b									
Now on active duty	242	148 164	1.1	0.9	1.4	952	689 250	1.2	1.0–1.4
On active duty in the past, but not now	1940	1 237 050	9.3	8.4	10.4	5001	3 991 737	6.9	6.5–7.3
Only on active duty for training in the Reserves or National Guard	367	222 286	1.7	1.4	2.0	1071	864 157	1.5	1.3–1.7
Never served in the military	16 017	11 641 254	87.9	86.8	88.9	54 205	52 112 537	90.4	89.9–90.8
Geographic region									
Northeast	5603	2 206 310	16.0	15.2	16.8	18 100	9 500 170	16.0	15.6–16.3
Midwest	7346	3 102 352	22.5	21.6	23.3	24 900	12 386 385	20.8	20.5–21.2
South	10 466	5 656 542	40.9	39.8	42.1	32 040	22 683 273	38.1	37.6–38.6
West	6886	2 851 590	20.6	19.5	21.8	26 433	14 948 536	25.1	24.6–25.7
Rural or urban ^c									
Metropolitan principal city	8300	4 557 000	33.0	31.7	34.3	27 500	19 130 000	32.1	31.4–32.8
Metropolitan statistical area, not principal city	16 000	7 516 000	54.4	53.1	55.7	54 500	33 710 000	56.6	55.9–57.3
Not in a metropolitan statistical area	5800	1 743 000	12.6	12.0	13.3	19 000	6 683 000	11.2	10.9–11.5
Number of qualifying criteria									
1 criteria	13 177	5 687 954	41.2	40.0	42.4	—	—	—	—
2 criteria	6573	3 027 594	21.9	20.9	23.0	—	—	—	—
3 criteria	5215	2 384 833	17.3	16.3	18.3	—	—	—	—
4 criteria	3236	1 682 034	12.2	11.2	13.2	—	—	—	—
5 criteria	2100	1 034 380	7.5	6.9	8.1	—	—	—	—
Type of qualifying criteria									
Prescription medication only (no other qualifying needs)	9729	4 04 891	29.3	28.2	30.3	—	—	—	—
Above-routine use of services or use of specialized	5054	2 492 037	18.0	17.1	19.0	—	—	—	—

TABLE 3 Continued

	Children and Youth With Special Health Care Needs				Children and Youth Without Special Health Care Needs				
	Sample <i>n</i>	Weighted <i>N</i>	(%)	(95% CI)	Sample <i>n</i>	Weighted <i>N</i>	(%)	(95% CI)	
services (no other qualifying needs)									
Prescription medication use and above-routine use of services		8440			3 699 841	26.8	25.7	27.9	—
Functional limitations (alone or in combination with other qualifying needs)	7078	3 583 026	25.9	24.7	27.2	—	—	—	—
Activity limitations									
Daily activities never affected	9729	4 044 652	35.4	34.1	36.7	—	—	—	—
Daily activities moderately affected or some of the time	11 539	5 224 777	45.7	44.3	47.1	—	—	—	—
Daily activities consistently affected or often or a great deal	4173	2 160 776	18.9	17.8	20.1	—	—	—	—

All χ^2 tests of independence were statistically significant at $P < .001$. FPL, federal poverty level; GED, general educational development. —, not applicable.

^a Single parenthood was assessed only for mothers in 2016; beginning in 2017, single fatherhood was also assessed.

^b Military status was not assessed in 2016; data are reflective of 81 562 children between 2017 and 2019.

^c Uses complete geographic information available on the restricted access file; the US Census Bureau reviewed this data product for unauthorized disclosure of confidential information and approved the disclosure avoidance practices applied to this release, CBDRB-FY21-POP001-0179.

^d Federal poverty threshold for a family of 4 was \$24 563 in 2016, \$25 094 in 2017, \$25 701 in 2018, and \$26 172 in 2019.²²

had 2 married parents (56.1% versus 67.7%). Geographic variation was observed by both region and state, with a lower percentage of CYSHCN compared with non-CYSHCN residing in the West (20.6% versus 25.1%) and state-level CYSHCN prevalence estimates ranging from 13.6% in Hawaii to 24.0% in West Virginia (Fig 1). No difference was observed by urban-rural residence.

After adjustment, observed bivariate associations generally remained, with a few notable exceptions (Table 4). The association between race and ethnicity and poverty with SHCN status were both attenuated and no longer significant after

adjustment, whereas the association between parental education and SHCN status reversed such that children of parents with less education were less, rather than more, likely to have a SHCN.

CYSHCN are a heterogeneous population and the nature and impact of their health status and needs can be characterized in multiple ways. For example, using the 5 screening criteria in the CSHCN screener, nearly two-thirds (63.1%) of CYSHCN qualified based on meeting 1 or 2 screening criteria, whereas only 7.5% were reported to meet 5 criteria. The most commonly reported type of SHCN was prescription

medication use without the need for or use of additional services (29.3%) followed by need and use of prescription medication service utilization at an above-routine rate (26.8%) and functional limitations (25.9%), whereas 18.0% needed and used elevated medical, mental health, or education services without some other qualifying impact (Table 3; Fig 2).

