

# Identifying Children With Special Health Care Needs: Development and Evaluation of a Short Screening Instrument

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**Background.**—Public agencies, health care plans, providers, and consumer organizations share the need to monitor the health care needs and quality of care for children with special health care needs (CSHCN). Doing so requires a definition of CSHCN and a precise methodology for operationalizing that definition.

**Research Objectives.**—The purpose of this study was to develop an efficient and flexible consequence-based screening instrument that identifies CSHCN across populations with rates commensurate with other studies of CSHCN.

**Methods.**—The CSHCN Screener was developed using the federal Maternal and Child Health Bureau (MCHB) definition of CSHCN and building on the conceptual and empirical properties of the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) and other consequence-based models for identifying CSHCN. The CSHCN Screener was administered to 3 samples: a national sample of households with children ( $n = 17985$ ), children enrolled in Medicaid managed care health plans ( $n = 3894$ ), and children receiving Supplemental Security Income (SSI) benefits in Washington State ( $n = 1550$ ). The efficiency, impact of further item reduction, and flexibility of administration mode were evaluated. Rates and expected variation in rates across demographic groups of children positively identified by one or more of the 5 CSHCN Screener item sequences in each sample were examined and multinomial logistic regression analysis were conducted to evaluate the effect of child characteristics in predicting positive identification.

**Results.**—The CSHCN Screener took approximately 1 minute per child to administer by telephone and 2.1 minutes per household. During self-administration, over 98% of respondents completed each of the 5 CSHCN Screener item sequences, and respondents accurately followed each of the item skip patterns 94% of the time. Mailed surveys and telephone-administered surveys led to similar rates of positive identification in the same sample. Two Screener items would have identified 80%–90% of children positively identified as CSHCN across the study samples, although using only 2 items eliminates some children with more complex health needs. Rates of children identified by the CSHCN Screener varied according to age, sex, race/ethnicity, health status, and utilization of health services.

**Conclusions.**—Results of this study indicate that the CSHCN Screener requires minimal time to administer, is acceptable for use as both an interview-based and self-administered survey, and that rates of children positively identified by the CSHCN Screener vary according to child demographic, health, and health care–need characteristics. The CSHCN Screener provides a comprehensive yet parsimonious and flexible method for identifying CSHCN, making it more feasible than existing measures for standardized use across public agencies, health care plans, and other users.

**KEY WORDS:** children; chronic conditions; identification; quality; screening; special health care needs

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Public agencies, health care plans and providers, and consumer organizations share the need to identify and monitor the health care needs and quality of care for children with special health care needs (CSHCN).<sup>1–5</sup> Not only do CSHCN consume the majority of health care dollars spent on children, their requirements for health services make them particularly vulnerable to access, cost, quality, and coverage weaknesses in the health care system.<sup>6–8</sup> Recent guidelines for state Medicaid programs to identify and monitor care for CSHCN reflect concerns about whether CSHCN are receiving needed and high-quality health care services.<sup>4</sup>

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With regard to CSHCN, monitoring their health care needs, quality of care, and the impact of changes in the organization and delivery of health care requires that we first identify those CSHCN. Doing so requires a definition of CSHCN and a precise methodology for operationalizing that definition. Such a methodology should be as efficient as possible and flexible for use in a variety of health care and community settings, should be based on a definition of CSHCN that is acceptable to a broad range of users, and should yield results that are commensurate with epidemiological studies of CSHCN.

Recent years have seen significant progress in establishing a common definition of CSHCN to guide program planning, service delivery, and monitoring efforts.<sup>9</sup> Specifically, the federal Maternal and Child Health Bureau (MCHB) spearheaded the development of a widely adopted definition that 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 generally.<sup>9</sup> With its focus on the full range of health conditions, the MCHB definition moves beyond conceptualizations of this population

of children that are based primarily on physical health problems. It also requires that a health condition have a service need or consequence for the child to be considered to have a special health care need. Finally, because it includes the concept of being "at risk" for a condition, the MCHB definition implies that a child may have a special health care need even if a health care provider has not yet formally diagnosed a condition.

