

Children with Special Health Care Needs in New York State

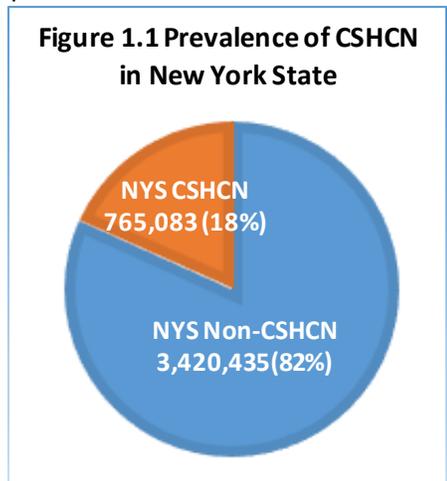
One of the priorities of the New York State Department of Health Title V Maternal and Child Health Services Block Grant program (Title V) is to increase supports to address the special health care needs of children and youth, and to improve health outcomes and the system of care for children with special health care needs (CSHCN) and their families.

According to the Health Resources and Service Administration Maternal and Child Health Bureau, CSHCN 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.

In the past (2001, 2005/2006 and 2009/2010) the National Center for Health Statistics at the Centers for Disease Control administered the National Survey of Children with Special Health Care Needs (NS-CSHCN). In 2016, for the first time, the National Survey of Children's Health (NSCH) was conducted by the US Census Bureau and consolidated content from the previous NSCH and NS-CSHCN. The 2016 NSCH was a random survey administered via web and mail (paper) based instruments. The survey used a validated screening tool to identify children 0-17 living in the household and a topical survey to collect information on factors related to the health and well-being of children. Children whose caregiver reported they experienced a functional limitation, prescription medication use, use of specialized services or a combination of prescription medications and service use were categorized as CSHCN.

The purpose of this report is to explore the demographic, health, and functional difficulty profile of the New York State CSHCN (NYS CSHCN) 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 CSHCN receive care in a well-functioning system. It is important to note that all frequencies shown throughout this report are weighted for the entire NYS population unless noted otherwise.

Caregivers for a sample of 193 CSHCN were surveyed in NYS. It is estimated that 765,083 children ages 0-17 years in New York State (18.3%) have a special health care need, as shown in Figure 1.1.



Demographics of NYS CSHCN

- The age distribution of NYS CSHCN was 13.9% 0-5 years old, 42.9% 6-11 years old, and 43.2% 12-17 years old;
- The racial distribution of NYS CSHCN was 45.7% White, non-Hispanic, 34.3% Hispanic, 9.0% Black, non-Hispanic, and 11.0% Other non-Hispanic;
- 91% of the NYS CSHCN lived in a household where English was the primary language;
- 49.1% of NYS CSHCN lived in a household with income between 0%-199% of the federal poverty level (FPL), 9.8% lived in a household between 200%-299% of FPL, 15.1% lived in a household between 300%-399% of FPL, and 26% lived in a household at 400% or greater of the FPL;
- Private insurance coverage was the most common, exclusively covering 44% of the NYS CSHCN sampled, followed by public insurance including Medicaid and Child Health Plus (37%), 15% with both public and private insurance, and 3% uninsured; and
- 36% of the NYS CSHCN sampled qualified based on prescription medications, 28% on functional limitation, 22% on a combination of prescription medication and above routine use of specialized services, and 14% qualified on above routine use of specialized services only.

Health Conditions and Functional Difficulties

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

Multiple Conditions

Many children surveyed experienced one or more co-morbid conditions. Nine percent (9%) of the CSHCN sampled had either no condition or the condition(s) was unknown. Table 1.1 shows the percent of NYS CSHCN experiencing one

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condition versus multiple conditions. Two-thirds (66%) of the population surveyed experienced more than one health condition.

Table 1.1 Number of Health Conditions Reported Among CSHCN

Number of Conditions	n (%) of NYS CSHCN
None/unknown	12 (8.7)
One	49 (25.2)
Two or more	132 (66.1)
Total	193 (100.0)

Table 1.2 shows the frequency and percent for each of the 27 health conditions surveyed, the severity of those conditions, and whether the condition was reported singularly, or along with another condition. Caregivers most commonly reported their child as being diagnosed with allergies (46%), followed by asthma (33%). Over half the health conditions reported occurred with another condition. Epilepsy (29%), asthma (26%), diabetes (25%) and allergies (19%) were most likely to occur alone.