The most common of 27 captured health conditions among CYSHCN was allergies (42.0%), followed by ADHD (33.8%), and behavior or conduct problems (27.4%). Eight of the top 10 health conditions among CYSHCN were developmental, mental, or

TABLE 4 Proportion of Children and Youth With Special Health Care Needs Meeting the Criteria for the 6 Core Quality Outcomes by Sociodemographic Characteristics, National Survey of Children's Health 2016 to 2019

	Core Outcome 1: Shared Decision Making ^a		Core Outcome 2: Medical Home		Core Outcome 3: Adequate Insurance ^b		Core Outcome 4: Preventive Medical and Dental Care		Core Outcome 5: Ease of Access		Core Outcome 6: Healthcare Transition Planning ^c		System of Care	
	(n = 13 571)	(95% CI)	(n = 14 673)	(95% CI)	(n = 18 572)	(95% CI)	(n = 24 294)	(95% CI)	(n = 27 385)	(95% CI)	(n = 34 53)	(95% CI)	(n = 48 59)	(95% CI)
Total	83.2	81.7–84.7	42.7	41.5–44	63	61.8–64.2	75.1	73.9–76.3	87.7	86.7–88.6	19.9	18.5–21.3	14.9	14.1–15.6
Sex														
Male	82.9*	80.9*–84.8*	42.1*	40.5*–43.7*	63.8*	62.2*–65.3*	74.1	72.4–75.7	87.4*	86.2*–88.6*	16.5	14.9–18.3	15.2*	14.2*–16.3*
Female	83.6*	81.1*–85.8*	43.7*	41.8*–45.6*	62.0*	60.0*–63.9*	76.6	74.7–78.3	88.1*	86.5*–89.6*	23.6	21.5–26	14.4*	13.3*–15.5*
Age, y														
0–5	81.2*	77.8*–84.2*	40.7*	37.8*–43.6*	66.2	63.4–68.9	64.5	61.5–67.4	89.9	88–91.6	—	—	19.7	17.6–22
6–11	83.6*	81.3*–85.6*	41.9*	39.9*–43.9*	63.2	61.2–65.2	78.3	76.2–80.2	86.9	85.2–88.5	—	—	23	21.5–24.6
12–17	83.9*	81.1*–86.3*	44.3*	42.5*–46.1*	61.6	59.7–63.4	76.7	74.9–78.5	87.5	86–88.9	19.9	18.5–21.3	6	5.4–6.6
Race and ethnicity														
White, non-Hispanic	85.8	84.4–87	47.6	46.4–48.9	61.2	60–62.4	78.4	77.2–79.5	90.1	89.3–90.8	20.7*	19.3*–22.1*	16.2	15.3–17.1
Black, non-Hispanic	80.8	74.4–86	39.6	36.1–43.1	67.4	63.7–70.8	70.7	67–74.1	84.5	80.7–87.6	19.0*	15.5*–23.0*	13.3	11.4–15.4
Hispanic	77.7	72.4–82.2	33.7	30.2–37.3	63.7	59.9–67.3	70.4	66.5–74	84.1	81.2–86.6	17.0*	13.1*–21.7*	12.3	10.3–14.5
American Indian or Alaska Native, non-Hispanic	72.3	52–86.2	37.1	28.4–46.7	65.8	55.8–74.6	66.6	55.8–75.9	82.8	72.6–89.7	18.0*	10.4*–29.3*	11.7	7.2–18.6
Asian, non-Hispanic	81.6	70.5–89.1	44.9	37.5–52.6	62.8	55.3–69.7	72.2	64.7–78.6	91.7	86.2–95.1	21.6*	14.1*–31.8*	16.2	10.5–24.1
Native Hawaiian or other Pacific Islander, non-Hispanic	90.3	64.3–98	24.2	13.4–39.8	64.6	44.2–80.9	66.4	46.6–81.8	79.4	54.7–92.5	13.5*	5.3*–30.0*	3.7	1.2–10.6
Multiple race, non-Hispanic	82.4	76.3–87.2	42.9	38.9–47	63.9	59.8–67.8	78.8	74.9–82.2	87.9	84.7–90.5	25.7*	20.8*–31.3*	17.5	14.8–20.5
Primary household language														
English	84.2	82.6–85.6	44.1	42.8–45.3	62.7*	61.5*–63.9*	76.2	75–77.4	88.1*	87.1*–89.0*	20.3	18.9–21.7	15.3	14.5–16.1
Non-English	68.6	57.9–77.7	29	23.5–35.1	66.1*	59.6*–72.1*	63	56.2–69.3	85.2*	79.7*–89.4*	13.5	8.7–20.4	10.5	7.3–14.9
Nativity of parents and caregivers														
Parents born in the US	84.8*	83.4*–86.2*	45.5	44.2–46.8	62.7*	61.4*–63.9*	77	75.7–78.2	88.7*	87.8*–89.6*	21	19.5–22.6	15.7	14.9–16.6
≥Parent born outside of US	80.3*	75.2*–84.5*	35	31.4–38.9	59.3*	55.2*–63.2*	70.9	66.6–74.8	86.8*	83.9*–89.2*	14.3	10.9–18.4	12.1	10–14.6
Family Structure ^d														
Family Structure ^d	86.2	84.5–87.7	48.2	46.6–49.7	59	57.4–60.5	78.7	77.1–80.3	90.6	89.6–91.6	20.2*	18.4*–22.2*	16.4	15.4–17.4