The MCHB definition of CSHCN was built on a foundation of work by several influential researchers whose empirical studies indicated that childhood chronic conditions often share similar consequences in terms of function and service use.<sup>10-14</sup> This recognition led to the development of 2 consequence-based definitional frameworks that also served as underpinnings for the MCHB definition.<sup>15,16</sup> Common to all of these definitional efforts is an emphasis on identifying the functioning and service need consequences children experience rather than simply identifying the presence of a chronic condition. In contrast to approaches that identify children only if parents and/or administrative records name a specific diagnosed health condition, these consequence-based approaches increase the probability of identifying children with ongoing health conditions that are either 1) not yet formally diagnosed even though they yield significant health and service need consequences or 2) less likely to be recalled or acknowledged by name by parents. In addition, consequence-based approaches that rely upon parent report and not on administrative data may identify children whose health conditions are less likely to appear in clinical or administrative records because of recording oversights, absence of payment incentives, lack of access to care, or poor continuity of care for children.

While it is not the case for adults, a large number of conditions, most with relatively low prevalence, characterize the epidemiology of childhood chronic conditions.<sup>14,17,18</sup> These rates make condition-specific monitoring unfeasible in most cases. Childhood diabetes, for example, has a prevalence of 1.8 per 1000 children.<sup>17,19,20</sup> An average-sized health plan comprising 90 000 covered lives and 30 000 children will have only 54 children with diabetes. Many other diagnoses, such as cystic fibrosis or juvenile arthritis, affect even fewer children. Consequently, monitoring any single childhood condition will not allow statistically robust assessments unless very large populations of children are included. Finally, single-condition monitoring provides an inadequate view of the overall quality and outcomes of care for children with chronic conditions.

The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) represents one way to operationalize a broad, consequence-based approach such as that embodied in the MCHB definition. The interviewer-administered QuICCC asks a parent if his or her child experiences one of 39 specific health-related consequences.<sup>16,18</sup> For most questions, if a parent answers "yes," the QuICCC next asks the parent 2 follow-up questions regarding the presence and duration of an ongoing condition. To qualify as having a special health care need, the

child must have at least one of the 39 consequences, and, for most of these consequences, each must be attributable to a medical, behavioral, or other condition lasting or expected to last at least 12 months.

The QuICCC is suitable for many applications. However, its use across public agencies or health plans creates several problems. The QuICCC and the related QuICCC-Revised (QuICCC-R) include 39 and 16 item sequences, respectively, which represents an administration burden that is greater than that which is generally desirable for large-scale survey efforts.<sup>21</sup> In addition, both versions of the QuICCC are validated only for interviewer administration and are not compatible for use with the self-administered surveys commonly used by states and health care plans. Finally, because the QuICCC is designed to identify children falling into "the gray area or boundary area . . . where there is uncertainty over whether a particular child has a chronic condition," it is less appropriate for users who seek to avoid the identification of children falling into this uncertain area.<sup>22</sup>

This article reports on the development and testing of a new parent survey-based screening instrument to identify CSHCN, referred to here as the CSHCN Screener. The CSHCN Screener is designed to fill a gap in currently available methods by providing an instrument that is efficient, flexible for use across different modes of administration, and that yields rates of CSHCN across populations of children that are commensurate with epidemiological studies of CSHCN. We report on 5 specific objectives. First, we assess the efficiency of the CSHCN Screener in terms of the time required for telephone administration. Next, recognizing the desire of many potential users of the CSHCN Screener to use the most parsimonious identification method possible, we evaluate the impact of further item reduction of the CSHCN Screener. Third, we evaluate the feasibility of using the CSHCN Screener as either a self- or interviewer-administered instrument. Fourth, we assess both the proportion and characteristics of children identified by the CSHCN Screener in each of the study samples and determine whether these rates of CSHCN vary by demographic characteristics, health status, and health care utilization, as has been observed in other studies of CSHCN.<sup>14,17,23,24</sup> Specifically, we examine whether rates of identification are higher for male children and for older children.

## METHODS

### Development of the CSHCN Screener

The CSHCN Screener was developed through a national collaborative process as part of the Child and Adolescent Health Measurement Initiative (CAHMI), the activities of which are coordinated by the Foundation for Accountability (FACCT). The collaborative effort included task force participation on the part of over 30 individuals representing federal and state program directors and policy makers, health care provider organizations, the health services research community, and consumer organizations. Members of the task force met 6 times in person

and more than a dozen times by teleconference, beginning in June 1998 (task force member list available from the authors). Developing the CSHCN Screener involved 4 major milestones:

- 1) Selection of the MCHB definition and a broad, consequence-based framework for defining and identifying CSHCN;
- 2) Review of existing parent survey items and instruments that may align with the federal MCHB definition and consequence-based model of identification;
- 3) Drafting, pilot testing, and revision of the CSHCN Screener; and
- 4) Field testing in a national sample of households with children and in statewide Medicaid managed care and Supplemental Security Income (SSI) samples.

