

# New York State Profile of Children and Youth with Special Health Care Needs, 2018-2019

## Children and Youth with Special Health Care Needs (CYSHCN) in New York State (NYS)

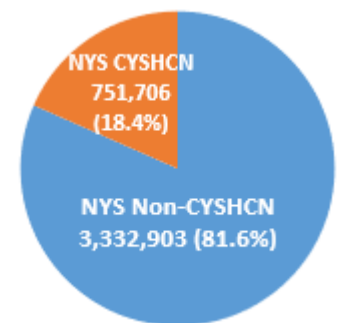
According to the Health Resources and Service Administration Maternal and Child Health Bureau, Children and Youth with Special Health Care Needs (CYSHCN) are defined as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.<sup>1</sup> A priority of the New York State 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 CYSHCN and their families.<sup>2</sup>

In 2016, the National Survey of Children's Health (NSCH) underwent key changes from prior years. Those changes included the consolidation of content from two previous surveys, the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs (NS-CSHCN), which were administered approximately every four years. Since 2016 the US Census Bureau administered the survey annually via web- and mail- (paper) based instruments.<sup>3</sup> The survey used a validated screening tool to identify children 0-17 living in the household and a topical survey to collect information on factors related to the health and well-being of children. 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 sample size of state-level data, combining multiple years of data into one data set allows for more in-depth analysis, please interpret with caution. Therefore, this report analyzes the combined 2018 and 2019 NSCH data for NYS.

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. It is important to note that all percentages shown throughout this report are weighted to represent the population of NYS non-institutionalized children 0 to 17 who live in housing units unless noted otherwise.

Caregivers for a sample of 253 CYSHCN were surveyed in NYS in 2018 and 2019. It is estimated that 751,706 children ages 0-17 years in NYS (18.4%) have a special health care need, as shown in Figure 1.1.

**Figure 1.1 Prevalence of CYSHCN in New York State**



## Demographics of NYS CYSHCN

- The age distribution of NYS CYSHCN was 19.7% 0-5 years old, 31.1% 6-11 years old, and 49.2% 12-17 years old;
- The racial distribution of NYS CYSHCN was 42.1% White, non-Hispanic, 30% Hispanic, 14.2% Black, non-Hispanic, and 13.7% Other non-Hispanic;

<sup>1</sup> Children and Youth with Special Health Care Needs. <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs>

<sup>2</sup> Title V Maternal and Child Health Services Block Grant Program. [https://www.health.ny.gov/community/infants\\_children/maternal\\_and\\_child\\_health\\_services/](https://www.health.ny.gov/community/infants_children/maternal_and_child_health_services/)

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

- 88.1 % of NYS CYSHCN lived in a household where English was the primary language;
- 45.3% of NYS CYSHCN lived in a household with income between 0%-199% of the federal poverty level (FPL), 23.5% lived in a household between 200%-399% of FPL, and 31.2% lived in a household at 400% or greater of the FPL;
- Private insurance coverage was the most common, exclusively covering 52.7% of NYS CYSHCN, followed by public insurance including Medicaid and Child Health Plus (37.7%), 7.4 % with both public and private insurance, and 2.2% uninsured; and
- 23.6% of NYS CYSHCN sampled qualified\* based on functional limitation, 24.6% on prescription medications, 29.1% on a combination of prescription medication and above routine use of specialized services, and 22.7% qualified on above routine use of specialized services only.

\*Qualified as a CYSHCN according to NSCH.

