

# New York State Profile of Children with Special Health Care Needs, 2016-2017

## Children with Special Health Care Needs in New York State

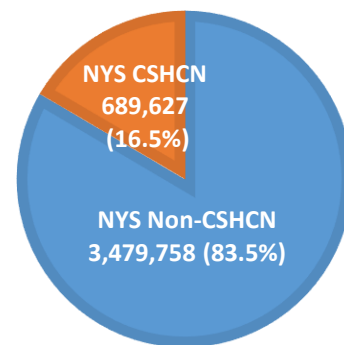
According to the Health Resources and Service Administration Maternal and Child Health Bureau, Children with Special Health Care Needs (CSHCN) are defined as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. A priority of the New York State Department of Health Title V Maternal and Child Health Services Block Grant program (Title V) is to increase supports to address the special health care needs of children and youth, and to improve health outcomes and the system of care CSHCN and their families.

In 2016, the National Survey of Children's Health (NSCH) underwent key changes from prior years. Those changes included the consolidation of content from two previous surveys, the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs (NS-CSHCN), which were administered approximately every four years. Since 2016 the US Census Bureau administered the survey annually via web- and mail- (paper) based instruments. The survey used a validated screening tool to identify children 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 CSHCN. Due to the sample size of state-level data, combining multiple years of data into one data set allows for more in-depth analysis. Therefore, this report analyzes the combined 2016 and 2017 NSCH data for New York State (NYS).

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 percentages shown throughout this report are weighted to represent the population of NYS non-institutionalized children 0-17 who live in housing units unless noted otherwise.

Caregivers for a sample of 273 CSHCN were surveyed in NYS in 2016 and 2017. It is estimated that 689,627 children ages 0-17 years in New York State (16.5%) have a special health care need, as shown in Figure 1.1.

**Figure 1.1 Prevalence of CSHCN in New York State**



## Demographics of NYS CSHCN

- \* The age distribution of NYS CSHCN was 20.6% 0-5 years old, 41.5% 6-11 years old, and 37.9% 12-17 years old;
- \* The racial distribution of NYS CSHCN was 48.2% White, non-Hispanic, 33.1% Hispanic, 9.9% Black, non-Hispanic, and 8.8% Other non-Hispanic;
- \* 92.4% of the NYS CSHCN lived in a household where English was the primary language;
- \* 50.3% of NYS CSHCN lived in a household with income between 0%-199% of the federal poverty level (FPL), 22.5% lived in a household between 200%-399% of FPL, and 27.2% lived in a household at 400% or greater of the FPL;

- \* Private insurance coverage was the most common, exclusively covering 46% of the NYS CSHCN, followed by public insurance including Medicaid and Child Health Plus (41%), 10% with both public and private insurance, and 2% uninsured; and
- \* 33% of the NYS CSHCN sampled qualified based on prescription medications, 29% on functional limitation, 21% on a combination of prescription medication and above routine use of specialized services, and 17% qualified on above routine use of specialized services only.

