



New York State Profile of Children and Youth with Special Health Care Needs, 2019-2020

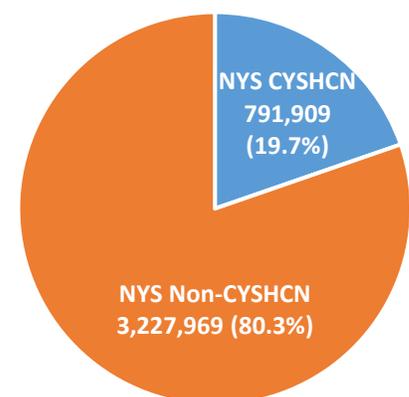
Background

Children and Youth with Special Health Care Needs (CYSHCN) are defined as children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.¹ A priority of the New York State (NYS) Department of Health Title V Maternal and Child Health Services Block Grant program (Title V) is to increase supports to address the special health care needs of children and youth, and improve health outcomes and the system of care for CYSHCN and their families.²

The purpose of this report is to explore the demographic, health, and functional difficulty profile of the NYS CYSHCN population, determine the impact that having special health care needs has on children and families, and identify areas in most need of improvement to ensure NYS CYSHCN receive care in a well-functioning system. Data from the National Survey of Children’s Health (NSCH) and NYS local health departments (LHDs) were analyzed. The U.S. Census Bureau administers the NSCH annually via electronic and mail (paper)-based instruments.³ The survey uses a validated screening tool to identify children ages 0-17 living in the household and a topical survey based on the child’s age to collect information on factors related to the health and well-being of children. Three age-based topical questionnaires are designed to collect information for children aged 0 through 5, 6 through 11, and 12 through 17. Children whose caregiver reported they experienced a functional limitation, prescription medication use, above routine use of specialized services, or a combination of prescription medications and above routine service use were categorized as CYSHCN. Due to the limited sample size of state-level data, the NSCH combines multiple years of data into one data set to allow for more in-depth analysis. This report analyzes the combined 2019 and 2020 NSCH data for NYS, and all percentages shown throughout this report are weighted to represent the population.

In 2019 and 2020, caregivers of a sample of 1,373 children were surveyed, of which 335 CYSHCN were identified. It is estimated that 791,909 (19.7%) children ages 0-17 years in NYS have a special health care need, as shown in Figure 1.

Figure 1. Prevalence of CYSHCN in New York State



¹ Children and Youth with Special Health Care Needs.

<https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs>

² Title V Maternal and Child Health Services Block Grant Program.

https://www.health.ny.gov/community/infants_children/maternal_and_child_health_services/

³ National Survey of Children’s Health. <https://www.census.gov/programs-surveys/nsch.html>

Demographics of NYS CYSHCN

- The sex of NYS CYSHCN was 62.5% male, and 37.5% female.
- The age distribution of NYS CYSHCN was 21.6% 0-5 years old, 30.1% 6-11 years old, and 48.3% 12-17 years old.
- The racial distribution of NYS CYSHCN was 48.7% non-Hispanic White, 27.3% Hispanic, 14.5% non-Hispanic Black, and 9.5% non-Hispanic Other/Multi-racial.
- 87.1% of NYS CYSHCN lived in a household where English was the primary language.
- 39.0% of NYS CYSHCN lived in a household with income between 0%-199% of the federal poverty level (FPL), 27.9% lived in a household between 200%-399% of FPL, and 33.1% lived in a household at 400% or greater of the FPL.
- Private insurance coverage was the most common, exclusively covering 53.1% of NYS CYSHCN, followed by 35.5% with public insurance including Medicaid and Child Health Plus, 10.8 % with both public and private insurance, and 0.5% uninsured.
- 27.4% of NYS CYSHCN sampled qualified* on above-routine use of services, 25.6% on prescription medication only, 24.7% on a combination of prescription medication and above routine use of services, and 22.3% on functional limitations.

*Qualified as a CYSHCN according to NSCH.

Health Conditions and Severity

The specific conditions included in the NSCH encompass many, but not all, of the conditions and difficulties experienced by the CYSHCN population.

