New York State Profile of Children and Youth with Special Health Care Needs, 2023-2024

EXCUTIVE SUMMARY

A priority of the New York State Department of Health Title V Maternal and Child Health Services Block Grant, funded by the Health Resources and Services Administration (HRSA), 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 States 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. This report uses the most recently available national data as well as current program information.

In 2023 and 2024, it was estimated that 27.7% (1,093,891) of children ages 0-17 years in New York State had a special health care need. Only 41.2% of children and youth with special health care needs have a medical home, and one in four 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 Department of Health 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 up to 21 years of age and their families. The Program is administered by 52 local health departments, including New York City for a total of 56 out of 62 counties, in New York State (as of June 2026). The county staff are positioned to provide their residents 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; designing family and community engagement plans; helping children and families transition between life stages and services; developing and strengthening strategic partnerships; and informing a Resource Directory to provide families and health care providers with current information about federal, state, and local services and supports.

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

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.

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 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.[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. However, concerns persist about the Screener's inability to capture some children on the special health care needs continuum, especially those children at risk for developing a special health care need and other children who may be missed due to parental/caregiver recall bias, parents' reluctance to label their children as children and youth with special health care needs and the non-categorical approach used to identify health consequences rather than identifying specific diagnoses. In May 2025, the Health Resources and Services Administration (HRSA) provided new guidance that uses a wider definition to include children whose caregivers report both a diagnosed condition and specific functional difficulty, regardless of designation by the Screener, resulting in an increase in the US prevalence of children and youth with special health care needs from 24.9% to 27.7%. The key to the additional individuals captured by the

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

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

expanded criteria is that they must have at least one condition AND at least one functional difficulty, not just one or the other. Moreover, the new approach captures more children who are Hispanic, uninsured, or live in households with lower educational attainment.[4,5]

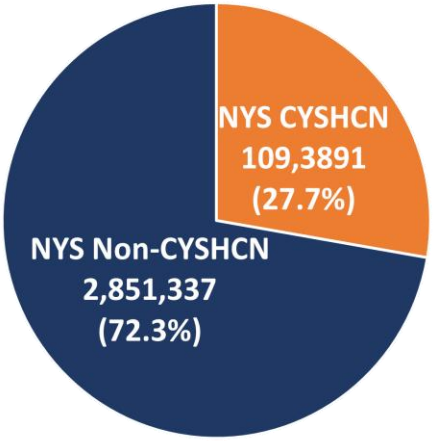
In 2022, New York State invested in an oversampling of the National Survey of Children's Health, aiming to enhance data and to obtain more data to represent children and youth with special health care needs. While the 2022–2023 data benefited from the oversampling project, the 2023–2024 data reflects the standard federal core sampling that was employed before 2022. In addition, 2023–2024 estimates utilize the expanded criteria, which broadens the definition of CYSHCN to include a wider continuum of children with co-occurring diagnoses and functional difficulties. 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 a household. For more information about National Survey of Children's Health data, please visit the Data Resource Center for Child and Adolescent Health website.[6] Analyses were conducted using SAS software version 9.4 (SAS Institute Inc., Cary, NC).

Findings

Demographics

It was estimated that 27.7% (1,093,891) children ages 0-17 years in New York State had a special health care need in 2023-2024, as shown in Figure 1.

Figure 1. 2023-2024 prevalence of children and youth with special health care needs in New York State



[4] Jeffrey P. Brosco, Reem M. Ghandour, Shirley Payne, Amy J. Houtrow; Reconsideration of the Calculation of Children and Youth with Special Health Care Needs. Pediatrics June 2024; 153 (6): e2023065107. 10.1542/peds.2023-065107

[5] Black LI, Ghandour RM, Brosco JP, Payne SI, Houtrow A, Kogan MD, Bethell CD. An Expanded Approach to the Ascertainment of Children and Youth with Special Health Care Needs. Pediatrics 2024 May 7; 153 (6): e2023065131. doi: 10.1542/peds.2023-065131. PMID: 38712452.

[6] Data Resource Center for Child and Adolescent Health (DRC). https://www.childhealthdata.org
Combined 2022and 2023 National Survey of Children's Health downloadable dataset is released on February 01, 2023, having an approximately 14 months lag.

- New York State children and youth with special health care needs were 58.0% male and 42.0% female.
- The age distribution of New York State children and youth with special health care needs was 17.2% 0-5 years old, 36.3% 6-11 years old, and 46.4% 12-17 years old.
- The racial distribution of New York State children and youth with special health care needs was 46.7% non-Hispanic White, 25.5% Hispanic, 14.6% non-Hispanic Black, 5.5% non-Hispanic Asian and 7.8% identified as non-Hispanic and either some other race and/or Multi-racial.
- 84.0% of New York State children and youth with special health care needs lived in a household where English was the primary language.
- 36.9% 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, 29.1% lived in a household between 200%-399% of federal poverty level, and 34.1% lived in a household at 400% or greater of the federal poverty level.
- Private insurance coverage was the most common, exclusively covering 51.1% of New York State children and youth with special health care needs, followed by 36.1% with public insurance including Medicaid and Child Health Plus, 10.1% with both public and private insurance, and 2.8% uninsured.
- 24.9% 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, 16.1% on prescription medication only, and 18.2% on a combination of prescription medication and above routine use of services.