### Health Conditions and Functional Difficulties

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

**Table 1.1 Health Conditions Surveyed\***

| Health Condition Surveyed      | NYS CSHCN<br>2016-2017<br>n (%) | NYS CSHCN<br>2016<br>n (%) | Increase/<br>Decrease<br>in %<br>affected | Severity<br>NYS CSHCN, 2016-2017 |                   |                 |
|--------------------------------|---------------------------------|----------------------------|---|----------------------------------|-------------------|-----------------|
|                                |                                 |                            |   | Mild<br>n (%)                    | Moderate<br>n (%) | Severe<br>n (%) |
| Allergies                      | 126 (46.9)                      | 88 (46.1)                  | 0.8%                                      | 54 (36.5)                        | 55 (47.9)         | 17 (15.6)       |
| Asthma                         | 72 (27.9)                       | 54 (32.8)                  | -4.9%                                     | 44 (45.6)                        | 24 (49.3)         | 4 (5.1)         |
| ADD or ADHD                    | 75 (23.6)                       | 52 (27.0)                  | -3.4%                                     | 28 (29.5)                        | 37 (49.9)         | 9 (20.6)        |
| Other Mental Health Condition  | 57 (18.5)                       | 44 (23.8)                  | -5.3%                                     | 22 (36.1)                        | 24 (40.6)         | 10 (23.3)       |
| Developmental Delay            | 59 (26.8)                       | 41 (22.5)                  | 4.3%                                      | 32 (58.0)                        | 21 (30.8)         | 6 (11.2)        |
| Anxiety                        | 67 (17.7)                       | 50 (21.9)                  | -4.2%                                     | 29 (42.4)                        | 34 (54.4)         | 4 (3.2)         |
| Learning Difficulty            | 63 (25.9)                       | 42 (21.7)                  | 4.2%                                      | 28 (51.0)                        | 26 (35.9)         | 8 (13.1)        |
| Behavioral/Conduct Problem     | 54 (16.9)                       | 41 (21.4)                  | -4.5%                                     | 23 (36.2)                        | 25 (44.0)         | 6 (19.9)        |
| Speech or Language Disorder    | 46 (17.9)                       | 29 (15.3)                  | 2.6%                                      | 20 (53.1)                        | 20 (36.4)         | 6 (10.6)        |
| Genetic or Inherited Condition | 31 (10.4)                       | 24 (11.6)                  | -1.2%                                     | 12 (34.3)                        | 15 (55.8)         | 3 (9.9)         |
| Autism or ASD                  | 37 (15.3)                       | 23 (10.2)                  | 5.1%                                      | 21 (58.0)                        | 12 (34.9)         | 3 (7.1)         |
| Migraines                      | 25 (7.9)                        | 14 (4.7)                   | 3.2%                                      | 8 (29.0)                         | 13 (46.3)         | 4 (24.8)        |
| Intellectual Disability        | 14 (3.7)                        | 11 (4.3)                   | -0.6%                                     | 2 (6.5)                          | 8 (61.5)          | 4 (32.0)        |
| Depression                     | 21 (4.2)                        | 14 (3.8)                   | 0.4%                                      | 9 (44.6)                         | 9 (43.8)          | 3 (11.6)        |
| Vision Problem                 | 6 (3.8)                         | 3 (3.6)                    | 0.2%                                      | --                               | --                | --              |
| Hearing Problem                | 10 (2.6)                        | 8 (3.3)                    | -0.7%                                     | --                               | --                | --              |
| Epilepsy/Seizure Disorder      | 8 (2.1)                         | 7 (3.0)                    | -0.9%                                     | 4 (79.1)                         | 2 (12.4)          | 1 (8.5)         |
| Heart Problem                  | 7 (2.1)                         | 4 (2.1)                    | 0.0%                                      | 6 (100.0)                        | 0 (0.0)           | 0 (0.0)         |
| Diabetes                       | 6 (1.7)                         | 4 (1.3)                    | 0.4%                                      | 1 (12.4)                         | 4 (87.6)          | 0 (0.0)         |
| Blood Disorders                | 3 (0.6)                         | 3 (1.2)                    | -0.6%                                     | 2 (100.0)                        | 0 (0.0)           | 0 (0.0)         |
| Tourette Syndrome**            | 4 (1.2)                         | 2 (1.2)                    | 0.0%                                      | 3 (84.2)                         | 1 (15.8)          | 0 (0.0)         |
| Head Injury                    | 5 (1.1)                         | 3 (1.0)                    | 0.1%                                      | 1 (35.4)                         | 3 (55.0)          | 1 (9.6)         |
| Cerebral Palsy                 | 3 (0.5)                         | 3 (0.8)                    | -0.3%                                     | 1 (28.8)                         | 2 (71.2)          | 0 (0.0)         |
| Down Syndrome**                | 3 (0.5)                         | 3 (0.8)                    | -0.3%                                     | 1 (31.4)                         | 2 (68.6)          | 0 (0.0)         |
| Arthritis/Joint Problem**      | 3 (1.5)                         | 1 (0.6)                    | 0.9%                                      | 2 (37.2)                         | 1 (62.8)          | 0 (0.0)         |
| Cystic Fibrosis                | 0 (0)                           | 0 (0)                      | 0.0%                                      | --                               | --                | --              |
| Substance Abuse disorder       | 0 (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.