Many children surveyed experienced one or more health conditions. Table 1 shows the percent of NYS CYSHCN experiencing one condition versus multiple conditions. Sixty-eight percent (68%) of NYS CYSHCN experienced more than one health condition. Seven and half percent (7.5%) of NYS CYSHCN did not report any of the 25 conditions included in the survey.

Table 1. Number of Health Conditions Reported Among CYSHCN

Number of Conditions	n (%) of NYS CYSHCN
Two or more	224 (68.1%)
One	89 (24.4%)
None/unknown	22 (7.5%)
Total	335 (100.0%)

Caregivers most commonly reported their child as being diagnosed with allergies (44.8%), followed by asthma (30.1%), anxiety (25.7%) and attention deficit disorder (ADD) or adult attention-deficit/hyperactivity disorder (ADHD) (25.3%). Compared to the 2017-2018 NSCH NYS CYSHCN data, the percent of children with behavioral or conduct problem saw the largest increase (10.4% to 22.5%) and autism saw the largest decrease (19.3% to 8.5%). Table 2 shows the frequency and percent for each health condition surveyed and the severity of those conditions.

Condition Severity

The conditions experienced by NYS CYSHCN occurred with varying levels of severity. Severity level (defined through caregivers - rated as mild, moderate, or severe) was assessed for 19 of the 25 conditions in Table 2. Allergies (21.7%) and speech or language disorder (21.2%) had the greatest proportion of children in the severe category when the sample size is greater than three (3).

Table 2. Health Conditions Surveyed*

Health Condition Surveyed	NYS CYSHCN	NYS CYSHCN	Increase/ Decrease in % affected	Severity NYS CYSHCN, 2019-2020		
	2019-2020 n (%)	2017-2018 n (%)		Mild n (%)	Moderate n (%)	Severe n (%)
Allergies	156 (44.8)	80 (38.4)	6.4	72 (39.1)	49 (39.3)	35 (21.7)
Asthma	91 (30.1)	46 (31.8)	-1.7	57 (54.6)	28 (38.3)	6 (7.1)
Anxiety	95 (25.7)	51 (19.7)	6	37 (42.5)	49 (49.1)	7 (8.4)
ADD or ADHD**	98 (25.3)	48 (19.3)	6	35 (36.5)	49 (50)	14 (13.5)
Developmental Delay	76 (23.7)	36 (28.8)	-5.1	35 (46.4)	30 (41.2)	9 (12.4)
Learning Difficulty	85 (22.8)	43 (25.9)	-3.1	38 (46.2)	32 (39.2)	12 (14.7)
Behavioral/Conduct Problem	77 (22.5)	31 (10.4)	12.1	28 (35.9)	38 (52.4)	10 (11.6)
Speech or Language Disorder	57 (16.6)	33 (22.3)	-5.7	24 (34.6)	20 (44.2)	11 (21.2)
Genetic or Inherited Condition	50 (12.1)	25 (13.9)	-1.8	--	--	--
Depression	36 (9.1)	26 (15.1)	-6	17 (39)	17 (58.1)	2 (2.9)
Autism	38 (8.5)	30 (19.3)	-10.8	17 (51.7)	18 (42.9)	2 (5.4)
Migraines	23 (5.0)	24 (12.7)	-7.7	14 (70.9)	8 (27)	1 (2)
Intellectual Disability	13 (3.0)	6 (4.3)	-1.3	3 (26.8)	7 (52.5)	3 (20.6)
Epilepsy/Seizure Disorder	7 (2.8)	6 (5.1)	-2.3	5 (70.3)	2 (29.7)	--
Hearing Problem	12 (2.5)	7 (3.8)	-1.3	--	--	--
Heart Problem	9 (2.3)	4 (3.2)	-0.9	7 (88.6)	1 (4.8)	1 (6.6)
Vision Problem	9 (2.2)	10 (4.5)	-2.3	--	--	--
Blood Disorders	7 (2.1)	2 (4.3)	-2.2	4 (54.6)	2 (25.9)	1 (19.4)
Diabetes	6 (1.4)	5 (4.4)	-3	3 (54.8)	--	3 (45.2)
Arthritis/Joint Problem	5 (1.2)	5 (3.7)	-2.5	3 (37.7)	--	2 (62.3)
Cerebral Palsy	2 (1.2)	2 (2.5)	-1.3	2 (100)	--	--
Down Syndrome	2 (0.3)	0 (0)	0.3	--	--	--
Tourette Syndrome	1 (0.1)	4 (1)	-0.9	1 (100)	--	--
Head Injury	0	7 (7.2)	-7.2	--	--	--
Cystic Fibrosis	0	***	0	--	--	--
Substance Use Disorder	***	0	0	--	--	--
Other Mental Health Condition	***	28 (13.4)	0	--	--	--

* Summation is greater than 100% as conditions were not mutually exclusive. Severity frequencies omit missing responses, therefore total of severities may not equal total of the health condition.