TABLE 4 Continued

	Core Outcome 1: Shared Decision Making ^a		Core Outcome 2: Medical Home		Core Outcome 3: Adequate Insurance ^b		Core Outcome 4: Preventive Medical and Dental Care		Core Outcome 5: Ease of Access		Core Outcome 6: Healthcare Transition Planning ^c		System of Care								
	(n = 13 571)	(95% CI)	(n = 14 673)	(95% CI)	(n = 18 572)	(95% CI)	(n = 24 294)	(95% CI)	(n = 27 385)	(95% CI)	(n = 3453)	(95% CI)	(n = 4939)	(95% CI)							
	%		%		%		%		%		%		%								
2 parents, married	79.9	72.8	85.5	33.3	28.6	38.4	68.7	64.1	72.9	72.3	67.7	76.6	85.1	80.9	88.5	20.4*	15.2*	26.8*	12.8	10.2	16
2 parents, unmarried	79.9	76.6	82.9	36.1	33.7	38.5	65.6	63	68	71	68.4	73.4	84.5	82.5	86.3	19.0*	16.5*	21.7*	12.6	11.2	14.2
Single mother or father	77.3	67.4	84.9	40.4	36	15	73.9	69.2	78.1	68.5	63.8	72.8	82.5	76.9	87	21.1*	16.6*	26.6*	15.4	12.9	18.3
Household income- to-poverty ratio, % FPL	74.8	69.8	79.3	31.8	28.9	34.9	71.3	68.2	74.1	67.7	64.4	70.8	84.5	81.9	86.7	18.2*	15.1*	21.7*	11.5	9.8	13.5
<100% FPL	79.3	74.3	83.5	39.5	36.6	42.5	66.9	63.8	69.9	70.1	66.6	73.3	84.5	81.3	87.2	17.8*	15.1*	21.0*	14.3	12.6	16.3
100% to 199% FPL	84.4	81.8	86.7	44.9	42.6	47.1	56.1	53.8	58.4	77.5	75.2	79.6	87.6	85.8	89.1	20.9*	17.9*	24.4*	14.8	13.4	16.3
200% to 399% FPL	89.5	87.8	91	52.7	50.8	54.5	59.3	57.4	61.1	83.4	81.6	85.1	93.2	91.8	94.4	21.5*	19.6*	23.5*	18.2	16.9	19.6
≥400% FPL																					
Household educational attainment	73.9	63.4	82.2	29.7	24	36.1	66.6	59.6	73	55.9	48.7	62.9	83.4	78.3	87.5	18.8*	13.2*	26.1*	10.4	7.4	14.4
<High school or GED test	77	70.5	82.4	34.5	31.6	37.5	70.2	67.2	73.1	66.7	63.5	69.7	86.4	83.3	89	18.3*	15.2*	22.0*	12.1	10.5	13.9
High school or GED test	81.3	78.5	83.8	41.8	39.4	44.2	63.5	61.1	65.8	74.3	72	76.4	84.5	82.4	86.4	18.8*	16.5*	21.3*	14.3	12.8	16
Some college or associate's degree	86.9	85.5	88.2	49.5	48	51	58.9	57.4	60.4	82.9	81.6	84.1	90.8	89.8	91.7	21.2*	19.4*	23.2*	17.3	16.3	18.4
≥Bachelor's degree																					
Insurance status and type	78.2	75.1	81.1	35.7	33.5	37.9	80.6	78.6	82.5	69.8	67.4	72.2	86.1	84.3	87.7	17.8*	15.5	20.3*	14.8	13.5	16.3
Public only	87.5	85.8	88.9	51	49.5	52.5	54.4	52.9	55.9	80.9	79.5	82.2	91.8	90.7	92.8	21.0*	19.3*	22.9*	16.2	15.2	17.2
Private only	78.3	69.4	85.2	35.7	31.5	40	61.8	56.5	66.8	78.5	74.6	82	79.8	74.4	84.2	21.3*	16.1*	27.6*	14.3	11.7	17.4
Public and private combined	78.5	66.6	87	28.3	22.9	34.4	—	—	—	54.7	47.6	61.6	68.9	61.5	75.5	14.3*	9.6*	20.7*	—	—	—
Not insured																					
Household military status ^e	81.5*	67.7*	90.3*	33.2*	23.4*	44.8*	79	63.2	89.2	74.2*	59.0*	85.2*	90.2*	80.9*	95.2*	12.4*	4.7*	28.8*	16.8*	9.3*	28.4*
Now on active duty	81.8*	70.9*	89.2*	43.7*	38.5*	49.3*	61.4	55.4	67.2	77.6*	73.2*	81.45*	83.5*	75.8*	89.1*	26.9*	19.7*	35.4*	15.9*	12.9*	19.6*
On active duty in the past, but not now																					

