

New York State Profile of Children and Youth with Special Health Care Needs, 2017-2018

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

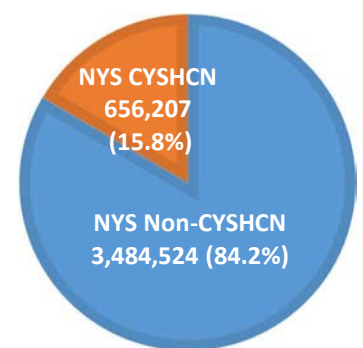
According to the Health Resources and Service Administration Maternal and Child Health Bureau, Children and Youth with Special Health Care Needs (CYSHCN) are defined as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. 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 to improve health outcomes and the system of care for CYSHCN and their families.

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. The survey used a validated screening tool to identify children ages 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 2017 and 2018 NSCH data for New York State (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 ages 0-17 who live in housing units unless noted otherwise.

Caregivers for a sample of 192 CYSHCN were surveyed in NYS in 2017 and 2018. It is estimated that 656,207 children ages 0-17 years in NYS (15.8%) 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 CSHCN

- The age distribution of NYS CYSHCN was 21.9% 0-5 years old, 36.4% 6-11 years old, and 41.7% 12-17 years old;
- The racial distribution of NYS CYSHCN was 41% White, non-Hispanic, 33.3% Hispanic, 14.4% Black, non-Hispanic, and 11.2% Other non-Hispanic;
- 90.2% of the NYS CYSHCN lived in a household where English was the primary language;

- 55.1% of NYS CYSHCN lived in a household with income between 0%-199% of the federal poverty level (FPL), 17.6% lived in a household between 200%-399% of FPL, and 27.3% lived in a household at 400% or greater of the FPL;
- Private insurance coverage was the most common, exclusively covering 49.2% of the NYS CYSHCN, followed by public insurance including Medicaid and Child Health Plus (43.3%), 4.7% with both public and private insurance, and 2.8% uninsured; and
- 31% of the NYS CYSHCN sampled qualified* based on functional limitation, 25% on prescription medications, 25% on a combination of prescription medications and above routine use of specialized services, and 19% 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 2017-2018 n (%)	NYS CYSHCN 2016-2017 n (%)	Increase/ Decrease in % affected	Severity NYS CYSHCN, 2017-2018		
				Mild n (%)	Moderate n (%)	Severe n (%)
Allergies	80 (38.4)	126 (46.9)	-8.5%	38 (46.8)	31 (37.9)	10 (15.3)
Asthma	46 (31.8)	72 (27.9)	+3.9%	28 (54.6)	15 (41.7)	2 (3.7)
Developmental Delay	36 (28.8)	59 (26.8)	2.0%	18 (58.5)	14 (35.2)	3 (6.3)
Learning Difficulty	43 (25.9)	63 (25.9)	0.0%	17 (57.5)	21 (35.3)	4 (7.2)
Speech or Language Disorder	33 (22.3)	46 (17.9)	+4.4%	16 (37.5)	14 (12)	3 (10.3)
Anxiety	51 (19.7)	67 (17.7)	+2.0%	26 (65.3)	19 (28.6)	5 (6.1)
ADD or ADHD	48 (19.3)	75 (23.6)	-4.3%	15 (39.1)	24 (43.7)	7 (17.2)
Autism or ASD	30 (19.3)	37 (15.3)	+4.0%	19 (52.7)	9 (15.3)	1 (3.8)
Depression	26 (15.1)	21 (4.2)	+10.9%	13 (31.6)	8 (58.8)	4 (9.6)
Genetic or Inherited Condition	25 (13.9)	31 (10.4)	+3.5%	--	--	--
Other Mental Health Condition	28 (13.4)	57 (18.5)	-5.1%	11 (50.1)	9 (27.5)	7 (22.3)
Migraines	24 (12.7)	25 (7.9)	+4.8%	9 (38.1)	11 (45.7)	4 (8.5)
Behavioral/Conduct Problem	31 (10.4)	54 (16.9)	-6.5%	16 (59.5)	12 (32.7)	3 (7.8)
Head Injury	7 (7.2)	5 (1.1)	+6.1%	3 (65.6)	3 (34.4)	--
Epilepsy/Seizure Disorder	6 (5.1)	8 (2.1)	+3.0%	5 (100)	--	--
Vision Problem	10 (4.5)	6 (3.8)	+0.7%	--	--	--
Diabetes	5 (4.4)	6 (1.7)	+2.7%		3 (53)	1 (47)
Intellectual Disability	6 (4.3)	14 (3.7)	+0.6%		4 (61.9)	2 (38.1)
Blood Disorders	2 (4.3)	3 (0.6)	+3.7%	--	--	--
Hearing Problem	7 (3.8)	10 (2.6)	+1.2%	--	--	--
Arthritis/Joint Problem	5 (3.7)	3 (1.5)	+2.2%	2 (22.1)	1 (14.1)	1 (67.2)
Heart Problem	4 (3.2)	7 (2.1)	+1.1%	4 (100)	--	--
Cerebral Palsy	2 (2.5)	3 (0.5)	+2.0%	1 (100)	--	--
Tourette Syndrome	4 (1)	4 (1.2)	-0.2%	2 (57.9)	2 (42.1)**	
Down Syndrome	0 (0)	3 (0.5)	-0.5%	--	--	--
Substance Use Disorder	0 (0)	0 (0)	0%	--	--	--
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.

**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 (38%), followed by asthma (32%), and Developmental Delay (29%). Compared to the 2016-2017 NSCH NYS data, percent of children with allergies saw the largest decrease (46.5% to 38.4%) and depression saw the largest increase (4.2% to 15.1%).

