

***Appendix #2***

***Children with  
Special Health Care  
Needs (CSHCN)  
Screener***



# ***Children with Special Health Care Needs (CSHCN) Screener*** †

## ***Technical Summary***

### **DESCRIPTION**

The Children with Special Health Care Needs (CSHCN) Screener is a set of five questions used to identify children with chronic or special health care needs. The questions are designed to be self-administered or telephone administered as part of a parent/caretaker survey. It was originally developed to identify a population for quality assessment and, with appropriate sampling, to estimate the prevalence of CSHCN.

The screener takes approximately one minute to administer for a single child and an average of two minutes to complete when screening all children in a household (range: 1 to 4½ minutes). English and Spanish language versions of the screening tool are available.

### ***Conceptual approach***

The CSHCN Screener was specifically designed to operationalize the children with special health care needs definition endorsed by the federal Maternal and Child Health Bureau (MCHB). This definition states that a child with a special health care need 1) has or is at risk for having a physical, developmental, behavioral, or emotional condition and 2) requires health or related services of a type or amount beyond that required by children.<sup>1</sup> Like the MCHB definition, the CSHCN Screener focuses on the health consequences a child experiences as a result of having an on-going health condition rather than on the presence of a specific diagnosis or type of disability.

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### ***Definitional criteria***

The screening tool uses consequences-based criteria to identify children with special health care needs. All of following must be present to qualify:

- The child currently experiences a specific consequence;
- The consequence is due to a medical, behavioral, or other health condition;
- The duration or expected duration of the condition is 12 months or longer.

The first part of each CSHCN Screener question asks whether a child experiences one of five different health consequences:

1. Use or need of prescription medication;
2. Above average use or need of medical, mental health or educational services;
3. Functional limitations compared with others of the same age;
4. Use or need of specialized therapies (e.g., OT, PT, speech);
5. Treatment or counseling for emotional, behavioral, or developmental problems.

The second and third parts of each screening question<sup>‡</sup> ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and, if so, whether that condition has lasted or is expected to last for at least 12 months.

All three parts of at least one screener question (or, in the case of question 5, both parts) must be answered “yes” in order for a child to meet the CSHCN Screener criteria.

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<sup>‡</sup> Question 5 of the screener is a two-part question; both are answered “yes” to qualify.

## BACKGROUND

The CSHCN Screener was developed in response to the need for an efficient, standardized method of identifying CSHCN for the purposes of quality assessment and other population-based applications.

The theoretical framework used by the CSHCN screener is based on that of a longer tool, the Questionnaire for Identifying Children with Chronic Conditions (QuICCC).<sup>2</sup> Like the QuICCC, the criteria used by the CSHCN screener to determine if a child has a chronic condition or special health care need are independent of specific diagnostic labels or formally recorded diagnoses.

The relatively low prevalence of any single childhood chronic condition and the large number of applicable diagnoses, many of which are very rare, makes condition-specific checklists and/or diagnosis-based case finding inadequate for capturing the full range of pediatric chronic disease. In addition, diagnoses-based approaches are known to miss many children due to coding errors, misdiagnoses, lack of access to care, and the global or developmental nature of some childhood problems.

In contrast, a non-condition specific approach identifies children across the range and diversity of childhood chronic conditions and special needs. The inclusion of a wide range of childhood chronic conditions allows a more comprehensive assessment of health care system performance than is attainable by focusing on any single diagnosis or type of special need. In addition, the low prevalence of most childhood chronic conditions makes it problematic to find adequate numbers with a specific diagnosis or type of special need. A non-condition specific approach such as that used by the CSHCN Screener makes it possible in many cases to identify enough children with special health care needs to allow statistically robust quality comparisons across health care systems and/or providers.

The CSHCN Screener was developed through the Child and Adolescent Health Measurement Initiative (CAHMI), a national effort focused on measuring and

improving the quality of health care for children and adolescents. The CAHMI is led by FACCT–The Foundation for Accountability.

## TESTING AND USE HISTORY

### ***Testing***

Over 36,000 cases of CSHCN Screener data were collected during its development. Testing included administration in commercial and Medicaid managed care, Medicaid Fee-for-Service, and primary care case management populations. The screening tool was also fielded in two national samples of households with children during pre-testing for the SLAITS National CSHCN Survey sponsored by the federal Maternal and Child Health Bureau.

Results from the CSHCN Screener have been compared with the QuICCC-R (a reduced version of the QuICCC), the 3M/CRG clinical classification system, medical chart reviews, and parental reports of their children's specific health conditions, service needs, and utilization levels. Overall, the CSHCN Screener identified numbers of children commensurate with other epidemiological studies of special health care needs. The screener did not systematically exclude categories of children according to the type and/or severity of their health conditions, and exhibited a high level of agreement with other methods.<sup>3</sup> For an in-depth description of the development and testing of the CSHCN Screener, refer to the two *Ambulatory Pediatrics* journal articles included in this appendix.

