



New York State Profile of Children and Youth with Special Health Care Needs, 2022

EXECUTIVE SUMMARY

A priority of the New York State Department of Health Title V Maternal and Child Health Services Block Grant program is to improve health outcomes and the system of care for children and youth with special health care needs and their families.¹ The purpose of this report is to update partners on the current characteristics and needs of children and youth with special health care needs and their families in New York State using the most recent public data from the National Survey of Children's Health administered by the United State Census Bureau. This report 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.

In 2022, it is estimated that 18.8% (767,276) of children ages 0-17 years in New York State had a special health care need. Only 39.2% of children and youth with special health care needs have a medical home, and less than one in five children and youth with special health care needs ages 12-17 received services needed for transition to adult health care in New York State. The New York State Children and Youth with Special Health Care Needs Program seeks to improve the system of care for children and youth with special health care needs from birth and up to 21 years of age and their families. The Program is administered by local health departments in 56 out of 62 counties in New York State. The staff are positioned to provide people in their county with information and referrals to federal, state, and local resources to support their health care needs and quality of life and well-being. The Program efforts include engaging families of children and youth with special health care needs in work groups, committees, task forces, and advisory committees to improve the system of care as well as inform local planning activities; develop and strengthen strategic partnerships; and inform a Resource Directory to provide families and health care providers with current information about federal, state, and local services and supports.

Introduction

Children and Youth with Special Health Care Needs 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.² The New York State Department of Health Title V Maternal and Child Health Services Block Grant program aims 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.³

The purpose of this report is to update partners 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

¹ Title V Maternal and Child Health Services Block Grant Program. https://www.health.ny.gov/community/infants_children/maternal_and_child_health_services/

² Children and Youth with Special Health Care Needs. <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs>

³ Title V Maternal and Child Health Services Block Grant Program. https://www.health.ny.gov/community/infants_children/maternal_and_child_health_services/

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.

Materials and Methods

Since 2016 the United States Census Bureau has administered the National Survey of Children’s Health annually via web- and mail- (paper) based instruments.⁴ 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.

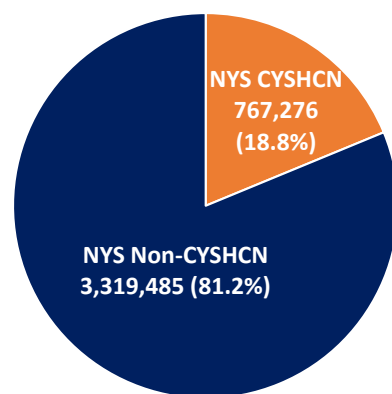
In 2022, New York State invested in an over-sampling of the National Survey of Children’s Health, aiming to obtain more data to represent children and youth with special health care needs. As a result of the over-sampling, caregivers for a sample of 1,039 children and youth with special health care needs were surveyed in New York State in 2022. The most recent 2022 National Survey of Children’s Health data is used in this report. It is important to note that, unless noted otherwise, 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. For more information about National Survey of Children’s Health data, please visit the Data Resource Center for Child and Adolescent Health website.⁵ Analyses were conducted using SAS software version 9.4 (SAS Institute Inc., Cary, NC).

Demographics

In 2022, it was estimated that 18.8% (767,276) children ages 0-17 years in New York State had a special health care need, as shown in Figure 1.

- New York State children and youth with special health care needs were 55.0% male and 45.0% female.
- The age distribution of New York State children and youth with special health care needs was 18.3% 0-5 years old, 34.9% 6-11 years old, and 46.7% 12-17 years old.
- The racial distribution of New York State children and youth with special health care needs was 50.4% non-Hispanic White, 26.4% Hispanic, 12.8% non-Hispanic Black, 2.5% non-Hispanic Asian and 7.8% identified as non-Hispanic and either some other race and/or Multi-racial.

Figure 1. 2022 prevalence of children and youth with special health care needs (CYSHCN) in New York State



⁴ National Survey of Children's Health. <https://www.census.gov/programs-surveys/nsch.html>

⁵ 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.