Many children surveyed experienced one or more health conditions. Nine percent (9%) of NYS CYSHCN did not report any of the 27 conditions included in the survey. Table 1.2 shows the percent of NYS CYSHCN experiencing one condition versus multiple conditions. Sixty-eight 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	15 (9.3)
One	47 (23.0)
Two or more	130 (67.7)
Total	192 (100.0)

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 20 of the 27 conditions in Table 1.1. Other mental health conditions (22%), ADD or ADHD (17%), and allergies (15%) had the greatest proportion of children in the severe category when the sample size is 3 and greater.

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 2017-2018 NSCN surveys, difficulty concentrating (27%), breathing or other respiratory problems (26%), and difficulty using hands (24%) 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
ALL AGES (n=192)	
Breathing or other respiratory problems	26.0%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	11.4%
Chronic physical pain including headaches or other back or body pain	20.2%
Eating or swallowing	4.2%
Seeing even when wearing glasses or contact lenses	4.6%
Deafness or problems with hearing	4.0%
AGES 0-5 (n=28)	
Coordination or moving around	16.3%
Difficulty using hands	24.4%
AGES 6-17 (n=164)	
Serious difficulty concentrating, remembering or making decisions	27.0%
Difficulty dressing or bathing	8.3%

Serious difficulty walking or climbing stairs	2.7%
AGES 12-17 (n=96)	
Difficulty doing errands alone	12.3%

* 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	66 (35.7)
One	75 (33.3)
Two or more	49 (31.1)
Total	190 (100.0)

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 seven NYS CYSHCN (13.6%) had their daily activities greatly affected by their health condition(s);
- One in nine NYS CYSHCN (11%) ages 6-17 missed 11 or more school days over the past year due to illness, compared to 2% of NYS children and youth without a SHCN; and
- Nearly half of NYS CYSHCN (48%) ages 6-17 reported having trouble making or keeping friends, compared to 15% 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	14.2%	0.3%
Family member reduced or stopped work due to child’s health	21.0%	3.2%
Avoided changing jobs due to concerns about health insurance	11.2%	5.4%
Out-of-pocket medical expenses \$1000 or more	16.4%	11.0%
Had problems paying medical bills past 12 months	30.6%	7.6%
Out-of-pocket costs are always reasonable	21.4%	30.6%
Insurance is adequate and insured all year	90.5%	94.6%
Child’s health insurance benefits always meet child’s needs	62.4%	69.0%

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 91% 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. The percent of NYS CYSHCN who reported always receiving each component ranged from 70% to 73% based on the NSCH. However, the percent NYS CYSHCN served by their LHD reported lower levels of family-centered care (range 52%-56%). 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	125 (72.4)	93 (51.4)
Doctors/Providers always listen carefully	124 (71.5)	99 (52.7)
Doctors/Providers are always sensitive to family values/customs	127 (72.9)	97 (55.7)
Doctors/Providers always provide needed information	123 (69.5)	98 (53.6)
Doctors/Providers always make family feel like a partner in care	123 (69.5)	102 (54.5)

*Percent is among NYS CYSHCN families who answered family-centered care questions and reported by LHD. Frequency answered ranged from 174 to 187 during the contract year of Oct 1, 2017 to Sep 30, 2018. Percent of NYS CYSHCN receiving services from LHD is not weighted and therefore comparisons between NSCH should use caution.

Analysis of National Performance Measures and National Outcome Measures

Two 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 CYSHCN 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 2017-2018, only 41.7% of NYS CYSHCN met all five components of medical home criteria, compared to 47.2% of non-CYSHCN in NYS. Of the five medical home components, effective care coordination was most frequently reported as being unmet (35.8%) by NYS CYSHCN. Less than one in five CYSHCN ages 12-17 (17.8%) received services needed for transition to adult health care. Only half of adolescents had a chance to speak to their health care provider alone at their last preventive check-up. While 73% of providers actively worked with adolescents with SHCN for preparing them the skills to manage their health, health care, and understand changes in health care happening at age 18, only 12% of providers discussed the shift to a provider who treats adults.

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
Received coordinated, ongoing, comprehensive care within a medical home	94 (41.7)	98 (58.3)	192
Child has personal doctor or nurse	159 (78.8)	33 (21.2)	192
Child has usual source of sick care	157 (74.4)	30 (15.6)	187
Care coordination was effective, among those that needed	92 (64.2)	55 (35.8)	147
Care was family-centered	155 (91.3)	11 (8.7)	166

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
Received services needed for transition to adult health care	21 (17.8)	74 (82.2)	95
Had time alone with health care provider at last preventive check-up	53 (59.6)	40 (32.8)	93
Health care provider worked with child to gain skills to manage health or understand health care changes at age 18	67 (73.1)	19 (26.9)	86
Provider discussed shift to adult health care providers (if needed)	14 (11.6)	53 (88.4)	67

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 receives early screening (both preventive medical and dental visits), child has adequate insurance, and child has no unmet need or barriers to access services. For adolescents age 12-17 years, preparation for transition to adult health care is included in addition to the five measures. In 2017-2018, only 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 for CYSHCN through existing relationships with three University Centers of Excellence in Developmental Disabilities (UCEDDs). From October 1, 2019 to September 30, 2021 the Regional Support Centers (RSCs) will improve services to CYSHCN through the following initiatives:

1. Completing a needs assessment with each local health department 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 regional resource guides for both families and providers. Resource guides 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 families of CYSHCN. 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. 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 is also working on the five-year 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 or 518-474-1961.