TABLE 4 Continued

	Core Outcome 1: Shared Decision Making ^a		Core Outcome 2: Medical Home		Core Outcome 3: Adequate Insurance ^b		Core Outcome 4: Preventive Medical and Dental Care		Core Outcome 5: Ease of Access		Core Outcome 6: Healthcare Transition Planning ^c		System of Care									
	(n = 13,571)	(95% CI)	(n = 14,673)	(95% CI)	(n = 18,572)	(95% CI)	(n = 24,294)	(95% CI)	(n = 27,385)	(95% CI)	(n = 3,453)	(95% CI)	(n = 4939)	(95% CI)								
Only on active duty for training in the Reserves or National Guard	86.3*	76.3*	92.5*	46.3*	37.7*	55.2*	58.5	49.5	67	82.2*	73.4*	88.5*	85.3*	77.4*	90.8*	21.1*	14.2*	30.3*	13.7*	9.5*	19.2**	
Never served in the military	83.3*	81.5*	85.1*	42.9*	41.3*	44.5*	61.7	60.2	63.3	74.4*	72.7*	76.0*	87.9*	86.8*	89.0*	20.7*	19.0*	22.5*	14.3*	13.4*	15.4*	
Geographic region																						
Northeast	84.3*	81.1*	87.1	42.8	40.2	45.6	64.8*	62.1*	67.4*	80.4	77.9	82.8	88.8	86.8	90.6	20.7	17.6	24.3	16.0*	14.1*	18.0*	
Midwest	84.1*	81.5*	86.4*	45.3	43.4	47.3	62.2*	60.2*	64.1*	75.4	73.4	77.3	88.3	86.6	89.7	22.7	20.4	25.2	15.8*	14.4*	17.2*	
South	82.7*	79.7*	85.3*	42.7	40.8	44.7	63.8*	61.8*	65.7*	73.3	71.4	75.2	85.9	84	87.7	16.6	14.9	18.5	14.3*	13.2*	15.5*	
West	82.5*	78.9*	85.6*	39.9	36.6	43.2	61.2*	57.7*	64.5*	74.4	70.8	77.7	89.8	88	91.3	22.1	18.2	26.6	14.1*	12.2*	16.3*	
Rural or urban ^f																						
Metropolitan	82.3*	78.9*	85.2*	39.3	36.9	41.8	64.9	62.5	67.3	73.8	71.4	76.1	86.6*	84.4*	88.4*	20.4*	17.6*	23.7*	13.8*	12.3*	15.3*	
principal city																						
Metropolitan statistical area, not principal city	83.6*	81.5*	85.4*	44.1	42.6	45.7	61.5	60	63.1	76.7	75	78.3	88.2*	86.9*	89.3*	19.2*	17.6*	20.9*	15.5*	14.5*	16.5*	
Not in a metropolitan statistical area	84.2*	81.2*	86.8*	45.7	43.1	48.4	64.6	61.7	67.3	71.9	69.3	74.4	88.8*	87.1*	90.3*	21.2*	18.6*	24.1*	15.2*	13.5*	17.0*	
Number of qualifying criteria																						
1 criteria	87.1	84.6	89.2	49.8	48	51.6	66.1	64.3	67.8	75.4*	73.7*	77.0*	93.2	92.1	94.2	21.8	19.5	24.3	18.4	17.1	19.7	
2 criteria	84.3	81.1	87.1	44.7	42.1	47.3	62.4	59.7	64.9	76.0*	73.3*	78.4*	90.2	88.3	91.8	17.7	15.4	20.3	14.8	13.1	16.6	
3 criteria	80.3	75.4	84.4	38.2	35.2	41.2	59.7	56.4	62.9	74.6*	71.1*	77.8*	83.9	80.3	86.9	21.3	18.3	24.7	11.9	10.4	13.4	
4 criteria	79.3	75.2	82.8	31	27.2	35.1	62.6	58.6	66.5	72.4*	67.7*	76.6*	80.3	77.1	83.2	17.3	13.7	21.5	10.5	8.8	12.5	
5 criteria	80.4	76.3	84	27.6	24.2	31.3	56.5	52	60.8	77.3*	73.3*	80.9*	71.2	67.2	74.9	14.6	10.8	19.5	9.8	7.7	12.2	
Type of qualifying criteria																						
Prescription medication only (no other qualifying needs)	90.3	88.1	92.2	54.5	52.4	56.6	67.8	65.7	69.8	78.3	76.5	80.1	96.2	95.3	97	22.4	19.7	25.4	20.9	19.4	22.6	
Above-routine use of services or specialized	77.4	72.7	81.5	37.8	35	40.6	61.9	59	64.7	68.3	65.3	71.2	84.5	81.6	87	18.9	15.5	22.9	11.6	10.2	13.2	

TABLE 4 Continued

	Core Outcome 1: Shared Decision Making ^a (n = 13 571) %	Core Outcome 2: Medical Home (n = 14 673) %	Core Outcome 3: Adequate Insurance ^b (n = 18 572) %	Core Outcome 4: Preventive Medical and Dental Care (n = 24 294) %	Core Outcome 5: Ease of Access (n = 27 385) %	Core Outcome 6: Healthcare Transition Planning ^c (n = 3453) %	System of Care (n = 4939) %														
services (no other qualifying needs)	85.3	87.5	44.4	42.1	46.8	63.3	60.9	65.5	78.4	76	80.7	90	88.6	91.2	20.9	18.7	23.2	15.1	13.6	16.6	
Prescription medication use and above-routine use of services	78.8	75.3	81.9	31.2	28.7	33.7	58.2	55.5	61	72.9	70.1	75.6	78	75.4	80.4	15.8	13.4	18.4	10.1	8.8	11.4
Functional limitations (alone or in combination with other qualifying needs)	86.8	82.7	90.1	52.3	50.1	54.5	66.6	64.4	68.8	78.7	76.6	80.6	94.1	92.3	95.5	21.2	18.7	24	19.2	17.7	20.7
Activity limitations Daily activities never affected	83.6	81.7	85.4	41.4	39.4	43.5	60.8	58.8	62.8	76.8	74.8	78.6	87.3	85.7	88.7	20.9	18.5	23.4	14.2	13	15.6
Daily activities moderately affected or some of the time	77.5	74.1	80.5	26.5	23.7	29.5	57.9	54.6	61.1	72.7	69.2	76	72.4	69.5	75.2	16.3	13.5	19.6	7.3	6	9
Daily activities consistently affected or often or a great deal																					

*Indicates nonsignificant ($P > .05$, χ^2 tests. —, not applicable; FPL, federal poverty level; GED, general educational development.

