



New York State Profile of Children and Youth with Special Health Care Needs, 2020-2021

Background

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.¹ A priority of the New York State Department of Health Title V Maternal and Child Health Services Block Grant program 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 children and youth with special health care needs and their families.²

The purpose of this report is to update stakeholders on the current characteristics and needs of children and youth with special health care needs and their families in New York State. It also provides considerations regarding the system of care to allow families, caregivers, and providers to make informed decisions related to the care and support of children and youth with special health care needs. Specifically, this report aims to: 1) explore the demographic, health, and functional difficulty profile of the New York State children and youth with special health care needs population; 2) determine the impact that having special health care needs has on children and families, and; 3) identify areas in most need of improvement to ensure New York State children and youth with special health care needs receive care in a well-functioning system.

Methods

Since 2016 the United State Census Bureau has administered the National Survey of Children's Health annually via web- and mail- (paper) based instruments.³ 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 children and youth with special health care needs.

Due to the sample size of state-level data, combining multiple years of data into one data set allowed for more in-depth analysis. As such, this report analyzes the combined 2020 and 2021 National Survey of Children's Health data for New York State. Caregivers for a sample of 364 children and youth with special health care needs were surveyed in New York State in 2020 and 2021. It is important to note that all percentages shown throughout this report are weighted to represent the population of New York State non-institutionalized children 0 to 17 who live in housing units unless noted otherwise. For more information about National Survey of Children's Health data, please visit the Data Resource Center for Child and Adolescent Health website.⁴

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>

⁴ Data Resource Center for Child and Adolescent Health (DRC). <https://www.childhealthdata.org/about-us/highlights-updates>

Combined 2020-2021 National Survey of Children's Health downloadable dataset is released on February 01, 2023, having an approximately 14 months lag.

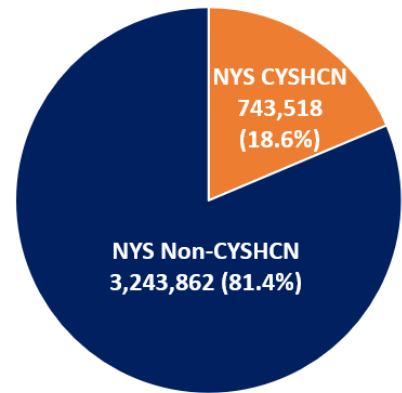
Demographics

It is estimated that between 2020 and 2021, 743,518 children ages 0-17 years in New York State (18.6%) had a special health care need, as shown in Figure 1.

- New York State children and youth with special health care needs were 57.6% male and 42.4% female.
- The age distribution of New York State children and youth with special health care needs was 19.9% 0-5 years old, 34.2% 6-11 years old, and 45.9% 12-17 years old.
- The racial distribution of New York State children and youth with special health care needs was 45.6% non-Hispanic White, 26.1% Hispanic, 19.8% non-Hispanic Black, and 8.5% non-Hispanic Other/Multi-racial.
- 86.3 % of New York State children and youth with special health care needs lived in a household where English was the primary language.
- 42.7% of New York State children and youth with special health care needs lived in a household with income between 0%-199% of the federal poverty level (FPL), 27.1% lived in a household between 200%-399% of FPL, and 30.2% lived in a household at 400% or greater of the FPL.
- Private insurance coverage was the most common, exclusively covering 46.6% of New York State children and youth with special health care needs, followed by 44.0% with public insurance including Medicaid and Child Health Plus, 7.7 % with both public and private insurance, and 1.7% uninsured.
- 31.8% of New York State children and youth with special health care needs sampled qualified* on functional limitations, 24.5% on above-routine use of services, 23.0% on prescription medication only, and 20.7% on a combination of prescription medication and above routine use of services.

*Qualified as a children and youth with special health care needs according to National Survey of Children’s Health.

Figure 1. 2020-2021 prevalence of CYSHCN in New York State



Health Conditions and Severity

The specific conditions included in the National Survey of Children’s Health encompass many, but not all, of the conditions and difficulties experienced by the children and youth with special health care needs population. A total of 24 conditions were asked about in the survey. Many children surveyed experienced one or more health conditions. Table 1 shows the percent of New York State children and youth with special health care needs experiencing one condition versus multiple conditions. Seventy percent of the New York State children and youth with special health care needs experienced more than one health condition, and 6.2% of New York State children and youth with special health care needs did not report any of the 24 conditions included in the survey.