** Attention deficit disorder (ADD) or adult attention-deficit/hyperactivity disorder (ADHD).

*** The question about cystic fibrosis was dropped in 2018, other mental health condition was dropped since 2019, substance use disorder was dropped in 2020.

Functional Difficulties

The NSCH contains survey questions to assess the presence of 12 functional difficulties. While the presence of functional difficulty was less common than the presence of health conditions, over 60% of NYS CYSHCN experienced at least one functional difficulty (Table 3).

Table 3. Number of Functional Difficulties Reported Among CYSHCN

Number of Conditions	n (%) of NYS CYSHCN
Two or more	93 (22.2%)
One	117 (38.9%)
None/unknown	124 (39.0%)
Total	334 (100.0%)

Half the functional difficulty questions applied to children of all ages and the other half were asked of only children in specific age groups. Among the 12 functional difficulties included in the 2019-2020 NSCH survey, difficulty concentrating (29.9%), breathing or other respiratory problems (24.3%), and coordination or moving around (14.8%) were the most frequently experienced by NYS CYSHCN within the applicable age group (Table 4).

Table 4. Functional Difficulty Experienced*

Functional Difficulty Experienced	(%) of NYS CYSHCN
ALL AGES (n=335)	
Breathing or other respiratory problems	24.3%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	12.7%
Chronic physical pain including headaches or other back or body pain	14.0%
Eating or swallowing	2.7%
Deafness or problems with hearing	2.5%
Seeing even when wearing glasses or contact lenses	2.2%
AGES 0-5 (n=47)	
Coordination or moving around	14.8%
Difficulty using hands	6.2%
AGES 6-17 (n=107)	
Serious difficulty concentrating, remembering or making decisions	29.9%
Difficulty dressing or bathing	3.9%
Serious difficulty walking or climbing stairs	1.8%
AGES 12-17 (n=139)	
Difficulty doing errands alone	12.0%

* Summation is greater than 100% as conditions were not mutually exclusive. Frequencies omit missing responses.

Impact of Special Health Care Needs on the Child

Analysis of the impact of having special health care needs on daily activities and schooling among NYS CYSHCN found that:

- Nearly one in 11 NYS CYSHCN (8.8%) had their daily activities greatly affected by their health condition(s).
- One in eight NYS CYSHCN (13.3%) ages 6-17 missed 11 or more school days over the past year due to illness, compared to 3.3% of NYS children and youth without a SHCN.
- Nearly half of NYS CYSHCN (45.2%) ages 6-17 reported having trouble making or keeping friends, compared to 18.5% of NYS children and youth without a SHCN.

Impact of Special Health Care Needs on the Family

Families of CYSHCN face more financial strain and spend more time coordinating their child’s care than families without a CYSHCN (Table 5). One in 10 families with CYSHCN reported spending at least one hour per week coordinating their child’s health care. Families of CYSHCN were more likely to reduce or stop working due to their child’s health, have high out-of-pocket medical expenses, and have problems paying medical bills. Ninety-nine percent (99%) of NYS CYSHCN have health insurance coverage all year; however, families of CYSHCN were less likely to have adequate health insurance or insurance benefits that meet their child’s needs.