Table 1.2 Health Conditions Surveyed*

Health Condition Surveyed	Total NYS		Severity			Two or More Conditions n (%)	Single Condition Only n (%)
	CSHCN n (%)	Mild n (%)	Moderate n (%)	Severe n (%)			
Allergies	88 (46.1)	39 (36.9)	36 (43.1)	13 (20.0)	71 (80.7)	17 (19.3)	
Asthma	54 (32.8)	34 (52.8)	17 (44.7)	3 (2.4)	40 (74.1)	14 (25.9)	
ADD or ADHD	52 (27.0)	22 (34.8)	24 (46.7)	5 (18.5)	50 (96.2)	2 (3.8)	
Other mental health condition	44 (23.8)	15 (27.4)	22 (48.8)	7 (23.7)	41 (93.2)	3 (6.8)	
Developmental Delay	41 (22.5)	21 (44.2)	15 (36.2)	5 (19.5)	40 (97.6)	1 (2.4)	
Anxiety	50 (21.9)	21 (41.7)	27 (56.5)	2 (1.8)	46 (92.0)	4 (8.0)	
Learning difficulty	42 (21.7)	18 (35.2)	17 (41.1)	7 (23.7)	42 (100.0)	0 (0.0)	
Behavioral/Conduct Problem	41 (21.4)	16 (31.4)	20 (44.1)	5 (24.8)	41 (100.0)	0 (0.0)	
Speech or language disorder	29 (15.3)	10 (49.9)	15 (41.6)	4 (8.5)	29 (100.0)	0 (0.0)	
Genetic or inherited condition	24 (11.6)	10 (33.3)	12 (60.2)	2 (6.5)	21 (87.5)	3 (12.5)	
Autism or ASD	23 (10.2)	12 (47.5)	9 (45.4)	2 (7.1)	22 (95.7)	1 (4.3)	
Migraines	14 (4.7)	5 (45.6)	9 (54.4)	0 (0.0)	14 (100.0)	0 (0.0)	
Intellectual Disability	11 (4.3)	2 (9.9)	6 (64.6)	3 (25.5)	11 (100.0)	0 (0.0)	
Depression	14 (3.8)	6 (48.0)	6 (40.3)	2 (11.7)	14 (100.0)	0 (0.0)	
Vision Problem	3 (3.6)	--	--	--	2 (66.6)	1 (33.3)	
Hearing Problem	8 (3.3)	--	--	--	8 (100.0)	0 (0.0)	
Epilepsy/Seizure Disorder	7 (3.0)	3 (70.3)	2 (17.6)	1 (12.1)	5 (71.4)	2 (28.6)	
Heart Problem	4 (2.1)	3 (100.0)	0 (0.0)	0 (0.0)	4 (100.0)	0 (0.0)	
Diabetes	4 (1.3)	1 (38.5)	2 (61.5)	0 (0.0)	3 (75.0)	1 (25.0)	
Blood Disorders	3 (1.2)	2 (100.0)	0 (0.0)	0 (0.0)	3 (100.0)	0 (0.0)	
Tourette Syndrome**	2 (1.2)	1 (70.3)	1 (29.7)	0 (0.0)	2 (100.0)	0 (0.0)	
Head Injury	3 (1.0)	0 (0.0)	2 (80.4)	1 (19.6)	3 (100.0)	0 (0.0)	
Cerebral Palsy	3 (0.8)	1 (28.8)	2 (71.2)	0 (0.0)	3 (100.0)	0 (0.0)	
Down Syndrome**	3 (0.8)	1 (31.4)	2 (68.6)	0 (0.0)	3 (100.0)	0 (0.0)	
Arthritis/Joint Problem	1 (0.6)	1 (100.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)	
Cystic Fibrosis	0 (0)	--	--	--	--	--	
Substance Abuse disorder	0 (0)	--	--	--	--	--	

* Summation is greater than 100% as conditions were not mutually exclusive. Frequencies of single condition vs. two or more conditions are not weighted. Severity frequencies omit missing responses, therefore total of severities may not equal total of the health condition.

**Down Syndrome and Tourette Syndrome combined Moderate/Severe; percentages are listed under moderate

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Condition Severity

The conditions experienced by NYS CSHCN occurred with varying levels of severity. Severity level (defined through self-report as mild, moderate, or severe) was assessed for 23 of the 27 conditions in Table 1.2. Intellectual disabilities (26%), behavioral problems (25%), learning difficulties (24%), and other mental health conditions (24%) had the greatest proportion of children in the severe category.