## Health Conditions and Functional Difficulties

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

**Table 1.1 Health Conditions Surveyed\***

Health Condition Surveyed	NYS CYSHCN 2018-2019 n (%)	NYS CYSHCN 2016-2017 n (%)	Increase/ Decrease in % affected	Severity NYS CYSHCN, 2018-2019		
				Mild n (%)	Moderate n (%)	Severe n (%)
Allergies	110 (39.8)	126 (46.9)	-7.1%	52 (42.4)	33 (35.2)	24 (22.3)
Asthma	63 (36.5)	72 (27.9)	+8.6%	43 (62.1)	16 (34.4)	3 (3.5)
Developmental Delay	46 (25.1)	59 (26.8)	-1.7%	22 (51.7)	17 (38.3)	6 (10)
Learning Difficulty	53 (21.6)	63 (25.9)	+4.3%	21 (46.8)	23 (40.9)	7 (12.3)
Speech or Language Disorder	34 (15.1)	46 (17.9)	-2.8%	17 (31.4)	11 (51.9)	6 (16.7)
Anxiety	72 (25.1)	67 (17.7)	+7.4%	33 (8.2)	31 (7.1)	6 (3.7)
ADD or ADHD	61 (19.2)	75 (23.6)	-4.4%	19 (41.6)	31 (47.2)	9 (11.2)
Autism or ASD	29 (11.2)	37 (15.3)	-4.1%	19 (51.1)	8 (45)	2 (3.8)
Depression	36 (15.5)	21 (4.2)	+11.3%	18 (32.3)	12 (59.2)	5 (8.4)
Genetic or Inherited Condition	38 (13.2)	31 (10.4)	+2.8%	--	--	--
Other Mental Health Condition	--**	57 (18.5)	--	--	--	--
Migraines	19 (8.5)	25 (7.9)	+0.6%	8 (59)	10 (39.7)	1 (1.3)
Behavioral/Conduct Problem	52 (15.7)	54 (16.9)	-1.2%	20 (41)	26 (50.7)	6 (3.9)
Head Injury	7 (6.9)	5 (1.1)	+5.8%	3 (56.9)	3 (43.1)	--
Epilepsy/Seizure Disorder	9 (6.5)	8 (2.1)	4.4%	7 (82.9)	--	--
Vision Problem	12 (3.5)	6 (3.8)	-0.3%	--	--	--
Diabetes	6 (3.8)	6 (1.7)	+2.1%	1 (12.6)	1 (8)	3 (20.5)
Intellectual Disability	7 (3.4)	14 (3.7)	-0.3%	1 (6.1)	3 (54.1)	3 (39.8)
Blood Disorders	6 (5.2)	3 (0.6)	+4.6%	--	--	--
Hearing Problem	11 (3.7)	10 (2.6)	+1.1%	--	--	--
Arthritis/Joint Problem	6 (2.7)	3 (1.5)	+1.2%	3 (37.4)	1 (16.8)	1 (45.8)
Heart Problem	4 (3.2)	7 (2.1)	+1.1%	4 (100)	--	--
Cerebral Palsy	4 (3.4)	3 (0.5)	+2.9%	3 (100)	--	--
Tourette Syndrome	3 (0.5)	4 (1.2)	-0.7%	1 (27.5)	2 (72.4)***	
Down Syndrome	1 (0.1)	3 (0.5)	-0.4%	--	--	--
Substance Use Disorder	1 (0.2)	0 (0)	+0.2%	--	--	--
Cystic Fibrosis	--	0 (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.

\*\* The question about other mental health conditions was dropped in 2019.

\*\*\*Tourette Syndrome combined Moderate/Severe.

Table 1.1 shows the frequency and percent for each of the 27 health conditions surveyed and the severity of those conditions. Caregivers most commonly reported their child as being diagnosed with allergies (39.8%), followed by asthma (36.5%), developmental delay (25.1%) and anxiety (25.1%). Compared to the 2016-2017 NSCH NYS CYSHCN data, percent of children with allergies saw the largest decrease (46.9% to 39.8%) but depression saw the largest increase (4.2% to 15.5%).

Many children surveyed experienced one or more health conditions. Six and half percent (6.5%) of NYS CYSHCN did not report any of the 25 conditions included in the survey. Table 1.2 shows the percent of NYS CYSHCN experiencing one condition versus multiple conditions. Seventy-three percent of the NYS CYSHCN experienced more than one health condition.