Table 5. Family Impacts of Supporting CYSHCN

	% NYS CYSHCN	% NYS non-CYSHCN
Spent at least one hour each week coordinating child’s health care	11.0%	0.5%
Family member reduced or stopped work due to child’s health	17.6%	4.0%
Avoided changing jobs due to concerns about health insurance	12.4%	4.8%
Out-of-pocket medical expenses \$1,000 or more	19.0%	10.4%
Had problems paying medical bills past 12 months	19.3%	10.2%
Out-of-pocket costs are always reasonable	26.2%	27.3%
Insurance is adequate* and insured all year	69.5%	73.3%
Child’s health insurance benefits always meet child’s needs	57.9%	70.8%

* The child’s current insurance was considered adequate when the following criteria were met: (a) the child currently has health insurance coverage, AND (b) benefits usually or always meet child’s needs, AND (c) the insurance usually or always allows the child to see needed providers, AND (d) the insurance either has no out-of-pocket expenses or out-of-pocket expenses are usually or always reasonable.

Family-Centered Care for CYSHCN

Family-centered care is an approach to planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Since the families are typically the decision makers and sources of support and information for children, a collaborative approach to health care is beneficial. NSCH data revealed that families of CYSHCN (81.6%) were less likely to receive family-centered care than families without a CYSHCN (87.5%). Individual components of family-centered care from the NSCH and from CYSHCN who

received information and referral services from NYS local health departments (LHDs) were evaluated.⁴ The percent of NYS CYSHCN who reported always receiving each component ranged from 50% to 65% based on the NSCH. Slightly wider ranges of family-centered care (range 60%-64%) were reported by their LHD. Comparisons should be interpreted cautiously since the percent of CYSHCN receiving services from their LHD is unweighted. Compared to all CYSHCN, it is possible that the families/children who seek information and referral services from their LHD have more complex needs or were more likely to have experienced a lack of assistance from their health care provider.

Table 6. Family-Centered Care Components

Family-Centered Care Components (n)	N (%) of NYS CYSHCN NSCH	N (%)* of NYS CYSHCN receiving services from LHD
Doctors/Providers always spend enough time with child	175 (50.4)	89 (60.1)
Doctors/Providers always listen carefully	208 (60.1)	94 (64.4)
Doctors/Providers always sensitive to family values/customs	223 (64.7)	92 (63.9)
Doctors/Providers always provide needed information	205 (60.6)	87 (60.8)
Doctors/Providers always make family feel like a partner in care	210 (60.6)	92 (63.4)

*Percent is among NYS CYSHCN families who answered family-centered care questions and reported by LHD. Frequency answered ranged from 143 to 146 during the contract year of Oct. 1, 2019, to Sep. 30, 2020. Percent of NYS CYSHCN receiving services from LHD is not weighted and therefore comparisons between NSCH should be used with caution.

Analysis of National Performance Measures and National Outcome Measures

Four Maternal Child Health National Performance Measures (NPM) and one National Outcome Measure (NOM) for CYSHCN are assessed in the NSCH. NPM 11, percent of CSHCN who have a medical home, and NPM 12, percent of adolescents with SHCN who received services necessary to transition to adult health care, were evaluated (Tables 7 and 8, respectively). In 2019-2020, only 40.8 % of NYS CYSHCN met all five components of medical home criteria compared to 50.6% of non-CYSHCN in NYS. Of the five medical home components, effective care coordination was most frequently reported as being unmet (47.5%) for NYS CYSHCN. Less than one in five CYSHCN ages 12-17 (19.1%) received services needed for transition to adult health care. Many adolescents (57.1%) had a chance to speak to their health care provider alone at their last preventive check-up. Most providers (76.2%) actively worked with adolescents with SHCN to gain the skills to manage their health and health care or understand changes in health care happening at age 18, while only 16% of providers discussed the shift to a provider who treats adults.

⁴ Children and Youth with Special Health Care Needs (CYSHCN) Program.
https://www.health.ny.gov/community/special_needs/

Table 7. NPM 11: Percent of children with special health care needs, ages 0-17, who have a medical home*

Medical Home and Components	Yes, n (%)	No, n (%)	Total
Received coordinated, ongoing, comprehensive care within a medical home	155 (40.8)	180 (59.2)	335
Child has personal doctor or nurse	282 (83.0)	52 (17.0)	334
Child has usual source of sick care	283 (83.2)	47 (16.8)	330
Care was family-centered	269 (81.6)	44 (18.4)	313
Care coordination was effective, among those that needed	154 (52.5)	109 (47.5)	263
Difficulties getting referrals, among those that needed	22 (16.3)	72 (83.7)	94

*To qualify as having a Medical Home, children must meet the criteria for adequate care on the first three components: personal doctor or nurse, usual source for care, and family-centered care. Additionally, any children who needed referrals or care coordination must also meet criteria for those components to qualify as having a medical home. Further information about the Medical Home concept and measurement is available in the [medical home manual](#).