- 89.0 % of New York State children and youth with special health care needs lived in a household where English was the primary language.
- 41.0% 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, 25.6% lived in a household between 200%-399% of federal poverty level, and 33.5% lived in a household at 400% or greater of the federal poverty level.
- Private insurance coverage was the most common, exclusively covering 54.3% of New York State children and youth with special health care needs, followed by 37.1% with public insurance including Medicaid and Child Health Plus, 6.5 % with both public and private insurance, and 2.1% uninsured.
- 24.5% of New York State children and youth with special health care needs sampled qualified* on functional limitations, 23.9% on above-routine use of services, 24.5% on prescription medication only, and 27.1% 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.

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 25 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. Six seven percent (67.0%) of New York State children and youth with special health care needs experienced more than one health condition, and 7.9% of New York State children and youth with special health care needs did not report any of the 25 conditions included in the survey.

Table 1. Number of Health Conditions Reported

Number of Conditions	n (%) of NYS CYSHCN
Two or more	717 (67.1%)
One	250 (24.9%)
None/unknown	72 (7.9%)
Total	1039 (100.0%)

Caregivers most commonly reported their child as being diagnosed with allergies (42.5%), followed by anxiety (31.8%), attention deficit disorder or attention-deficit/hyperactivity disorder (31.2%), learning difficulty (25.5%) and behavioral/conduct problem (23.4%). Compared to the 2016-2021 National Survey of Children’s Health New York State children and youth with special health care needs data, the percent of children with anxiety saw the largest increase (23.5% to 31.8%) and asthma saw the largest decrease (30.1% to 20.6%). 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 18 of the 25 conditions in Table 2. Autoimmune disease (37.3%) and genetic or inherited condition (23.6%) 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 2022 n (%)	NYS CYSHCN 2016-2021 n (%)**	Increase or Decrease in % affected	Severity NYS CYSHCN, 2022		
				Mild n (%)	Moderate n (%)	Severe n (%)
Allergies	474 (42.5)	396 (42.1)	0.4	236 (48.2)	173 (38.5)	61 (13.3)
Anxiety	379 (31.8)	256 (23.5)	8.3	150 (38.6)	190 (47.9)	37 (13.6)
ADD or ADHD***	317 (31.2)	239 (23.6)	7.6	110 (28.7)	168 (57.3)	38 (14)
Learning difficulty	259 (25.5)	214 (24.6)	0.9	102 (37.7)	119 (45.7)	35 (16.6)
Behavioral/Conduct Problem	203 (23.4)	178 (19.1)	4.3	94 (43.0)	91 (45.8)	17 (11.3)
Developmental Delay	218 (23.0)	190 (24.6)	-1.6	83 (38.6)	103 (43.2)	32 (18.2)
Speech or language disorder	188 (20.7)	166 (21.2)	-0.5	76 (37.7)	74 (43.6)	37 (18.8)
Asthma	212 (20.6)	227 (30.1)	-9.5	129 (58.5)	72 (35.5)	9 (6.0)
Autism	131 (14.3)	109 (13.9)	0.4	62 (39.5)	52 (49.0)	15 (11.5)
Genetic or inherited condition	145 (14.3)	121 (13.6)	0.7	48 (29.3)	63 (47.2)	28 (23.6)
Depression	157 (14.1)	104 (11.2)	2.9	67 (42.5)	74 (48.1)	15 (9.4)
Head Injury***	98 (7.7)	34 (2.5)	5.2	--	--	--
Migraines	63 (6.3)	70 (7.1)	-0.8	29 (48.5)	30 (44.7)	4 (6.8)
Intellectual Disability	47 (5.4)	41 (5.0)	0.4	14 (24.5)	23 (56.7)	10 (18.9)
Vision Problem	28 (3.8)	27 (3.8)	--	--	--	--
Epilepsy/Seizure Disorder	33 (3.4)	23 (3.7)	-0.3	15 (39.1)	13 (47.2)	4 (13.7)
Autoimmune Disease***	46 (3.1)	--	--	11 (32.3)	17 (30.3)	18 (37.3)
Heart Problem	28 (2.7)	22 (2.7)	--	22 (72.0)	5 (24.0)	1 (3.9)
Hearing Problem	23 (1.7)	28 (2.9)	-1.2	--	--	--
Cerebral Palsy	11 (1.4)	8 (1.5)	-0.1	4 (54.1)	5 (26.0)	2 (19.8)
Blood Disorders	11 (1.3)	13 (2.2)	-0.9	6 (71.1)	1 (5.2)	3 (23.7)
Down Syndrome	15 (1.3)	7 (0.9)	0.4	--	--	--
Tourette Syndrome	13 (1.3)	8 (0.6)	0.7	--	--	--
Type 2 Diabetes***	2 (0.1)	--	--	--	--	--
Cystic Fibrosis	0 (0)	3 (0.8)	-0.8	--	--	--

