# Taking Stock of the CSHCN Screener: A Review of Common Questions and Current Reflections

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## ABSTRACT

Since 2000, the Children with Special Health Care Needs (CSHCN) Screener (CS) has been widely used nationally, by states, and locally as a standardized and brief survey-based method to identify populations of children who experience chronic physical, mental, behavioral, or other conditions and who also require types and amounts of health and related services beyond those routinely used by children. Common questions about the CS include those related to its development and uses; its conceptual framework and potential for under- or overidentification; its ability to stratify CSHCN by complexity of service needs and daily life impacts; and its potential application in clinical settings and comparisons with other identification approaches. This review recaps the development, design, and findings from the use of the CS and synthesizes findings from studies conducted over the past 13 years as well as updated findings on the CS to briefly address the 12 most common questions asked about this tool through technical assistance provided regarding the CS since 2001. Across a range of analyses, the CS consistently identifies a subset of children with chronic conditions who need or use more than a routine type or amount of medical- and health-related services and who share common needs for health care, including care coordination, access to specialized and community-based services, and enhanced family engagement. Scoring algorithms exist to stratify CSHCN by complexity of needs and higher costs of care. Combining CS data with clinical diagnostic code algorithms may enhance capacity to further identify meaningful subgroups. Clinical application is most suited for identifying and characterizing populations of patients and assessing quality and system improvement impacts for children with a broad range of chronic conditions. Other clinical applications require further implementation research. Use of the CS in clinical settings is limited because integration of standardized patient-reported health information is not yet common practice in most settings or in electronic health records. The CS continues to demonstrate validity as a non-condition-specific, population-based tool that addresses many of the limits of condition or diagnosis checklists, including the relatively low prevalence of many individual conditions and substantial within-diagnosis variations and across-diagnoses similarities in health service needs, functioning, and quality of care.

**KEYWORDS:** children with chronic conditions; children with special health care needs; complex CSHCN; Medical Expenditures Panel Survey; National Survey of Children With Special Health Care Needs; National Survey of Children's Health

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## WHAT'S NEW

In response to renewed national focus on children with special health care needs (CSHCN), we recap the development, design features, and findings on the use of the CSHCN Screener since 2000. Current perspectives on common questions about is validity and use in research, policy, and practice are addressed.

SINCE 1998, LEGISLATIVE mandates have required the Maternal and Child Health Bureau (MCHB) to monitor system performance for US children with special health care needs (CSHCN), a process that requires population-based identification of CSHCN. For this purpose, CSHCN are broadly defined as those who "have or who are at increased risk of having a physical, mental, emotional or other type of health condition requiring a type or amount of health and related services beyond that required by children generally."[1] More recent national legislation requires health systems and/or providers to identify CSHCN to assess accessibility and quality of health care services for this growing population of children.[2–8] Specifically, the