The established consensus among public agencies as well as the merits of the MCHB definition and consequence-based framework reviewed earlier led to their use in the development of the CSHCN Screener. We identified a wide range of functioning and health service-related consequences for incorporation into the CSHCN Screener. A parent survey approach was necessary to allow the integration of the CSHCN Screener into current efforts to monitor and assess health care quality for children, many of whom utilize client surveys such as the self-administered Consumer Assessment of Health Plans Study (CAHPS) survey.<sup>25</sup> This integration was important because an explicit goal for the CSHCN Screener is its usefulness for standardized assessment of health care quality for CSHCN enrolled in managed health care plans. As such, the Screener needed to be acceptable to organizations vested with accreditation and assessment of health plan performance as well as to state Medicaid agencies, through which many children are enrolled in managed care health plans.

Items from existing surveys were reviewed, including the QuICCC and questions on limitation of activity and functional status included in the National Health Interview Survey (NHIS), both of which use consequence-based criteria.<sup>17,18</sup> Items and instruments reviewed varied as to the type, scope, and intensity of health and health service need consequences addressed and in the specific types and duration of conditions required (eg, medical, mental, behavioral, or developmental conditions; duration of 3 vs 12 months) to qualify a child as having a special health care need. The items and instruments also varied in the number, wording, content, and formatting of survey items used.

A pilot version of the CSHCN Screener consisted of 3 items related to a child's functioning, need for health care services, and/or dependence on devices or prescription medicines. These items were selected, in part, based on information about which QuICCC items had the highest frequency of positive responses. Drawing on the QuICCC format, each question included one follow-up item asking whether a specific functional limitation, service need, or dependency on devices or medication was due to a medical, behavioral, or other health condition that has lasted

or is expected to last for at least 12 months. One item included a checklist of 7 health care service use or need consequences often experienced by CSHCN. The pilot version of the CSHCN Screener was evaluated through 18 cognitive interviews with parents of children with and without special health care needs. The draft version was then tested by mail and telephone in 4 health plan samples ( $n = 1995$ ).

The draft version of the CSHCN Screener was modified based on findings from the pilot that raised concerns about the reliability of the checklist format and the readability of the single follow-up item to establish the presence of an underlying chronic condition. To improve the reliability and readability of the CSHCN Screener, 2 service use or need items replaced the checklist format. As with the QuICCC, the single follow-up item was divided into 2 items. Final wording edits ensured the compatibility of the CSHCN Screener with the CAHPS survey.<sup>25</sup>

### The CSHCN Screener

The final version of the CSHCN Screener consists of 5 question sequences, each of which asks about a specific health consequence. Parents who respond "yes" to any of the 5 consequence questions are then asked up to 2 follow-up questions to determine if the consequence is attributable to a medical, behavioral, or other health condition lasting or expected to last at least 12 months. The 5 health consequences queried include whether the child 1) is limited or prevented in any way in his or her ability to do things most children of the same age can do; 2) needs or uses medications prescribed by a doctor (other than vitamins); 3) needs or uses specialized therapies such as physical, occupational, or speech therapy; 4) has above-routine need or use of medical, mental health, or educational services; or 5) needs or receives treatment or counseling for an emotional, behavioral, or developmental problem. Only children with positive responses to one or more items and each of the associated follow-up questions qualify as having a special health care need.

As was the case with the QuICCC and the NHIS, we selected a 12-month period rather than a shorter duration of condition requirement in order to minimize the probability that the CSHCN Screener identifies children with acute rather than chronic health needs. Also, as with the QuICCC and the NHIS, the CSHCN Screener not only attempts to identify CSHCN who currently use health services and who require devices and medicines but also those who may need but are not receiving these things. See the Appendix for a copy of the CSHCN Screener.