**Table 1.2 Number of Health Conditions Reported Among CYSHCN**

Number of Conditions	n (%) of NYS CYSHCN
None/unknown	16 (6.5%)
One	61 (20.8%)
Two or more	176 (72.7%)
<b>Total</b>	<b>253 (100.0%)</b>

### Condition Severity

The conditions experienced by NYS CYSHCN occurred with varying levels of severity. Severity level (defined through self-report as mild, moderate, or severe) was assessed for 19 of the 25 conditions in Table 1.1. Allergies (22.3%) and speech or language disorder (16.7%) had the greatest proportion of children in the severe category when the sample size is greater than 3.

### Functional Difficulties

The NSCH contains survey questions to assess the presence of 12 functional difficulties. 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 2018-2019 NSCH surveys, difficulty concentrating (25.7%), breathing or other respiratory problems (31.1%), and difficulty using hands (17.5%) were the most frequently experienced by NYS CYSHCN within the applicable age group (Table 1.3).

**Table 1.3 Functional Difficulty Experienced\***

Functional Difficulty Experienced	(%) of NYS CYSHCN
<b>ALL AGES (n=253)</b>	
Breathing or other respiratory problems	31.1%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	12.9%
Chronic physical pain including headaches or other back or body pain	19.6%
Eating or swallowing	3.1%
Seeing even when wearing glasses or contact lenses	3.6%
Deafness or problems with hearing	3.7%
<b>AGES 0-5 (n=38)</b>	
Coordination or moving around	10.7%
Difficulty using hands	17.5%
<b>AGES 6-17 (n=215)</b>	
Serious difficulty concentrating, remembering or making decisions	25.7%
Difficulty dressing or bathing	5.7%
Serious difficulty walking or climbing stairs	2.0%
<b>AGES 12-17 (n=139)</b>	
Difficulty doing errands alone	13.8%

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

While the presence of functional difficulty was less common than the presence of a health conditions, two-thirds of NYS CYSHCN experienced at least one functional difficulty (Table 1.4).

**Table 1.4 Number of Functional Difficulties Reported Among CYSHCN**

Number of Conditions	n (%) of NYS CYSHCN
None/unknown	89 (33.7%)
One	91 (37.1%)
Two or more	72 (29.2%)
<b>Total</b>	<b>252 (100.0%)</b>

### 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 eight NYS CYSHCN (12%) had their daily activities greatly affected by their health condition(s);
- One in six NYS CYSHCN (16.4%) ages 6-17 missed 11 or more school days over the past year due to illness, compared to 3.5% of NYS children and youth without a SHCN; and
- Nearly half of NYS CYSHCN (49%) ages 6-17 reported having trouble making or keeping friends, compared to 20.8% 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 1.5). One in seven 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. Families of CYSHCN were also less likely to have adequate health insurance throughout the year and have insurance benefits that meet their child's needs.

**Table 1.5 Family Impacts of Supporting CYSHCN**

	% NYS CYSHCN	% NYS non-CYSHCN
Spent at least one hour each week coordinating child’s health care	9.0%	0.1%
Family member reduced or stopped work due to child’s health	23.0%	4.1%
Avoided changing jobs due to concerns about health insurance	14.5%	5.0%
Out-of-pocket medical expenses \$1000 or more	17.0%	11.7%
Had problems paying medical bills past 12 months	28.1%	9.3%
Out-of-pocket costs are always reasonable	28.8%	31.0%
Insurance is adequate and insured all year	95.5%	92.6%
Child’s health insurance benefits always meet child’s needs	55.4%	72.6%

**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 82% of NYS CYSHCN received family-centered care. 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.<sup>4</sup> The percent of NYS CYSHCN who reported always receiving each component ranged from 53% to 62% based on the NSCH. Slightly lower levels of family-centered care (range 53%-57%) were reported by their LHD. Comparisons should be interpreted cautiously since the percent of CYSHCN receiving services from their LHD is unweighted. It is possible that the 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 (hence them seeking services from the LHD than all CYSHCN in NYS).