^a Shared decision making is calculated for children whose parents and caregivers reported that such decision making was needed.

^b Adequate insurance includes consistency of coverage for the 12 mo before the survey response.

^c Transition planning is only assessed for children 12 to 17 y of age at the time of survey response.

^d Single parenthood was assessed only for mothers in 2016; beginning in 2017, single parenthood was also assessed.

^e Military status was not assessed in 2016; data are reflective of 13 475 children from 2017 to 2019.

^f Uses complete geographic information available on the restricted access file; the US Census Bureau reviewed these data product for unauthorized disclosure of confidential information and approved the disclosure avoidance practices applied to this release. CBDRB-FY21-POP001-0179.

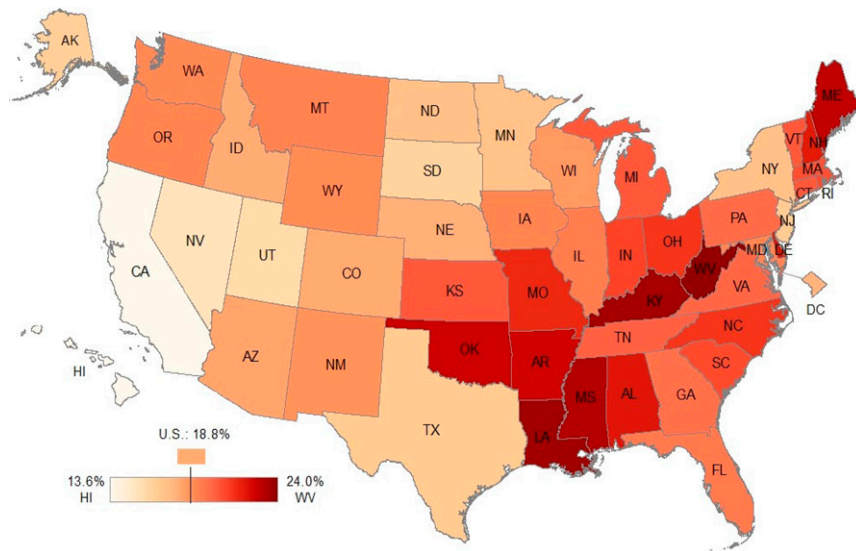


FIGURE 1 Prevalence of special health care needs among children and youth ages 0 to 17 years by state of residence from the National Survey of Children’s Health 2016 to 2019.

behavioral conditions (Fig 3). Among those with a condition, over one-third (35.4%) were reported to have no activity limitations, whereas 45.7% were reported to have moderately affected daily activities, and nearly one-fifth (18.9%) were reported to have consistently affected daily activities (Fig 4).

Overall, only 14.9% of CYSHCN were reported to receive care in a well-organized system (Table 5). The proportion of CYSHCN who met each of the core outcomes ranged from 19.9% for healthcare transition planning to 87.7% for ease of access to community-based services. Less than half of CYSHCN (42.7%) received care in a Medical

Home whereas nearly two-thirds (63.0%) were reported to have both continuous and adequate insurance coverage. Significant differences in the proportion of CYSHCN receiving care in a well-organized system were observed. Specifically, rates were higher among younger, non-Hispanic White children living in the United States, born in English-speaking households with greater educational attainment and income. However, after adjustment, race and ethnicity, primary household language, and educational attainment were not significantly associated with receiving services in a well-organized system, whereas child age and SHCN type had the largest rate ratios indicating an approximately 50% to 75% lower likelihood among older CYSHCN and those with qualifying needs beyond prescription medication (Supplemental Table 2).

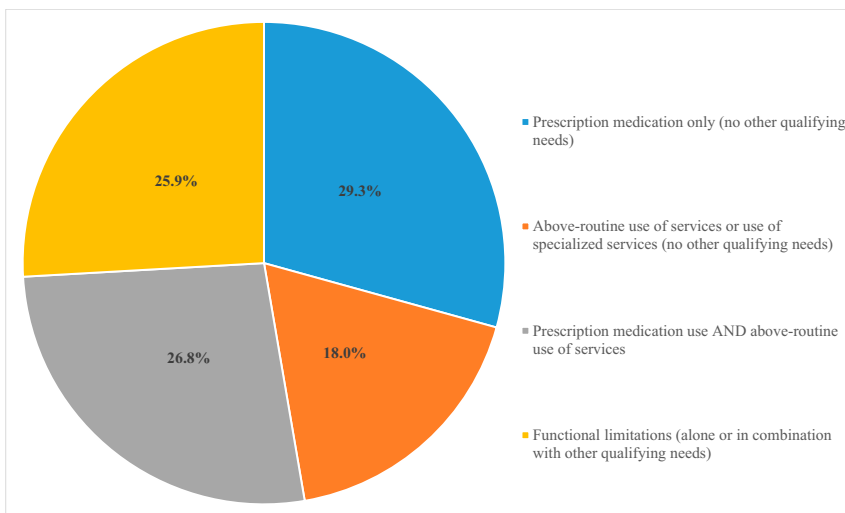


FIGURE 2 Prevalence of children and youth with special health care needs, by number and type of qualifying criteria among CYSHCN ages 0 to 17 from the National Survey of Children’s Health 2016 to 2019.