Table 1. Number of Health Conditions Reported Among CYSHCN

Number of Conditions	n (%) of NYS CYSHCN
Two or more	247 (70.0%)
One	92 (23.8%)
None/unknown	25 (6.2%)
Total	364 (100.0%)

Caregivers most commonly reported their child as being diagnosed with allergies (41.9%), followed by speech or language disorder (30.1%), anxiety (28.9%), learning difficulty (27.1%), asthma (27.0%) and attention deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD) (26.7%). Compared to the 2018-2019 National Survey of Children’s Health New York State children and youth with special health care needs data, the percent of children with a speech or language disorder problem saw the largest increase (15.1% to 30.1%) but asthma saw the largest decrease (36.5% to 27.2%). Table 2. shows the frequency and percent for each health condition surveyed and the severity of those conditions.

Condition Severity

The conditions experienced by New York State children and youth with special health care needs occurred with varying levels of severity. Severity level (defined through caregivers - rated as mild, moderate, or severe) was assessed for 19 of the 24 conditions in Table 2. Genetic or inherited condition (40.0%) and intellectual disability (32.2%) had the greatest proportion of children in the severe category when the sample size is greater than 3.

Table 2. Health Conditions Surveyed*

Health Condition Surveyed	NYS CYSHCN 2020-2021 n (%)	NYS CYSHCN 2018-2019 n (%)	Increase or Decrease in % affected	Severity NYS CYSHCN, 2020-2021		
				Mild n (%)	Moderate n (%)	Severe n (%)
Allergies	160 (41.9)	110 (39.8)	2.1	77 (44.7)	54 (35.3)	29 (20.0)
Speech or Language Disorder	86 (30.1)	34 (15.1)	15.0	33 (36.8)	39 (45.6)	12 (17.6)
Anxiety	117 (28.9)	72 (25.1)	3.8	41 (29.6)	62 (49.2)	13 (21.2)
Learning Difficulty	98 (27.1)	53 (21.6)	5.5	41 (39.1)	40 (34.3)	16 (26.6)
Asthma	92 (27.0)	63 (36.5)	-9.5	55 (49.5)	32 (46.2)	4 (4.3)
ADD or ADHD**	103 (26.7)	61 (19.2)	7.5	40 (35.6)	55 (55.6)	8 (8.8)
Developmental Delay	85 (24.8)	46 (25.1)	-0.3	32 (35.2)	39 (45.1)	12 (19.7)
Behavioral/Conduct Problem	72 (23.1)	52 (15.7)	7.4	32 (47.0)	26 (33.0)	11 (20.0)
Genetic or Inherited Condition	51 (13.8)	38 (13.2)	0.6	11 (13.8)	26 (46.2)	10 (40.0)
Autism	43 (13.7)	29 (11.2)	2.5	16 (36.2)	22 (58.7)	3 (5.2)
Depression	47 (12.8)	36 (15.5)	-2.7	18 (32.4)	26 (64.8)	2 (2.9)
Intellectual Disability	20 (7.6)	7 (3.4)	4.2	4 (11.7)	12 (56.1)	4 (32.2)
Migraines	26 (4.8)	19 (8.5)	-3.7	17 (58.1)	8 (38.4)	1 (3.5)
Vision Problem	9 (2.8)	12 (3.5)	-0.7	--	--	--
Heart Problem	11 (2.7)	4 (3.2)	-0.5	7 (72.3)	2 (8.7)	2 (19.0)
Diabetes	7 (2.4)	6 (3.8)	-1.4	4 (68.4)	2 (27.5)	1 (4.1)
Down Syndrome	3 (2.1)	1 (0.1)	2.0	--	--	--
Hearing Problem	7 (2.0)	11 (3.7)	-1.7	--	--	--
Epilepsy/Seizure Disorder	6 (1.4)	9 (6.5)	-5.1	4 (64.7)	1 (6.6)	1 (28.7)
Arthritis/Joint Problem	5 (1.3)	6 (2.7)	-1.4	4 (69.2)	--	1 (30.8)
Blood Disorders	4 (1.0)	6 (5.2)	-4.2	2 (24.4)	1 (51.2)	1 (24.4)
Cystic Fibrosis	1 (1.0)	--	1	--	--	--
Cerebral Palsy	1 (0.4)	4 (3.4)	-3.0	--	--	1 (100)
Tourette Syndrome	1 (0.2)	3 (0.5)	-0.3	1 (100)	--	--
Head Injury***	34 (7)	7 (6.9)	--	--	--	--
Substance Use Disorder***	--	1 (0.2)	--	--	--	--

* 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.

** ADD or ADHD stands for attention deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD).

*** The question about head injury has been modified in 2020 and cannot compare with 2018-2019 data. The question about substance use disorder was dropped in 2020, and other mental health condition question was dropped since 2019 (not included in the list).

Functional Difficulties

The National Survey of Children’s Health 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 58.7% of New York State children and youth with special health care needs experienced at least one functional difficulty (Table 3).