\*\*Arthritis/Joint Problem, Down Syndrome and Tourette Syndrome combined Moderate/Severe; percentages are listed under moderate.

Table 1.1 shows the frequency and percent for each of the 27 health conditions surveyed and the severity of those conditions. Caregivers most commonly reported their child as being diagnosed with allergies (46%), followed by asthma (28%), and ADD or ADHD (24%). Compared to the 2016 NSCH data, percent of children

with other mental health conditions saw the largest decrease (23.8% to 18.5%) and autism saw the largest increase (10.2% to 15.3%).

Many children surveyed experienced one or more health conditions. Twelve percent (12%) of NYS CSHCN did not have any of the 27 conditions included in the survey. Table 1.2 shows the percent of NYS CSHCN experiencing one condition versus multiple conditions. Sixty-one percent of the NYS CSHCN experienced more than one health condition.

**Table 1.2 Number of Health Conditions Reported Among CSHCN**

| Number of Conditions | n (%) of NYS CSHCN |
|----------------------|--------------------|
| None/unknown         | 21 (12.1)          |
| One                  | 70 (27.0)          |
| Two or more          | 182 (60.9)         |
| <b>Total</b>         | <b>273 (100.0)</b> |

### 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 24 of the 27 conditions in Table 1.1. Intellectual disabilities (32%), severe headaches or migraines (25%), and other mental health conditions (23%) had the greatest proportion of children in the severe category.

### Functional Difficulties

The NSCH contains survey questions to assess the presence of 12 functional difficulties. Half the functional difficulty questions applied to children of all ages and the other half were asked of only children in specific age groups. Among the 12 functional difficulties included in the 2016-2017 NSCN surveys, difficulty concentrating (35%), breathing or other respiratory problems (26%), and difficulty coordinating or moving around (27%) were the most frequently experienced by NYS CSHCN within the applicable age group (Table 1.3).

**Table 1.3 Functional Difficulty Experienced**

| Functional Difficulty Experienced  | (%) of NYS CSHCN |
|--|------------------|
| <b>ALL AGES (n=273)</b>  |                  |
| Breathing or other respiratory problems  | 26.3%            |
| Digesting food, including stomach/intestinal problems, constipation, or diarrhea | 17.0%            |
| Chronic physical pain including headaches or other back or body pain             | 13.9%            |
| Eating or swallowing   | 4.8%             |
| Seeing even when wearing glasses or contact lenses                               | 3.8%             |
| Deafness or problems with hearing  | 2.6%             |
| <b>AGES 0-5 (n=32)</b>   |                  |
| Coordination or moving around  | 26.6%            |
| Difficulty using hands   | 19.5%            |
| <b>AGES 6-17 (n=109)</b>   |                  |
| Serious difficulty concentrating, remembering or making decisions                | 34.5%            |
| Difficulty dressing or bathing   | 8.7%             |
| Serious difficulty walking or climbing stairs                                    | 4.8%             |
| <b>AGES 12-17 (n=132)</b>  |                  |
| Difficulty doing errands alone   | 17.2%            |

While the presence of functional difficulty was less common than the presence of a health conditions, two-thirds of NYS CSHCN experienced at least one functional difficulty (Table 1.4).

**Table 1.4 Number of Functional Difficulties Reported Among CSHCN**

| Number of Conditions | n (%) of NYS CSHCN |
|----------------------|--------------------|
| None/unknown         | 94 (33.0)          |
| One                  | 100 (38.0)         |
| Two or more          | 77 (29.0)          |
| <b>Total</b>         | <b>271 (100.0)</b> |

**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:

- \* Nearly one in seven NYS CSHCN (13%) had their daily activities greatly affected by their health condition(s);
- \* One in nine NYS CSHCN (11%) missed 11 or more school days over the past year due to illness, compared to 2% of NYS children without a SHCN; and
- \* Nearly half of NYS CSHCN (46%) reported having trouble making or keeping friends, compared to 11% of NYS children without a SHCN.

**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 per week 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 pocket medical expenses, and have problems paying medical bills. Families of CSHCN were also less likely to have adequate health insurance throughout the year and have insurance benefits that meet their child’s needs.