### Field Testing the CSHCN Screener

To address study objectives, we fielded the final version of the CSHCN Screener in one national sample of households with children, a sample of children enrolled in Medicaid managed care through the Temporary Aid to Needy Families (TANF) program, and a sample of children receiving SSI benefits in Washington State. These samples provide information for a range of children with different health insurance and socioeconomic characteristics.

### *National Sample*

The national sample was obtained through the second round of pretesting for the National Survey of CSHCN, which included the CSHCN Screener.<sup>26</sup> MCHB sponsored this pretest, which was conducted in the fall of 2000 and used the State and Local Area Integrated Telephone Survey (SLAITS) mechanism. The National Center for Health Statistics (NCHS) conducts the SLAITS and utilizes the large random-digit-dial sampling frame from the National Immunization Survey (NIS).<sup>27</sup> From the NIS sampling frame, 141 391 telephone numbers were randomly generated and selected using the area codes and telephone exchanges for each of the 50 states. The sample sizes of numbers randomly generated for each state and for each of 28 metropolitan areas were roughly equal. When households with children were successfully contacted, all children under the age of 18 years were screened for special health care needs using the CSHCN Screener. The respondent was the parent or guardian who the initial household contact determined to be most knowledgeable about the health and health care of the children living in the household. Abt Associates, Inc, under contract to NCHS, collected the data for the National CSHCN Survey pretest. Using survey items included in the National Survey of CSHCN, demographic data such as age, race/ethnicity, and sex of the child were collected for all children, including those who were not positively identified by the CSHCN Screener. A more in-depth interview was then conducted for a subset of households with children positively identified by the CSHCN Screener. In households with more than one CSHCN, this in-depth interview was conducted for one randomly selected child. Using survey items that were eventually included in the National Survey of CSHCN, the in-depth interviews asked about the child's health and functional status, presence and adequacy of health insurance, utilization and access to health care, care coordination, satisfaction and experience of care, and the impact of the child's health on the family.<sup>26</sup>

### *Medicaid Managed Care Sample*

A statewide sample of children enrolled across 9 managed care health plans through the TANF program was obtained through the administration of the CAHPS survey in the state of Washington. The CSHCN Screener was incorporated into the CAHPS survey and was administered by mail with a telephone follow-up administration for those not responding to the mailed survey.<sup>28</sup> DataStat, Inc conducted the survey under contract to PROWest, Inc, on behalf of the Washington State Medical Assistance Administration.

The sampling frame included all child Medicaid clients under the age of 13 years who were continuously enrolled in a managed care health plan for at least 6 months as of March 2000. Up to a 1-month break in enrollment was allowed. Separate samples of 1050 children were randomly selected from the eligible population in each of the 9 participating health plans, yielding an overall starting

sample size of 9450 children. A target child was randomly selected for households with more than one eligible child. Households flagged in the Medicaid enrollment files as having Spanish as the primary language were given a choice of responding in English or Spanish. CSHCN Screener responses were obtained for each child, as was information about child health status, utilization of and access to care, and experience of care. Children are eligible for Medicaid under TANF in the state of Washington if their family income is less than or equal to 200% of the federal poverty level and if the child is under the age of 19 years.

### *SSI Sample*

Like the Medicaid managed care sample, the SSI sample was obtained through the administration of the CAHPS survey to a statewide sample of families with children under the age of 13 years who were currently receiving SSI benefits in the state of Washington as of March 2000. A sample of 2500 children was randomly selected from all children currently receiving SSI benefits. The majority of the children in the sample received health care through Medicaid fee-for-service programs; however, a few also had additional third-party payer coverage. All surveys were collected in English only using the same survey instrument and administration protocol described for the statewide Medicaid managed care sample.

### **Analytical Methods**

The assessment of the efficiency of the CSHCN Screener is limited to an estimate of the time required to administer by telephone in the National CSHCN Survey, as reported to the NCHS by Abt Associates, Inc. The impact of further reducing the number of items in the Screener was partially assessed by examining differences in the proportion of children identified as CSHCN and the characteristics of children who would not be identified if lower frequency Screener items were removed. The feasibility of administering the CSHCN Screener as a self-administered instrument was evaluated by examining the proportion of parents in the Medicaid managed care sample who fully answered Screener items and who appropriately followed the CSHCN Screener item skip patterns. The proportions of children positively identified when the instrument was administered by mail or through the telephone follow-up in the Medicaid managed care sample were compared to assess the different administration modes.