**Table 1.6 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	135 (53.0)	136 (53.1)
Doctors/Providers always listen carefully	147 (59.7)	148 (57.4)
Doctors/Providers are always sensitive to family values/customs	154 (61.5)	146 (57.0)
Doctors/Providers always provide needed information	145 (59.6)	138 (54.3)
Doctors/Providers always make family feel like a partner in care	146 (57.4)	147 (56.8)

\*Percent is among NYS CYSHCN families who answered family-centered care questions and reported by LHD. Frequency answered ranged from 254 to 259 during the contract year of Oct. 1, 2018 to Sep. 30, 2019. Percent of NYS CYSHCN receiving services from LHD is not weighted and therefore comparisons between NSCH should be used with caution.

<sup>4</sup> Children and Youth with Special Health Care Needs (CYSHCN) Program [https://www.health.ny.gov/community/special\\_needs/](https://www.health.ny.gov/community/special_needs/)

## 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. For 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, each component was evaluated (Tables 1.7 and 1.8, respectively). In 2018-2019, only 35.5 % of NYS CYSHCN met all five components of medical home criteria, compared to 48.8% of non-CYSHCN in NYS. Of the five medical home components, effective care coordination was most frequently reported as being unmet (55.7%) by NYS CYSHCN. Less than one in four CYSHCN ages 12-17 (23.5%) received services needed for transition to adult health care. Many adolescents (64.8%) had a chance to speak to their health care provider alone at their last preventive check-up. Most providers (78.6 %) 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. Per NPM 13.2, most CYSHCN (84.1%), age 1-17, had a preventive dental visit in the past year compared to 76.1% of non-CYSHCN in NYS. For adolescents age 12-17 years, NPM 9 showed 41.3% CYSHCN are bullied and 18.8% CYSHCN bullied others in NYS.

**Table 1.7 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
<b>Received coordinated, ongoing, comprehensive care within a medical home</b>	<b>117 (35.5)</b>	<b>136 (64.5)</b>	<b>253</b>
Child has personal doctor or nurse	212 (81.2)	41 (18.8)	253
Child has usual source of sick care	213 (77.5)	34 (22.5)	247
Care coordination was effective, among those that needed	106 (44.3)	87 (55.7)	193
Care was family-centered	198 (82.0)	28 (18.0)	226

**Table 1.8 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
<b>Received services needed for transition to adult health care</b>	<b>29 (23.5)</b>	<b>110 (76.4)</b>	<b>139</b>
Had time alone with health care provider at last preventive check-up	84 (64.8)	54 (35.2)	138
Health care provider worked with child to gain skills to manage health or understand health care changes at age 18	99 (78.6)	29 (21.3)	128
Provider discussed shift to adult health care providers (if needed)	21 (16.2)	84 (83.8)	105

NOM 17.2 is defined as the percent of CYSHCN, age 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 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. For adolescents age 12-17 years, preparation for transition to adult health care is included in addition to these five measures. In 2018-2019, only 11 % 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 for CYSHCN through existing relationships with three HRSA-designated University Centers of Excellence in Developmental Disabilities (UCEDDs). From October 1, 2019 to September 30, 2024 the Regional Support Centers (RSCs)<sup>5</sup> will improve services to CYSHCN through the following initiatives:

1. Completing needs assessment 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. 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. The care mapping feedback sessions conducted in 2017-2018 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. Feedback will be sought from families in areas of the state that were not included in care mapping as well as including a focus on racial, ethnic and language diversity.
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 next five-year Maternal Child Health Services Block Grant cycle. Listening sessions with consumers across New York State, including families of CYSHCN, took place in the fall of 2019. 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](mailto:CYSHCN@health.ny.gov) or 518-474-1961.

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<sup>5</sup> 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/](https://www.health.ny.gov/community/special_needs/rsc/)