**Table 1.5 Family Impacts of Supporting CSHCN**

|  | % NYS CSHCN | % NYS non-CSHCN |
|--|-------------|-----------------|
| Spent at least one hour each week coordinating child’s health care | 12.8%       | 0.3%            |
| Family member reduced or stopped work due to child’s health        | 13.2%       | 3.3%            |
| Avoided changing jobs due to concerns about health insurance       | 9.4%        | 5.3%            |
| Out-of-pocket medical expenses \$1000 or more                      | 19.5%       | 8.7%            |
| Had problems paying medical bills past 12 months                   | 22.5%       | 8.6%            |
| Out-of-pocket costs are always reasonable                          | 15.3%       | 26.8%           |
| Insurance is adequate and insured all year                         | 64.9%       | 74.9%           |
| Child’s health insurance benefits always meet child’s needs        | 67.1%       | 70.9%           |

**Family-Centered Care for CSHCN**

Family-centered care is an approach to planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Since the families are typically the decision makers and sources of support and information for children, a collaborative approach to health care is beneficial. NSCH data revealed that 87% of NYS CSHCN received family-centered care. Individual components of family-centered care from the NSCH and from CSHCN who received information and referral services from NYS local health departments (LHDs) were evaluated. The percent of NYS CSHCN who reported always receiving each component ranged from 66% to 76% based on the NSCH. However, the

percent NYS CSHCN served by their LHD reported lower levels of family-centered care (range 52%-56%). Comparisons should be interpreted cautiously since the percent of CSHCN receiving services from their LHD is unweighted. It is possible that the children who seek information and referral services from their LHD have more complex needs or were more likely to have experienced a lack of assistance from their health care provider (hence them seeking services from the LHD) than all CSHCN in NYS.

**Table 1.6 Family-Centered Care Components**

| Family-Centered Care Components                                  | Percent of NYS CSHCN, NSCH | Percent* of NYS CSHCN receiving services from LHD |
|--|----------------------------|---|
| Doctors/Providers always spend enough time with child            | 174 (65.9)                 | 93 (51.4)   |
| Doctors/Providers always listen carefully                        | 183 (73.6)                 | 99 (52.7)   |
| Doctors/Providers are always sensitive to family values/customs  | 198 (75.7)                 | 97 (55.7)   |
| Doctors/Providers always provide needed information              | 188 (74.1)                 | 98 (53.6)   |
| Doctors/Providers always make family feel like a partner in care | 191 (74.3)                 | 102 (54.5)  |

\* Percent of NYS CSHCN receiving services from LHD is not weighted and therefore comparisons between NSCH should use caution. Percent is among CSHCN who answered family-centered care questions. Frequency answered ranged from 174 to 187.

### Analysis of National Performance Measures and National Outcome Measures

Two Maternal Child Health National Performance Measures (NPM) and one National Outcome Measure (NOM) for CSHCN are assessed in the NSCH. For NPM 11, percent of CSHCN who have a medical home, and NPM 12, percent of adolescents with SHCN who received services necessary to transition to adult health care, each component was evaluated (Tables 1.7 and 1.8, respectively). In 2016-2017, only 44.8% of NYS CSHCN met all five components of medical home criteria, compared to 51.7% of non-CSHCN in NY. Of the five medical home components, effective care coordination was most frequently reported as being unmet (32.3%) by NYS CSHCN. Less than one in seven CSHCN age 12-17 (13.7%) received services needed for transition to adult health care. Only half of adolescents had a chance to speak to their health care provider alone at his or her last preventive check-up. While 72% of providers actively worked with adolescents with SHCN to gain the skills to manage his/her health and health care or understand changes in health care happening at age 18, only 7% of providers discussed the shift to a provider who treats adults.