Table 3. Number of Functional Difficulties Reported

Number of Conditions	n (%) of NYS CYSHCN
Two or more	90 (24.8%)
One	118 (33.9%)
None/unknown	156 (41.3%)
Total	364 (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 2020-2021 National Survey of Children’s Health, difficulty concentrating (37.3%), breathing or other respiratory problems (18.4%), and coordination or moving around (12.1%) were the most frequently experienced by New York State children and youth with special health care needs within the applicable age group (Table 4).

Table 4. Functional Difficulty Experienced*

Functional Difficulty Experienced	(%) of NYS CYSHCN
ALL AGES (n=364)	
Breathing or other respiratory problems	18.4%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	11.9%
Chronic physical pain including headaches or other back or body pain	13.9%
Eating or swallowing	3.7%
Seeing even when wearing glasses or contact lenses	2.8%
Deafness or problems with hearing	2.0%
AGES 0-5 (n=59)	
Coordination or moving around	12.1%
Difficulty using hands	4.7%
AGES 6-17 (n=304)	
Serious difficulty concentrating, remembering, or making decisions	37.3%
Difficulty dressing or bathing	5.5%
Serious difficulty walking or climbing stairs	3.8%
AGES 12-17 (n=181)	
Difficulty doing errands alone	18.0%

* 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 New York State children and youth with special health care needs found that:

- Nearly one in nine New York State children and youth with special health care needs (11.5%) had their daily activities greatly affected by their health condition(s).
- One in ten New York State children and youth with special health care needs (10.1%) ages 6-17 missed 11 or more school days over the past year due to illness, compared to 1.8% of New York State children and youth without a special health care needs.

- Nearly half of New York State children and youth with special health care needs (45.3%) ages 6-17 reported having trouble making or keeping friends, compared to 14.5% of New York State children and youth without a special health care needs.

Impact of Special Health Care Needs on the Family

Families of children and youth with special health care needs face more financial strain and spent more time coordinating their child’s care than families without children and youth with special health care needs (Table 5). One in ten families with children and youth with special health care needs reported spending at least one hour per week coordinating their child’s health care. Families of children and youth with special health care needs 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 of the New York State children and youth with special health care needs have health insurance coverage all year; however, families of children and youth with special health care needs were less likely to have adequate health insurance and have insurance benefits that meet their child’s needs.

Table 5. Family Impacts of Supporting Children and Youth with Special Health Care Needs

	% NYS CYSHCN	% NYS Non-CYSHCN
Spent at least one hour each week arranging child’s medical care	10.1%	0.7%
Family member reduced or stopped work due to child’s health	16.1%	4.1%
Avoided changing jobs due to concerns about health insurance	11.6%	6.1%
Out-of-pocket medical expenses \$1000 or more	16.4%	9.6%
Had problems paying medical bills past 12 months	16.2%	9.9%
Out-of-pocket costs are always reasonable	19.6%	27.2%
Insurance is adequate* and insured all year	71.9%	71.4%
Child’s health insurance benefits always meet child’s needs	57.4%	69.1%

* 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 Children and Youth with Special Health Care Needs

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. National Survey of Children’s Health data revealed that families of children and youth with special health care needs (85.9%) were less likely to receive family-centered care than families without children and youth with special health care needs (87.0%). Individual components of family-centered care from the National Survey of Children’s Health and from children and youth with special health care needs who received information and referral services from New York State local health departments (LHDs) were evaluated.⁵ The percent of New York State children and youth with special health care needs who reported always receiving each component ranged from 57% to 70% based on the National Survey of Children’s Health. Higher percent of family-centered care (range 72%-79%) were reported by the local health departments. Comparisons should be interpreted cautiously since the percent of children and youth with special health care

⁵ Children and Youth with Special Health Care Needs (CYSHCN) Program <https://health.ny.gov/CYSHCN>

needs receiving services from the local health departments is unweighted and response rates for these questions are about 24%. Children and youth with special health care needs served by the local health departments likely have more complex needs, hence they seek services from the local health departments more than all children and youth with special health care needs in New York State.