Functional Difficulties

The 2016 NSCH contained 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. Three quarters of NY CSHCN were reported to have at least one functional difficulty (Table 1.3).

Table 1.3 Number of Functional Difficulties Reported Among CSHCN

Number of Conditions	n (%) of NYS CSHCN
None/unknown	65 (24.9)
One	70 (41.5)
Two or more	58 (33.6)
Total	193 (100.0)

Among the 12 functional difficulties included in the 2016 NSCN survey, difficulty concentrating (38%), breathing or other respiratory problems (34%), and difficulty coordinating or moving around (31%) were the most frequently experienced by NYS CSHCN within the applicable age group.

Table 1.4 Functional Difficulty Experienced

Functional Difficulty Experienced	(%) of NYS CSHCN
ALL AGES (n=193)	
Breathing or other respiratory problems	33.8%
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	22.6%
Chronic physical pain including headaches or other back or body pain	14.1%
Eating or swallowing	5.8%
Seeing even when wearing glasses or contact lenses	3.6%
Deafness or problems with hearing	3.3%
AGES 0-5 (n=20)	
Coordination or moving around	30.6%
Difficulty using hands	21.2%
AGES 6-17 (n=76)	
Serious difficulty concentrating, remembering or making decisions	37.7%
Difficulty dressing or bathing	9.4%
Serious difficulty walking or climbing stairs	5.5%
AGES 12-17 (n=97)	
Difficulty doing errands alone	22.8%

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 CSHCN found that:

- One in seven NYS CSHCN (14%) had their daily activities greatly affected by their health condition(s);
- One in six NYS CSHCN (16%) missed 11 or more school days over the past year due to illness, compared to 3% of NYS children without a SHCN;
- Nearly half of NYS CSHCN (47%) reported having trouble making or keeping friends, compared to 11% of NYS children without a SHCN.

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Impact of Special Health Care Needs on the Family

Families of CSHCN face more financial strain and spend more time coordinating their child's care than families without a CSHCN (Table 1.5). One in eight families with CSHCN reported spending at least one hour coordinating their child's health care. Families of CSHCN 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 CSHCN were also less likely to have adequate insurance throughout the year and have insurance benefits that meet their child's needs.

Table 1.5 Family Impacts of Supporting CSHNC

	% NYS CSHCN	% NYS non-CSHCN
Family member reduced or stopped work due to child's health	9.7%	4.3%
Spent at least one hour each week coordinating child's health care	12.5%	0.2%
Avoided changing jobs due to concerns about health insurance	11.8%	6.2%
Out of pocket medical expenses \$1000 or more	19.7%	8.4%
Had problems paying medical bills past 12 months	14.0%	6.2%
Insurance is adequate and insured all year	62.6%	73.8%
Child's health insurance benefits always meet child's needs	61.9%	75.6%
Out-of-pocket costs are always reasonable	13.7%	27.0%

Analysis of Medical Home Components

In the past, having a medical home appeared to be a mitigating factor for most of the selected impact factors. In 2016, only 38.5% of NYS CSHCN met all five components of medical home criteria, compared to 55.3% of non-CSHCN in NY. Medical home components were evaluated to assess which were most frequently inadequate among those NYS CSHCN not meeting medical home status shown in Table 1.6. Of the five medical home components, effective care coordination was most frequently reported as being unmet (40%) by NYS CSHCN. Tables 1.7 and 1.8 report the frequency of components of care coordination and family-centered care, respectively. Receiving help with care coordination (27.6%), provider spending enough time with child (55.4%), and doctor-to-doctor communication (63.5%) were the components of family-centered care and care coordination least likely to be met among NYS CSHCN.