**Table 1.7 NPM 11: Percent of children with special health care needs, ages 0-17, who have a medical home**

| Medical Home and Components  | Yes n (%)         | No n (%)          | Total      |
|--|-------------------|-------------------|------------|
| <b>Received coordinated, ongoing, comprehensive care within a medical home</b> | <b>139 (44.8)</b> | <b>134 (55.2)</b> | <b>273</b> |
| Child has personal doctor or nurse   | 234 (81.2)        | 39 (18.8)         | 273        |
| No problems getting referral when needed                                       | 70 (80.8)         | 18 (19.1)         | 88         |
| Child has usual source of sick care  | 236 (79.9)        | 35 (20.1)         | 271        |
| Care coordination was effective, among those that needed                       | 141 (67.7)        | 87 (32.3)         | 228        |
| Care was family-centered   | 228 (87.3)        | 35 (12.7)         | 263        |

**Table 1.8 NPM 12: Percent of adolescents with special health care needs, ages 12-17, who received services necessary to make transitions to adult health care**

| Transition to Adult Care and Components  | Yes n (%)        | No n (%)          | Total      |
|--|------------------|-------------------|------------|
| <b>Received services needed for transition to adult health care</b>  | <b>16 (13.7)</b> | <b>111 (86.3)</b> | <b>127</b> |
| Had time alone with health care provider at last preventive check-up   | 65 (50.3)        | 57 (49.7)         | 122        |
| Health care provider worked with child to gain skills to manage health or understand health care changes at age 18 | 83 (71.9)        | 35 (28.1)         | 118        |
| Provider discussed shift to adult health care providers (if needed)  | 6 (6.6)          | 85 (93.4)         | 91         |

NOM 17.2 is defined as the percent of CSHCN, age 0-17, who receive care in a well-functioning system. The NSCH uses over 50 different survey questions to construct this measure. The measure is comprised of five measures for children 0-11: the family feels like a partner in their child's care, child has a medical home, child receives early screening (both preventive medical and dental visits), child has adequate insurance, and child has no unmet need or barriers to access services. For adolescents age 12-17 years, preparation for transition to adult healthcare is included in addition to the five measures. In 2016-2017, only 15% of NYS CSHCN received care in a well-functioning system.

### **Program Considerations**

The system of care for CSHCN should be comprehensive, community-based, family-centered and coordinated. Results from the 2016-2017 NSCH demonstrate that interventions are needed to improve the number of NYS CSHCN children receiving care in a well-functioning system. NYS is committed to maintaining and improving a state CSHCN Program that is responsive to families' needs. Using information that was gathered from families and service providers of CSHCN in 2017-2018, Title V is funding three Regional Support Centers for CSHCN through existing relationships with three University Centers of Excellence in Developmental Disabilities (UCEDDs). From October 1, 2019 to September 30, 2021 the Regional Support Centers (RSCs) will improve services to CSHCN through the following initiatives:

1. Completing a needs assessment with each local health department and providing technical assistance to improve information and referral services to families of CSHCN. RSCs will work with LHDs to build capacity to serve families through improved outreach and program promotion.
2. Developing regional resource guides for both families and providers. Resource guides will include a comprehensive catalog of available resources, enabling LHDs to make more timely and effective referrals to services.
3. Gathering family feedback through listening sessions and telephone interviews with families of CSHCN. The care mapping feedback sessions conducted in 2017-2018 provided NYSDOH valuable information on the challenges families and providers encountered in caring for CSHCN. Continuous feedback is vital to ensuring challenges are addressed and to evaluate how the information received is aligned with local program and NSCH data. Feedback will be sought from families in areas of the state that were not included in care mapping as well as including a focus on racial, ethnic and language diversity.
4. Developing educational materials. RSCs will develop training and educational materials for families and providers, including training videos and short video vignettes on the importance of a medical home, transition of adolescents with SHCN to adult health care, and other topics determined from family feedback gathered.

In addition to the activities of the RSCs, Title V is also beginning work on the five-year Needs Assessment to determine the priorities of the next five-year Maternal Child Health Services Block Grant cycle. Listening sessions with consumers across New York State, including families of CSHCN, will take place in the fall of 2019. Title V will continue to monitor NSCH data on CSHCN to see how family feedback differs or aligns with national survey data and share trends with RSCs and local CSHCN Programs.

For more information, contact the New York State Department of Health Children and Youth with Special Health Care Needs (CYSHCN) Program at [CYSHCN@health.ny.gov](mailto:CYSHCN@health.ny.gov) or 518-474-1961