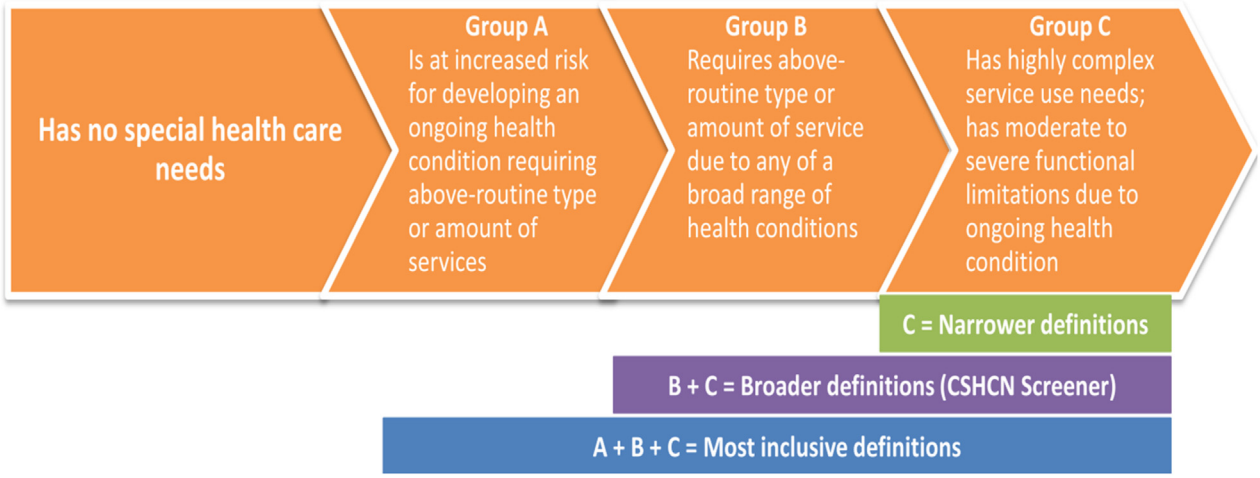


**Figure 1.** *Continuum for defining a consequences-based, noncategorical, non-condition-specific MCHB definition of CSHCN.*

Children's Health Insurance Plan Reauthorization Act (CHIPRA) and the Patient Protection and Affordable Care Act (ACA) require quality measures to be reported separately for CSHCN.[6–8] ACA-related initiatives to incentivize the development of primary care medical homes include similar requirements, and the Centers for Medicare and Medicaid Services (CMS) has issued a set of administrative data-based diagnostic codes to assist in doing so.[4,9]

The CSHCN Screener (CS) has been widely used as a method to identify CSHCN based primarily on the MCHB definition. This 5-item, parent-reported screening instrument requires an average of 1 minute for parents to complete and identifies 15% to 20% of US children, depending on their health and service needs and the presence of any kind of chronic condition.[10] Nationally, data on the CS for over 1.5 million children have been collected through the 2001, 2005–2006, and 2009–2010 National Survey of CSHCN (NS-CSHCN; n = 1,106,974); the 2003, 2007, and 2011–2012 National Survey of Children's Health (NSCH; n = 289,672); and the Medical Expenditure Panel Survey (MEPS) since the year 2000 (n = 113,729).

In response to the persistent and growing need to identify CSHCN for population health and quality measurement and improvement purposes, we recap the development, design features, and population prevalence findings using the CS since 2000, and we briefly address commonly posed questions about its conceptual framework, potential for under- and overidentification, ability to stratify children once identified, and application in clinical settings and in combination with administrative data approaches.

## Review of CS Development, Design, and Prevalence Findings

The CS was designed during 1998–2000 through a national collaborative led by the Child and Adolescent Health Measurement Initiative (CAHMI) and supported by the David and Lucile Packard Foundation and Agency for Healthcare Research and Quality.[11–13] It was initially designed to identify a robust and sufficiently large group of children for measuring quality of care for CSHCN across health plans in the Consumer Assessment of Health Plans Survey for Children With Chronic Condition (CAHPS-CCC). Subsequently, it was validated as a population-based tool for estimating the prevalence of CSHCN and for comparing needs and health care system performance across states and population subgroups in the NS-CSHCN.[13]

CSHCN can be characterized along a continuum according to the types of chronic health conditions experienced and the frequency, consistency, scope, and intensity of services required (Fig. 1). With a focus on quality measurement and system performance measurement, the national collaboration assembled to develop the CS agreed to not include children at risk for special health care needs (SHCN) but instead to focus on identifying children with existing SHCN who are most vulnerable to weakness in quality and system performance. They also agreed to target identification of a broad range of children, requiring only that the child experience any type of ongoing health condition that results in a need for an above-routine type or amount of health and related services.

After careful review of a range of conceptual models, including administrative data–based methods, the conceptual and empirical foundation from the Questionnaire to Identify Children With Chronic Conditions (QuICCC)[14] and the Questionnaire for Identifying Children with Chronic Conditions—Revised (QuICCC-R)[15] was selected as the framework for the CS. Key features include: 1) a noncategorical definition that is not dependent upon diagnostic lists; 2) the use of service need and/or functional consequences of ongoing conditions as the method of identifying children; and 3) confirmation of eligibility based on the presence of any type of chronic condition and duration of at least 12 months.[12–20] Exhibit A and Exhibit B (available online at http://www.academicpedsjnl.net) provide a synthesis of the specific questions and key design parameters considered during the 2-year collaborative development of the CSHCN Screener (CS) survey-based tool.