DISCUSSION

CYSHCN remain a sizable and diverse population within the United States, representing nearly one-fifth of all

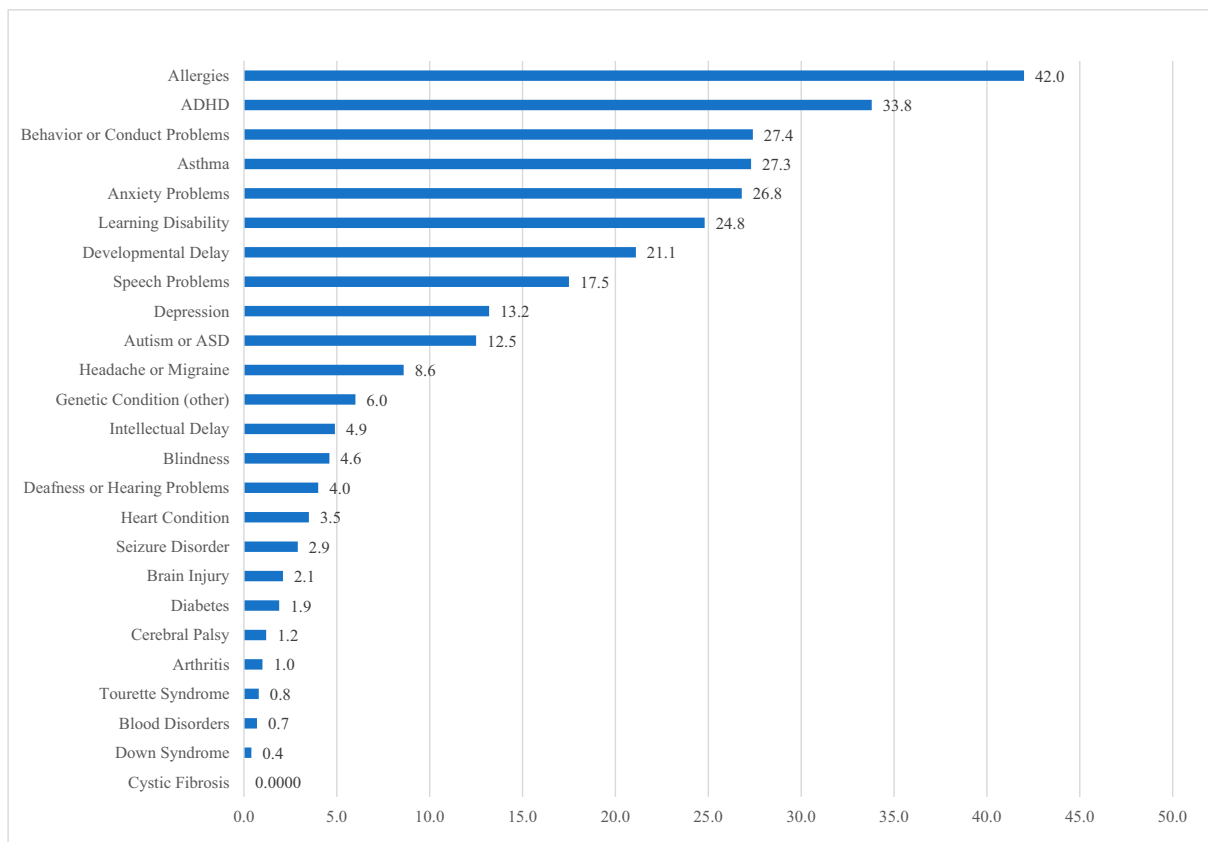


FIGURE 3
Prevalence of selected health conditions among CYSHCN ages 0 to 17 in years 2016 to 2019.

children. Our results highlight important sociodemographic and health-related patterns among the CYSHCN population and their families and are consistent with previous research regarding both the prevalence of SHCN and disparities in access to a high-quality, well-organized system of

care. Importantly, race and ethnicity and poverty were not associated with SHCN status after adjustment. However, the finding that first generation children and those in non-English speaking households are about a third less likely to have a SHCN after controlling for other

sociodemographic characteristics suggests that there may be persistent access barriers to diagnosis and/or that the screener may be less sensitive for these children. Unfortunately, only 1 in 5 CYSHCN receive care in a well-functioning system with the most opportunity for improvement for the medical home and adolescent transition to adult health care, supporting the longstanding selection of these indicators as Title V performance measures. That receipt of well-functioning systems of care is even lower for those who need it most—those with more qualifying criteria, more complex needs, and those with more activity limitations—continues to be striking and an area in major need for improvement. The lower rates of well-functioning systems of care for first generation and lower income CYSHCN even after

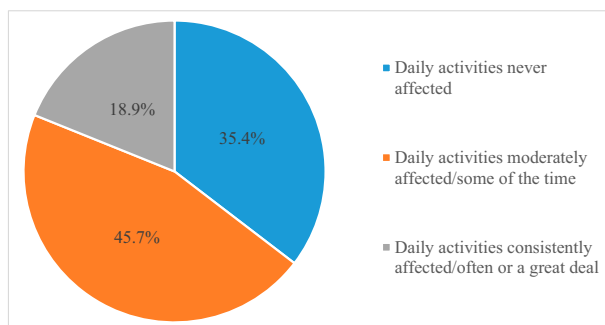


FIGURE 4
Percentage of children and youth with special health care needs by activity limitations among CYSHCN ages 0 to 17 in years 2016 to 2019.