*Qualified as a children and youth with special health care needs who met the Screener and expanded criteria for CYSHCN 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 percentage of New York State children and youth with special health care needs experiencing one condition versus multiple conditions. About 90% of New York State children and youth with special health care needs experienced at least one health condition, and 10.4% 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	324 (65.7%)
One	126 (23.9%)
None/unknown	47 (10.4%)
Total	**497 (100.0%)**

Caregivers most commonly reported their child as being diagnosed with allergies (43.4%), followed by learning difficulty (32.3%), attention deficit disorder or attention-deficit/hyperactivity disorder (27.4%), anxiety (27.1%), and developmental delay (26.3%). Compared to the 2022-2023 National Survey of Children's Health New York State children and youth with special health care needs data, the percent of children with learning difficulties saw the largest increase (24.8% to 32.3%) and depression saw the largest decrease (13.3% to 9.2%). 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 25 conditions in Table 2. Speech or language disorder (22.0%) and Autism (21.5%) 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 2023-2024 n (%)	NYS CYSHCN 2022-2023 n (%) **	Increase or Decrease in % affected	Severity NYS CYSHCN, 2023-2024		
				Mild n (%)	Moderate n (%)	Severe n (%)
Allergies	229 (43.4)	720 (45.1)	-1.7	116 (51.8)	78 (35.7)	33 (13.0)
Anxiety	138 (27.1)	486 (28.7)	-1.6	63 (48.7)	67 (41.5)	8 (9.7)
ADD or ADHD* **	136 (27.4)	405 (27.9)	-0.5	48 (32.0)	69 (48.0)	18 (20.0)
Learning difficulty	127 (32.3)	346 (26.5)	5.8	50 (45.2)	60 (41.3)	15 (13.4)
Behavioral/Conduct Problem	104 (24.0)	270 (23.5)	0.5	45 (43.0)	48 (41.7)	11 (15.3)
Developmental Delay	106 (26.3)	290 (23.7)	2.6	43 (45.9)	47 (36.3)	15 (17.8)
Speech or language disorder	112 (22.5)	267 (19.4)	3.1	57 (45.6)	39 (32.4)	15 (22.0)
Asthma	107 (19.9)	293 (18.3)	1.6	71 (63.4)	33 (32.9)	3 (3.6)
Autism	78 (17.6)	174 (13.4)	4.2	28 (29.7)	39 (48.8)	10 (21.5)
Genetic or inherited condition	--	--	--	--	--	--
Depression	49 (9.2)	193 (11.2)	-2.0	25 (47.2)	22 (46.0)	2 (6.8)
Concussion/Brain Injury* **	31 (5.6)	123 (6.8)	-1.2	--	--	--
Migraines	28 (5.7)	103 (5.0)	0.7	14 (57.7)	11 (32.1)	3 (10.2)
Intellectual Disability	24 (5.6)	62 (5.7)	-0.1	9 (30.5)	13 (58.6)	2 (10.9)
Vision Problem	13 (3.6)	51 (3.9)	-0.3	--	--	--
Epilepsy/Seizure Disorder	6 (1.0)	37 (2.2)	-1.2	1 (12.3)	3 (69.6)	2 (18.1)
Autoimmune Disease* **	19 (2.0)	54 (1.9)	0.1	7 (34.1)	8 (46.4)	4 (19.6)
Heart Problem	11 (1.5)	41 (2.2)	-0.7	6 (70.0)	4 (22.2)	1 (7.7)
Hearing Problem	11 (3.8)	32 (1.5)	2.3	--	--	--
Cerebral Palsy	3 (0.3)	11 (0.5)	-0.2	2 (60.2)	1 (39.8)	0 (0.0)
Blood Disorders	8 (1.4)	18 (1.4)	0.0	5 (39.7)	2 (46.5)	1 (13.9)
Down Syndrome	1 (0.2)	16 (0.7)	-0.5	--	--	--
Tourette Syndrome	1 (0.2)	14 (0.6)	-0.4	1 (100.0)	--	--
Type 2 Diabetes* **	--	0 (0.0)	0	--	--	--
Cystic Fibrosis	0 (0)	0 (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.
** Direct longitudinal comparison between these periods should be interpreted with caution. While the 2022–2023 data benefited from a high-density state oversampling project, the 2023–2024 data reflects the standard federal core sample. Moreover, the 2023–2024 estimates utilize the expanded criteria, which broadens the definition of CYSHCN to include a wider continuum of children with co-occurring diagnoses and functional difficulties. Caregivers for a sample of 1510 and 497 children and youth with special health care needs were surveyed in New York State from 2022-2023 and 2023-2024 respectively.
*** ADD or ADHD stands for attention deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD). Head Injury question has been modified in 2020 and is now labelled Concussion/Brain Injury. Autoimmune disease and type 2 diabetes question were 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 71.6% 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	124 (28.5%)
One	209 (43.1%)
None/unknown	163 (28.5%)
Total	**496 (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 2023-2024 National Survey of Children's Health, difficulty concentrating (41.3%), difficulty with coordination or moving around (26.4%), and breathing or other respiratory problems (24.4%) 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=497)	
Breathing or other respiratory problems	24.4%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	16.2%
Chronic physical pain including headaches or other back or body pain	11.4%
Eating or swallowing	4.2%
Seeing even when wearing glasses or contact lenses	3.6%
Deafness or problems with hearing	3.8%
AGES 0-5 (n=107)	
Coordination or moving around	26.4%
Difficulty using hands	17.2%
AGES 6-17 (n=390)	
Serious difficulty concentrating, remembering, or making decisions	41.3%
Difficulty dressing or bathing	7.5%
Serious difficulty walking or climbing stairs	3.0%
AGES 12-17 (n=230)	
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 (17.4%) 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 (10.8%) ages 6-17 missed 11 or more school days over the past year due to illness, compared to 1.6% of New York State children and youth without special health care needs.
- Half of New York State children and youth with special health care needs (53.6%) ages 6-17 reported having trouble making or keeping friends, compared to 14.6% of New York State children and youth without 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 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-six 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	41.9%	15.7%
Family member reduced or stopped work due to child's health	18.2%	4.1%
Avoided changing jobs due to concerns about health insurance	9.7%	5.8%
Out-of-pocket medical expenses $1000 or more during the past 12 months	19.0%	10.9%
Had problems paying medical bills during the past 12 months	14.0%	5.3%
Out-of-pocket costs are always reasonable	14.4%	16.4%
Insurance is adequate* and insured all year	63.4%	74.5%
Child's health insurance benefits always meet child's needs	60.5%	70.5%