* 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.

** Due to the sample size limit of the state-level data each year, 2016 to 2021 data were combined for comparison. Caregivers for a sample of 890 children and youth with special health care needs were surveyed in New York State from 2016 to 2021.

*** ADD or ADHD stands for attention deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD). Head Injury question has been modified in 2020; therefore, for the comparison contains 2020 and 2021 data only. Autoimmune disease and type 2 diabetes question are added in 2022.

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 60.1% 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	253 (26.9%)
One	338 (33.2%)
None/unknown	447 (39.9%)
Total	1038 (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 2022 National Survey of Children’s Health, difficulty concentrating (37.9%), breathing or other respiratory problems (19.0%), and coordination or moving around (19.1%) 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=1039)	
Breathing or other respiratory problems	19.0%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	14.0%
Chronic physical pain including headaches or other back or body pain	13.7%
Eating or swallowing	3.7%
Seeing even when wearing glasses or contact lenses	3.7%
Deafness or problems with hearing	1.7%
AGES 0-5 (n=171)	
Coordination or moving around	19.1%
Difficulty using hands	13.0%
AGES 6-17 (n=859)	
Serious difficulty concentrating, remembering, or making decisions	37.9%
Difficulty dressing or bathing	7.4%
Serious difficulty walking or climbing stairs	3.1%
AGES 12-17 (n=536)	
Difficulty doing errands alone	18.5%

* 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 (18.1%) 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 (17.3%) ages 6-17 missed 11 or more school days over the past year due to illness, compared to 4.8% 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 (49.0%) ages 6-17 reported having trouble making or keeping friends, compared to 13.9% 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 spend more time coordinating their child’s care than families without children and youth with special health care needs (Table 5). About four 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-seven percent of 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	38.0%	23.6%
Family member reduced or stopped work due to child’s health	19.5%	5.2%
Avoided changing jobs due to concerns about health insurance	12.5%	4.9%
Out-of-pocket medical expenses \$1000 or more during the past 12 months	22.5%	11.1%
Had problems paying medical bills during the past 12 months	12.8%	6.3%
Out-of-pocket costs are always reasonable	11.5%	17.5%
Insurance is adequate* and insured all year	66.7%	72.6%
Child’s health insurance benefits always meet child’s needs	55.5%	67.7%

* 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 (81.8%) were less likely to receive family-centered care than families without children and youth with special health care needs (84.3%). 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 were evaluated.⁶ The percent of New York State children and youth with special health care needs who reported always receiving each component ranged from 54% to 69% based on the National Survey of Children’s Health. Higher percent of family-centered care (range 67%-73%) were reported by the local health departments. Comparisons should be interpreted cautiously since the percent of children and youth with special health care needs receiving services from the local health departments is unweighted and response rates for these questions are about 29%. 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	553 (54.4)	242 (67.2)
Doctors/Providers always listen carefully	646 (66.9)	248 (68.7)
Doctors/Providers are always sensitive to family values/customs	673 (68.8)	253 (73.1)
Doctors/Providers always provide needed information	644 (66.8)	243 (66.8)
Doctors/Providers always make family feel like a partner in care	659 (67.8)	247 (69.2)