Table 8. NPM 12: Percent of adolescents with special health care needs, ages 12-17, who received services necessary to make transitions to adult health care

Transition to Adult Care and Components	Yes, n (%)	No, n (%)	Total
Received services needed for transition to adult health care	30 (19.1)	150 (80.9)	180
Had time alone with health care provider at last preventive check-up	105 (57.1)	73 (42.9)	178
Health care provider worked with child to gain skills to manage health or understand health care changes at age 18	120 (76.2)	49 (23.8)	169
Provider discussed shift to adult health care providers (if needed)	22 (15.9)	121 (84.1)	143

NOM 17.2 is defined as the percent of CYSHCN, ages 0-17, who receive care in a well-functioning system. The NSCH uses over 50 different survey questions to construct this measure. The measure is comprised of five measures for children ages 0-11: the family feels like a partner in their child’s care, child has a medical home, child had a past-year preventive medical and dental visit, child has adequate insurance, and child did not have a time when they needed health care that was not received and was not frustrated in receiving health care. Per NPM 13.2, most CYSHCN (82.9%) ages 1-17 had a preventive dental visit in the past year compared to 75.7% of non-CYSHCN in NYS. For adolescents ages 12-17 years, preparation for transition to adult health care is included in addition to these five measures. In 2019-2020, only 12.7 % of NYS CYSHCN received care in a well-functioning system.

Program Considerations

The system of care for CYSHCN should be comprehensive, community-based, family-centered, and coordinated. Results from the NSCH demonstrate that interventions are needed to improve the number of NYS CYSHCN children receiving care in a well-functioning system. NYS is committed to maintaining and improving a state CYSHCN Program that is responsive to families' needs. Using information that was gathered from families and service providers of CYSHCN in 2017-2018, Title V is funding three Regional Support Centers (RSCs)⁵ for CYSHCN through existing relationships with the U.S. Health Resources and Services Administration (HRSA) designated University Centers of Excellence in Developmental Disabilities (UCEDDs). From October 1, 2019, to September 30, 2024, the RSCs will improve services to CYSHCN through the following initiatives:

1. Completing needs assessments with local health departments and providing technical assistance to improve information and referral services to families of CYSHCN. RSCs will work with LHDs to build capacity to serve families through improved outreach and program promotion.
2. Developing a resource directory for both families and providers. The resource directory will include a comprehensive catalog of available resources, enabling LHDs to make more timely and effective referrals to services.
3. Gathering family feedback through listening sessions and telephone interviews with CYSHCN and families/caregivers. These feedback sessions conducted in 2019-2020 provided NYSDOH valuable information on the challenges families and providers encountered in caring for CYSHCN. Continuous feedback is vital to ensuring challenges are addressed and to evaluate how the information received is aligned with local program and NSCH data.
4. Developing educational materials and conducting webinars. RSCs will develop training and educational materials for families and providers, including training videos and short video vignettes on the importance of a medical home, transition of adolescents with SHCN to adult health care, and other topics determined from family feedback gathered.

In addition to the activities of the RSCs, Title V also conducted a Needs Assessment to determine the priorities of the current five-year Maternal Child Health Services Block Grant cycle. Listening sessions with consumers across NYS, including families of CYSHCN, took place in the fall of 2019. Also, NYS is participating in an over-sampling of NSCH in 2022 that will provide more robust CYSHCN and other data in 2023. Title V will continue to monitor NSCH data on CYSHCN to see how family feedback differs or aligns with national survey data and share trends with RSCs and local CYSHCN programs.

For more information, contact the New York State Department of Health Children and Youth with Special Health Care Needs (CYSHCN) Program at CYSHCN@health.ny.gov or 518-474-1961.

⁵ Regional Support Centers (RSCs) for the Children and Youth with Special Health Care Needs (CYSHCN) Program. https://www.health.ny.gov/community/special_needs/rsc/