* 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 (84.0%) were less likely to receive family-centered care than families without children and youth with special health care needs (85.7%). 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.[7] The percentage of New York State children and youth with special health care needs who reported always receiving each component ranged from 53% to 69% based on the National Survey of Children's Health. A lower percentage of family-centered care (range 52%-56%) was reported by the local health departments. Comparisons should be interpreted cautiously since the percentage 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 54%. 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	249 (53.0)	404 (52.1)
Doctors/Providers always listen carefully	293 (64.8)	408 (53.5)
Doctors/Providers are always sensitive to family values/customs	318 (67.0)	424 (55.7)
Doctors/Providers always provide needed information	300 (64.7)	412 (54.6)
Doctors/Providers always make family feel like a partner in care	310 (68.8)	408 (55.1)

*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 404 to 424 based on 2342 children and youth with special health care needs served by the LHDs during the contract year of Oct. 1, 2023, to Sep. 30, 2024. 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.

[7] Children and Youth with Special Health Care Needs (CYSHCN) Program https://health.ny.gov/CYSHCN

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 the medical home national performance measure, percent of children and youth with special health care needs who have a medical home, and the transition to adult health care national performance measure, 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 2023 and 2024, only 41.2% of New York State children and youth with special health care needs met all five components of medical home criteria, compared to 46.7% of children and youth without special health care needs. 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 care needs. One in four children and youth with special health care needs ages 12-17 (22.5%) received services needed for transition to adult health care. Many adolescents (58.9%) had a chance to speak to their health care provider alone at their last preventive check-up. Most providers (69.0%) 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 20.0% of providers discussed the shift to a provider who treats adults.

Table 7. NPM: 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	**207 (41.2)**	**289 (58.8)**	**496**
Child has personal doctor or nurse	418 (84.0)	76 (16.0)	494
Child has usual source of sick care	400 (78.1)	88 (21.9)	488
Care was family-centered	385 (84.0)	72 (16.0)	457
Care coordination was effective, among those that needed	214 (55.9)	176 (44.1)	390
Difficulties getting referrals, among those that needed	47 (22.8)	141 (77.2)	188

Table 8. NPM: 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	**64 (22.5)**	**165 (77.5)**	**229**
Had time alone with health care provider at last preventive check-up	142 (58.9)	86 (41.1)	228
Health care provider worked with child to gain skills to manage health or understand health care changes at age 18	150 (69.0)	41 (15.8)	225
Provider discussed shift to adult health care providers (if needed)	39 (20.0)	124 (80.0)	163

Lastly, systems of care national outcome measure are defined as the percentage 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 2023 and 2024, only 15.4% 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, with funding from the Title V Maternal and Child Health Services Block Grant. The Children and Youth with Special Health Care Needs Center of Excellence promotes 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 statewide 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. 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 that represent demographic, economic, racial, ethnic, and language diversity.

In addition to the activities of the Center of Excellence, the New York State Department of Health Title V program recently conducted 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:

Email: CYSHCN@health.ny.gov
Phone: 518-474-1961
Website: https://health.ny.gov/CYSHCN