*Percent is among New York State (NYS) children and youth with special health care needs (CYSHCN) families who answered family-centered care questions and reported by the local health departments (LHDs). Frequency answered ranged from 346 to 364 based on 1224 children and youth with special health care needs served by the LHDs during the contract year of Oct. 1, 2021, to Sep. 30, 2022. Percent of New York State children and youth with special health care needs receiving services from LHDs is not weighted and therefore comparisons between National Survey of Children’s Health (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 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 2022, only 39.2% of New York State children and youth with special health care needs met all five components of medical home criteria, compared to 46.0% 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 (44.1%) for New York State children and youth with special health

⁶ Children and Youth with Special Health Care Needs (CYSHCN) Program <https://health.ny.gov/CYSHCN>

care needs. Less than one in five children and youth with special health care needs ages 12-17 (22.0%) received services needed for transition to adult health care. Many adolescents (57.4%) had a chance to speak to their health care provider alone at their last preventive check-up. Most providers (65.4%) 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 22.9% 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	443 (39.2)	596 (60.8)	1039
Child has personal doctor or nurse	851 (79.1)	186 (20.9)	1037
Child has usual source of sick care	864 (81.8)	159 (18.2)	1023
Care was family-centered	809 (81.8)	145 (18.2)	954
Care coordination was effective, among those that needed	467 (55.9)	359 (44.1)	826
Difficulties getting referrals, among those that needed	89 (27.9)	281 (72.1)	370

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	121 (22.0)	417 (78.0)	538
Had time alone with health care provider at last preventive check-up	333 (57.4)	202 (42.6)	535
Health care provider worked with child to gain skills to manage health or understand health care changes at age 18	367 (65.4)	95 (21.5)	462
Provider discussed shift to adult health care providers (if needed)	89 (22.9)	332 (77.1)	421

Per national performance measure 13.2, most children and youth with special health care needs (82.2%), age 1-17, had a preventive dental visit in the past year compared to 74.2% of children and youth without special health care needs in New York State. For adolescents ages 12-17 years, national performance measure 9 showed 49.6% of children and youth with special health care needs are bullied compared to 22.5% of children and youth without special health care needs in New York State. In contrast, national performance measure 9 showed 19.1% of children and youth with special health care needs bullied others compared to 6.1 % of children and youth without special health care needs 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 2022, only 13.6% 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 system of care for New York State children and youth with special health care needs. 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. The New York State Department of Health transitioned from supporting three Health Resources and Services Administration designated University Centers of Excellence in Developmental Disabilities from October 1, 2019, to September 30, 2024, to a Children and Youth with Special Health Care Needs Center of Excellence from October 1, 2024, to September 30, 2029, using the Title V Maternal and Child Health Services Block Grant. The Children and Youth with Special Health Care Needs Center of Excellence promote a standard of excellence for local programs statewide through the provision of training, technical assistance, and family engagement. The Children and Youth with Special Health Care Needs Center of Excellence will:

1. Complete a statewide needs assessment with each local health department to determine effective ways to build capacity in their communities to serve children and youth with special health care needs and their families.
2. Provide professional training and technical assistance for local health department staff and create a Family/Community Engagement Plan annually to outline county-specific actions and strategies for increasing family and community outreach.
3. Develop a public facing, online, searchable state-wide resource guide for professional staff as well as children and youth with special health care needs and their families. The resource guide will include a statewide comprehensive catalog of available federal, state, local, and community-based organization resources to enhance the physical and mental health of children and youth with special health care needs.
4. Engage children and youth with special health care needs and families in planning and systems work, including those to address health equity, reduce disparities, and the impact of social determinants of health. The Children and Youth with Special Health Care Needs Center of Excellence will gather feedback through listening sessions and telephone interviews with children and youth with special health care needs and their families throughout the state and represent demographic, economic, racial, ethnic, and language diversity.

In addition to the activities of the Regional Support Centers and Center of Excellence, Title V programs will conduct a Needs Assessment to determine the priorities of the next five-year Maternal Child Health Services Block Grant cycle. Additional data analysis based on the over-sampling of the National Survey of Children's Health in 2022 will be conducted. 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 the Center of Excellence 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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