Table 1.6 Frequency of Medical Home Components

Medical Home Component	Yes n (%)	No n (%)	Total
Child has personal doctor or nurse	165 (79.7)	28 (20.3)	193
No problems getting referral when needed	50 (75.3)	14 (24.7)	64
Child has usual source of sick care	168 (78.3)	25 (21.7)	193
Care coordination was effective, among those that needed	91 (60.0)	66 (40.0)	157
Care was family-centered	154 (78.7)	34 (21.3)	188

Table 1.7 Frequency of Effective Care Coordination Components

Effective Care Coordination Components	Yes n (%)	No n (%)	Total
Received some type of help with care coordination, among those that need it	30 (27.6)	124 (72.4)	154
Very satisfied with doctor-to-doctor communication	92 (63.5)	59 (36.5)	151
Very satisfied with doctor communication to other providers or programs	42 (70.9)	12 (29.1)	54

Table 1.8 Frequency of Family-Centered Care Components

Family-Centered Care Components	Yes n (%)	No n (%)	Total
Doctors/Providers always spend enough time with child	114 (55.4)	74 (44.6)	188
Doctors/Providers always listen carefully	122 (64.9)	66 (35.1)	188
Doctors/Providers are always sensitive to family values/customs	138 (72.2)	49 (27.9)	187
Doctors/Providers always provide needed information	129 (71.1)	56 (28.8)	185
Doctors/Providers always make family feel like a partner in care	131 (69.5)	55 (30.5)	186

Program Considerations

The system of care for CSHCN should be comprehensive, community-based, family-centered and coordinated. Results from the 2016 NSCH demonstrate that interventions are needed to increase the family-centered care and care coordination for NYS CSHCN. NYS is committed to maintaining and improving a state CSHCN Program that is responsive to families' needs. To further delineate how to be responsive and supportive to families of CSHCN, the CSHCN Program gathered input about the current systems of care from families of CSHCN across NYS in 2017-2018 by use of a care mapping process. The feedback from 138 caregivers involved in the care mapping process support many of the findings from the 2016 NSCH. Families wanted: 1) information readily available; 2) more opportunities for connections amongst caregivers and CSHCN; and 3) improved health insurance coverage and financial assistance.

Families wanted information about specialists and community resources provided at the time of diagnosis. Families across the state have expressed the desire for better doctor-to-doctor communication and between physicians and other service providers. Many caregivers said they were left on their own to find resources after they received their child's diagnosis. Caregivers wanted a single place, such as an information hub, where they could find information on State programs. Although the CSHCN Program is available to provide linkages to services in most counties of the state, most families were not aware of the local CSHCN programs available. In the next procurement for local CSHCN Programs, Title V will promote visibility of the program to caregivers by requiring local staff participation in community engagement activities.

Care coordination, when delivered effectively, provides family caregivers with information sought to help them navigate systems of care. It is expected that Children's Health Homes will continue to develop as a key point in care management services for the Medicaid insured population of the state and a source of information for Title V to learn of needs, barriers and disparities. Title V has provided training on Children's Health Homes to local CSHCN Programs so they can link families to this resource, and training about CSHCN Programs has been provided to Health Homes case managers. Title V's continuing communication, consultation and partnership with the Office of Health Insurance Program's Health Home team is critical to ensuring a comprehensive system of services and supports are available and maintained across the state.

Families that participated in care mapping also stressed the financial strain of supporting a child with special health care needs, which is also evident in the 2016 NSCH (Table 1.5). The costs of copays and high deductibles for medications and medical services, equipment, therapies not covered by school or insurance, transportation to long distance specialists, and specialized child care are often a concern for families. Families would like to see more comprehensive health insurance coverage, compensation for at-home child care, and availability of other types of financial assistance to help pay the costs not covered by insurance. Title V currently offers the Physically Handicapped Children's Program (PHCP) through LHDs. Due to the requirement for LHDs to match state funds, participation in this program has decreased over time with only 28 LHDs participating in 2017.

Families wanted more opportunities for connections amongst caregivers and CSHCN and integration into their communities. This includes making communities more accessible to CSHCN, identifying parent support groups to share information and experiences, having more group activities for the children and family members, and connecting caregivers with respite opportunities. This year Title V hosted webinars for LHDs to share best practices in two areas: 1) supporting and linking families of CSHCN with other families; and 2) increasing opportunities to involve CSHCN and their families in community activities. These webinars provided LHDs an opportunity to share success stories and engage other LHDs in suggestions for overcoming barriers to social support for CSHCN and their families.

Since the NSCH will now be available annually, Title V will monitor progress to see how family feedback differs or aligns with national survey data and share trends with local CSHCN Programs. Title V is examining ways to strengthen LHD capacity to provide information, referrals and supports to families. Title V is considering a procurement that will identify a contractor(s) to provide training and technical assistance to local CSHCN Programs and assist with resource

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identification and compilation. Caregiver feedback will continue to be gathered to understand whether these changes in supports to local CSHCN programs are responsive to the needs identified by families of CSHCN.