### ***Proportion identified***

In a general population sample of households with children age 0 to 17 years, the CSHCN Screener identified 15-16 percent of children as having special health care needs.<sup>4</sup> In a statewide sample of families with children enrolled in Medicaid managed care through Temporary Aid to Needy Families (TANF), 21 percent of children age 0 to 13 years were identified.<sup>4</sup> In the same study, nearly 95 percent of children receiving Supplemental Security Income (SSI) benefits met the CSHCN Screener criteria. When administered in a sample of families with children enrolled in the Florida Healthy Kids Program, the

CSHCN Screener identified approximately 24 percent of children age 5 to 19 years as having a special health care need.<sup>5</sup>

As in other studies of children with special health care needs<sup>6,7</sup> the proportions identified by the CSHCN Screener vary according to the age (higher for older children), gender (higher for males), and race/ethnicity of the child. In particular, children of Hispanic origin are less likely to be identified as having a special health care need. Other researchers also report lower rates among Hispanic children; these differences are not fully understood and deserve further study.<sup>5,8</sup>

### ***Use History***

The CSHCN Screener is currently being used in several national and statewide surveys, including the National Survey of Children with Special Health Care Need, and as part of the CAHPS® survey items in the Medical Expenditure Panel Survey (MEPS). The Agency for Healthcare Research and Quality (AHRQ) has included the screener as an integral part of the new CAHPS 2.0 Child Survey. The screener is also formally integrated into the CAHPS 2.0H Child Survey to identify the Children with Chronic Conditions Measurement Set, a component of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set (HEDIS®).

The CSHCN Screener is answered by parents of adolescents in several of these surveys. There is some concern, however, whether parents or the adolescents themselves are more reliable responders to these types of questions. The screener has also been administered directly to adolescents in several large samples. The question of adolescent self-report versus parent proxy-report will be evaluated in future studies.

The Spanish language translation of the CSHCN Screener is being used in both national and statewide survey applications. As with all survey-based measures, continued study is necessary to ensure the cultural competency of such methods.

## AVAILABILITY and COST

The CSHCN Screener is available at no cost from FACCT–The Foundation for Accountability. To fill out a User’s Form and download a copy of the CSHCN Screener, go to [www.facct.org/cahmi](http://www.facct.org/cahmi).

## TECHNICAL SUPPORT

Technical support for administering, scoring, and interpreting results of the CSHCN Screener can be obtained by e-mailing [childs@facct.org](mailto:childs@facct.org). Scoring programs, test data sets, and supporting materials are also available upon request.

## OTHER CONSIDERATIONS

The CSHCN Screener was originally developed to identify a population for quality assessment and monitoring. All formal testing of the screener to date has occurred in the context of confidential, point in time (cross-sectional) surveys of parents or other caretakers. More study is needed to understand its use in non-confidential settings such as patient assessment during a physician office visit or as a component of a health plan enrollment interview.

The pressing need for a self-administered, standardized method has led many State Medicaid agencies and MCOs to adopt the CSHCN Screener as a method for screening new Medicaid or health plan enrollees to identify CSHCN for the purposes of further follow up and evaluation. The use of the screening tool to identify individual CSHCN for case management and other types of assessments or tracking is just beginning to be studied on a formal basis.

The CSHCN Screener has not been evaluated for use as a risk adjustment method, nor has it been fielded across the full range of clinical and community settings. Both self-administration and telephone interview administration of the instrument are well tested but further study is needed to assess in-person interview and online methods.



## REFERENCES

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- <sup>5</sup> Shenkman E, Vogel B, Brooks R, Wegner D H, Naff R. Race, ethnicity, and identification of special needs children. *Health Care Financing Review*. 2001;23(2):35-51.
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***CSHCN  
Screener***



# Children with Special Health Care Needs (CSHCN) Screener<sup>®</sup>

(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
  - Yes → Go to Question 1a
  - No → Go to Question 2
  - 1a. Is this because of ANY medical, behavioral or other health condition?
    - Yes → Go to Question 1b
    - No → Go to Question 2
  - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
    - Yes
    - No
  
2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
  - Yes → Go to Question 2a
  - No → Go to Question 3
  - 2a. Is this because of ANY medical, behavioral or other health condition?
    - Yes → Go to Question 2b
    - No → Go to Question 3
  - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
    - Yes
    - No
  
3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
  - Yes → Go to Question 3a
  - No → Go to Question 4
  - 3a. Is this because of ANY medical, behavioral or other health condition?
    - Yes → Go to Question 3b
    - No → Go to Question 4
  - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
    - Yes
    - No
  
4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
  - Yes → Go to Question 4a
  - No → Go to Question 5
  - 4a. Is this because of ANY medical, behavioral or other health condition?
    - Yes → Go to Question 4b
    - No → Go to Question 5
  - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
    - Yes
    - No
  
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
  - Yes → Go to Question 5a
  - No
  - 5a. Has this problem lasted or is it expected to last for at least 12 months?
    - Yes
    - No

## Scoring the Children with Special Health Care Needs (CSHCN) Screener<sup>®</sup>

The CSHCN Screener<sup>®</sup> uses consequences-based criteria to screen for children with chronic or special health care needs. To qualify as having chronic or special health care needs, the following criteria must be met:

- a) The child currently experiences a specific consequence.
- b) The consequence is due to a medical or other health condition.
- c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

- 1) Use or need of prescription medication.
- 2) Above average use or need of medical, mental health or educational services.
- 3) Functional limitations compared with others of same age.
- 4) Use or need of specialized therapies (OT, PT, speech, etc.).
- 5) Treatment or counseling for emotional or developmental problems.

The second and third parts\* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

*\*NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered “yes” to qualify.*

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for a child to meet CSHCN Screener<sup>®</sup> criteria for having a chronic condition or special health care need.

The CSHCN Screener<sup>®</sup> has three “definitional domains:”

- 1) Dependency on prescription medications.
- 2) Service use above that considered usual or routine.
- 3) Functional limitations.

The definitional domains are not mutually exclusive categories. A child identified by the CSHCN Screener<sup>®</sup> can qualify on one or more definitional domains (*see diagram*).