TABLE 5 Adjusted Risk Ratio Special Health Care Needs, National Survey of Children's Health 2016 to 2019 (*n* = 120 104)

	aRR	(95% CI)
Sex		
Male	ref	0.73–0.80
Female	0.76	0.73–0.80
Age, y		
0–5	ref	ref
6–11	2.07	1.93–2.23
12–17	2.50	2.33–2.68
Race and ethnicity		
White, non-Hispanic	ref	ref
Black, non-Hispanic	0.99	0.91–1.08
Hispanic	1.02	0.94–1.10
American Indian or Alaska Native, non-Hispanic	0.98	0.79–1.22
Asian, non-Hispanic	0.87	0.75–1.02
Native Hawaiian or other Pacific Islander, non-Hispanic	0.87	0.57–1.34
Multiple race, non-Hispanic	1.13	1.04–1.24
Primary household language		
English	ref	ref
Non-English	0.66	0.57–0.78
Nativity of parents and caregivers		
Parents born in the United States	ref	ref
≥Parents born outside of United States	0.73	0.66–0.80
Family structure		
2 parents, married	ref	ref
2 parents, unmarried	1.04	0.94–1.14
Single mother or father	1.23	1.16–1.31
Other	1.26	1.05–1.51
Household income-to-poverty ratio, % FPL		
<100% FPL	1.02	0.92–1.13
100% to 199% FPL	0.92	0.85–1.01
200% to 399% FPL	0.95	0.89–1.00
≥400% FPL	ref	ref
Household educational attainment		
<High school or GED test	0.84	0.71–1.00
High school or GED test	0.83	0.76–0.90
Some college or associate's degree	0.93	0.8–0.99
≥Bachelor's degree	ref	ref
Insurance status and type		
Public only	1.62	1.51–1.75
Private only	ref	ref
Public and private combined	2.08	1.89–2.28
Not insured	0.80	0.67–0.95
Geographic region		
Northeast	ref	ref
Midwest	1.00	0.94–1.07
South	1.00	0.94–1.07
West	0.91	0.84–0.99
Rural or urban ^a		
Metropolitan principal city	ref	ref
Metropolitan statistical area, not principal city	0.95	0.90–1.01
Not in a metropolitan statistical area	0.93	0.86–1.01

FPL, federal poverty level; GED, general educational development; ref, reference.

^a Uses complete geographic information available on the restricted access file; the US Census Bureau reviewed this data product for unauthorized disclosure of confidential information and approved the disclosure avoidance practices applied to this release, CBDRB-FY21-POP001-0179.

adjustment indicates additional inequities in access to quality health care that must be addressed.

Of note, these analyses provide the foundation for the critical work featured in this Special Issue that

investigates the intersection of factors such as race, ethnicity, condition severity, complexity, and poverty. Taken together, these studies and the blueprint provide a set of priorities and actionable recommendations to support the health and wellbeing of CYSHCN and their families.

One such mechanism will continue to be the use of the NSCH as the primary national and state-level surveillance mechanism for this population. Although the annual administration has the capacity to produce both state- and national-level estimates, and breadth of content remain significant strengths, the NSCH is not without limitations. Specifically, work may be needed to assure that the CSHCN screener appropriately captures the full breadth of the SHCN population. Previous work has found discordance between the proportion of children for whom a diagnosed condition or functional difficulty was reported and the proportion identified as having a SHCN based on the same parent or caregiver's responses to the CSHCN screener.¹⁷ The drivers of this discordance may be varied, ranging from the transient nature of pediatric conditions and/or health needs, inaccurate diagnosis and reporting, and/or differences in cultural norms and expectations related to health status and care seeking.¹⁷ Further work is needed to assess who is captured using the screener, who is missed, and why.

Second, since 1998, the HRSA MCHB definition of CYSHCN has retained a reference to children "at risk" for developing SHCN and yet the survey continues to lack a standardized measure for this population. Newacheck et al proposed a conceptual model for the development of SHCN based on the presence of factors in multiple domains, operating at the child,

family, and community levels, which together, over time, create the conditions necessary for a SHCN.^{6,20} The application of this model to the first iteration of the NSCH found a wide range of factors to be associated with a higher risk for SHCN, as well as protective factors, but did not provide a clear risk profile, in large part because of the cross-sectional nature of the data and a paucity of indicators in some domains.²⁰ Using this broad lens to revisit the first limitation noted above, the observed incongruity between the proportion of children meeting 1 or more criteria of the CSHCN screener and the proportion of those with a diagnosed condition or noted limitation may reflect some portion of the at risk population – those with a condition that does not result in the impact(s) required by the screener. Further analyses are needed to test and refine a model toward the specification of policy- and programmatic-relevant approaches to defining risk that can ultimately inform research and prevention efforts.