Table 6. Family-Centered Care Components

Family-Centered Care Components (n)	N (%) of NYS CYSHCN NSCH	N (%) * of NYS CYSHCN receiving services from LHDs
Doctors/Providers always spend enough time with child	195 (56.9)	168 (71.8)
Doctors/Providers always listen carefully	227 (60.1)	180 (75.9)
Doctors/Providers are always sensitive to family values/customs	250 (70.4)	175 (78.8)
Doctors/Providers always provide needed information	228 (63.7)	171 (75.4)
Doctors/Providers always make family feel like a partner in care	234 (63.5)	178 (75.4)

*Percent is among New York State children and youth with special health care needs families who answered family-centered care questions and reported by LHDs. Frequency answered ranged from 222 to 237 based on 982 children and youth with special health care needs served by the local health departments during the contract year of Oct. 1, 2020, to Sep. 30, 2021. Percent of New York State children and youth with special health care needs receiving services from local health departments is not weighted and therefore comparisons between National Survey of Children’s Health 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 children and youth with special health care needs are assessed in the National Survey of Children’s Health. For national performance measure 11, percent of children and youth with special health care needs who have a medical home, and national performance measure 12, percent of adolescents with special health care needs who received services necessary to transition to adult health care, each component was evaluated (Tables 7 and 8, respectively). In 2020-2021, only 39.6 % of New York State children and youth with special health care needs met all five components of medical home criteria, compared to 48.5% of children and youth without special health care needs in New York State. Of the five medical home components, effective care coordination was most frequently reported as being unmet (37.5%) for New York State children and youth with special health care needs. Less than one in five children and youth with special health care needs ages 12-17 (11.8%) received services needed for transition to adult health care. Many adolescents (53.2%) had a chance to speak to their health care provider alone at their last preventive check-up. Most providers (75.0 %) actively worked with adolescents with special health care needs 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.

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	160 (39.6)	204 (60.4)	364
Child has personal doctor or nurse	308 (81.2)	55 (18.8)	363
Child has usual source of sick care	290 (73.8)	69 (26.2)	359
Care was family-centered	293 (85.9)	47 (14.1)	340
Care coordination was effective, among those that needed	171 (62.5)	114 (37.5)	285
Difficulties getting referrals, among those that needed	22 (21.8)	79 (78.2)	101

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	31 (11.8)	149 (88.2)	180
Had time alone with health care provider at last preventive check-up	111 (53.2)	68 (46.8)	179
Health care provider worked with child to gain skills to manage health or understand health care changes at age 18	123 (75.0)	47 (25.0)	170
Provider discussed shift to adult health care providers (if needed)	25 (20.7)	119 (79.3)	144

Per national performance measure 13.2, most children and youth with special health care needs (76.5%), age 1-17, had a preventive dental visit in the past year compared to 71.2% of children and youth without special health care needs in New York State. For adolescents ages 12-17 years, national performance measure 9 showed 51.8% of children and youth with special health care needs are bullied and 18.4% of children and youth with special health care needs bullied others in New York State.

National outcome measure 17.2 is defined as the percent of children and youth with special health care needs, ages 0-17, who receive care in a well-functioning system. The National Survey of Children’s Health uses over 50 different survey questions to construct this measure. The measure is comprised of five measures for children 0-11 years old: 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 ages 12-17 years, preparation for transition to adult health care is included in addition to these five measures. In 2020-2021, only 11.3 % of New York State children and youth with special health care needs received care in a well-functioning system.

Program Considerations

The system of care for children and youth with special health care needs should be comprehensive, community-based, family-centered, and coordinated. Results from the National Survey of Children’s Health demonstrate that interventions are needed to improve the number of New York State children and youth with special health care needs receiving care in a well-functioning system. New York State is committed to maintaining and improving a state children and youth with special health care needs program that is responsive to families’ needs. Using information that was gathered from families and service providers of children and youth with special health care needs in 2017-2018, Title V is funding three Regional Support Centers for children and youth with special health care needs 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)⁶ will improve services to children and youth with special health care needs 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 children and youth with special health care

⁶ 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/

needs. Regional Support Centers work with local health departments to build capacity to serve families through improved outreach and program promotion.

2. Developing a resource directory for both families and providers. Resource directory includes a comprehensive catalog of available resources, enabling local health departments to make more timely and effective referrals to services.
3. Gathering family feedback through listening sessions and telephone interviews with children and youth with special health care needs and families/caregivers. The family feedback sessions conducted in 2020-2021 provided New York State valuable information on the challenges families and providers encountered in caring for children and youth with special health care needs. Continuous feedback is vital to ensuring challenges are addressed and to evaluate how the information received is aligned with local program and National Survey of Children's Health data. Feedback is 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. Regional Support Centers developed or are developing 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 special health care needs to adult health care, and other topics determined from family feedback gathered.

In addition to the activities of the Regional Support Centers, Title V also conducted a Needs Assessment to determine the priorities of the current five-year Maternal Child Health Services Block Grant cycle. New York State is participating in an over-sampling of National Survey of Children's Health in 2022 with data becoming available in late 2023. Title V will continue to monitor National Survey of Children's Health data on children and youth with special health care needs to see how family feedback differs or aligns with national survey data and share trends with Regional Support Centers and local children and youth with special health care needs programs.

For more information, contact the New York State Department of Health Children and Youth with Special Health Care Needs (CYSHCN) Program:

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