Data from the NSCH are subject to at least 3 additional limitations. (1) Information is reported by parents and caregivers and thus, susceptible to response bias. Additionally, many of the component measures which comprise the core outcomes can be subjective in nature and parent and caregiver reports may be influenced by prior experiences and expectations. For example, a parent may not report unmet healthcare needs if they do not know of or expect their child to have access to particular services. Social desirability may also impact parental reports of health risk behaviors and, in some cases, diagnoses. (2) Because of changes in both sampling and mode of

administration, comparison of estimates from the redesigned NSCH to those from previous iterations of either the NSCH or the NS-CSHCN should not be made, thus precluding longer-term trend analyses. 3) Finally, the sampling strategy employed does not permit the collection of self-reported data from older adolescents (≥ 18 years) and young adults. As such, the capacity to assess the impact of healthcare transition planning is limited.

Looking Forward

Since the early 2000s, the NSCH has been a key source of information on the health, wellbeing, and needs of CYSHCN. The 2016 redesign ushered in important advances; however, opportunities exist to extend the utility of the survey. One recent evolution is the capacity for states to support oversamples that can be used to produce more robust analyses of rare outcomes or more granular geographic estimates. Additionally, HRSA MCHB is now planning to administer a longitudinal follow-up survey of respondents to previous NSCH surveys to assess the lasting effects of the COVID-19 pandemic on the health, wellbeing, and development of children in the United States. Although it is expected that the survey will yield important insights for all children, information on the experience of CYSHCN, particularly those who may have lost access to service supports and specialized care, will be critical to the development of future programs and policies. Through these advances and the release of high-quality, timely data from the annual NSCH, HRSA MCHB will continue to support critical research on the health status and needs of this vulnerable population to inform the development of effective programs

to serve CYSHCN and their families.

ABBREVIATIONS

NSCH: National Survey of Children's Health
 HRSA: Health Resources and Services Administration
 MCHB: Maternal and Child Health Bureau
 CYSHCN: Children and Youth with Special Health Care Needs

REFERENCES

1. US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Title v maternal and child health services block grant program. 2020; <https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program>. Accessed 2/25/2022
2. Perrin EC, Newacheck P, Pless IB, et al. Issues involved in the definition and classification of chronic health conditions. *Pediatrics*. 1993;91(4): 787–793
3. Stein RE, Bauman LJ, Westbrook LE, Coupey SM, Ireys HT. Framework for identifying children who have chronic conditions: the case for a new definition. *J Pediatr*. 1993; 122(3):342–347
4. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 Pt 1):137–140
5. Strickland BB, van Dyck PC, Kogan MD, et al. Assessing and ensuring a comprehensive system of services for children with special health care needs: a public health approach. *Am J Public Health*. 2011;101(2):224–231
6. Newacheck PW, Rising JP, Kim SE. Children at risk for special health care needs. *Pediatrics*. 2006;118(1): 334–342
7. van Dyck PC, McPherson M, Strickland BB, et al. The national survey of

- children with special health care needs. *Ambul Pediatr*. 2002;2(1):29–37
8. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002;2(1):38–48
 9. Bethell CD, Read D, Neff J, et al. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambul Pediatr*. 2002;2(1):49–57
 10. Carle AC, Blumberg SJ, Poblenz C. Internal psychometric properties of the children with special health care needs screener. *Acad Pediatr*. 2011;11(2):128–135
 11. Ghandour RM, Jones JR, Lebrun-Harris LA, et al. The design and implementation of the 2016 national survey of children's health. *Matern Child Health J*. 2018;22(8):1093–1102
 12. U.S. Census Bureau. 2016 national survey of children's health: methodology report. Available in: <https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/methodology/2016-NSCH-Methodology-Report.pdf>. Accessed July 6, 2018
 13. U.S. Census Bureau. 2017 national survey of children's health: methodology report. Available at: <https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/methodology/2017-NSCH-Methodology-Report.pdf>. Accessed February 25, 2022
 14. U.S. Census Bureau. 2018 national survey of children's health: methodology report. Available at: <https://www2.census.gov/programs-surveys/nsch/technical-documentation/methodology/2018-NSCH-Methodology-Report.pdf>. Accessed February 25, 2022
 15. U.S. Census Bureau. 2019 national survey of children's health: methodology report. Available at: <https://www2.census.gov/programs-surveys/nsch/technical-documentation/methodology/2019-NSCH-Methodology-Report.pdf>. Accessed February 25, 2022
 16. Health Resources and Services Administration MaCHB. National survey of children's health questionnaires, datasets, and supporting documents. Available at: <https://mchb.hrsa.gov/national-survey-childrens-health-questionnaires-datasets-supporting-documents> Accessed February 14, 2022
 17. Bethell CD, Blumberg SJ, Stein RE, Strickland B, Robertson J, Newacheck PW. Taking stock of the CSHCN screener: a review of common questions and current reflections. *Acad Pediatr*. 2015;15(2):165–176
 18. Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. *Matern Child Health J*. 2009;13(2):151–163
 19. Bureau USC. Metropolitan and micro-politan. Available at: <https://www.census.gov/programs-surveys/metro-micro.html>. Accessed July 7, 2021
 20. Newacheck PW, Kim SE, Blumberg SJ, Rising JP. Who is at risk for special health care needs: findings from the national survey of children's health. *Pediatrics*. 2008;122(2):347–359
 21. Ilango SM, Lebrun-Harris LA, Jones JR, et al. Associations between health care transition preparation among youth in the US and other components of a well-functioning system of services. *J Adolesc Health*. 2021;69(3):414–423
 22. U.S. Census Bureau. Poverty thresholds. Available at: <https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html>. Accessed: June 1, 2021