Positive identification on the CSHCN Screener was determined for each child based on responses to the screening questions and the scoring algorithm described earlier. The proportions of children positively identified were calculated separately for the national, Medicaid managed care, and SSI samples as well as for subgroups of children within each sample according to child's age, sex, and race/ethnicity. The statistical significance of observed variation in rates of identification across subgroups of children was evaluated for each sample using standard chi-square tests of statistical significance. The effect of child characteristics in predicting the likelihood of positive identification

**TABLE 1.** Summary of Characteristics of Child Respondents and Survey Administration Mode

	National Sample	Statewide Medicaid Managed Care Sample	Statewide SSI Sample
Mode	Telephone	Mail with telephone follow-up	Mail with telephone follow-up
Response rate	60.0%*	57.7%†	62.8%‡
Number of cases	n = 17 985‡	n = 3894§	n = 1550
Age range	0–17 y	0–13 y	0–13 y
Mean age	8.7 y	6.9 y	8.7 y
% Male	51.2	51.2	62.7
% Hispanic	10.7	13.8	7.0
% White/non-Hispanic	66.1	72.8	79.6
% Black/non-Hispanic	18.5	7.8	7.7
% Other/non-Hispanic	4.6	5.7	5.7

SSI, Supplemental Security Income.

\*American Association for Public Opinion Research (AAPOR) response rate for random-digit-dialing surveys with screening for eligible subpopulations.<sup>24</sup>

†Adjusted response rate = complete surveys/total eligible sample.

‡This is the final sample after removing Spanish-language surveys. All results reported are based on this sample.

§This is the final sample after removing Spanish-language surveys and surveys in which a parent mistakenly responded for more than one child. All results reported are based on this sample.

on the CSHCN Screener was determined separately for each sample using multivariate logistic regression methods. Each model included age, sex, and race as covariates. In addition, multivariate models for the Medicaid managed care and SSI samples included parent ratings of child health status and the number of child outpatient visits to a doctor's office or clinic in the past 6 months. These variables were not available for all children in the national sample. All analyses were conducted using SPSS version 9.0 software.

Only data from surveys completed in English are used in these analyses. This decision was made to allow for comparable analysis across all 3 samples, not all of which used the same version of the Spanish translation of the CSHCN Screener. Also, the survey administered to the SSI sample did not include a Spanish version. All comparisons presented in the results are significant at a level of .05 or less.

## RESULTS

### Survey Respondents

The 3 study samples represent a total of 26 062 cases. Of these, 23 429 cases were used for the analyses reported in this paper. Table 1 summarizes the survey and response rates for each of the 3 samples as well as the age, sex, and racial/ethnic characteristics of the children included.

For the national sample, CSHCN Screener data were collected for 19 507 children from 10 178 telephone households in all 50 states and 28 metropolitan areas. Household interviews were conducted in both English (n = 9 421 households and 17 985 children) and Spanish (n = 695 households and 1 522 children). Data for the 17 985 children whose interviews were completed in English were used in this analysis. In addition, 2 274 in-depth CSHCN interviews were completed from among the 2 753 children positively identified by the CSHCN Screener. Using the American Association for Public Opinion Research standard definitions for response rates, the overall

survey response rate was 60.0%, which includes the rates for resolving whether generated telephone numbers are residential or nonresidential (87.4%), for screening contacted households for the presence of children (91.1%), for screening households with children for the presence of CSHCN (76.6%), and for completing detailed interviews in households with CSHCN (98.3%).<sup>29</sup>

In the statewide Medicaid managed care sample, the overall response rate, adjusted for cases lacking valid addresses or phone numbers, was 57.7%, or 4 972 usable surveys. A total of 3 894 cases were used in this analysis, after removing surveys completed in Spanish and cases in which it appeared that respondents may have mistakenly answered for more than one child. The final response rate for the SSI sample was 62.8%, or 1 583 usable surveys, after adjusting for cases lacking valid addresses or telephone numbers. After removing surveys in which it appeared that respondents may have mistakenly answered for more than one child, a total of 1 550 SSI cases were used in this analysis. Respondents in the Medicaid managed care and SSI samples completed the mail version of the survey 80% and 83% of the time, respectively, with the remainder of responses obtained by telephone interview during follow-up phone calls.

### Time to Administer the CSHCN Screener

As reported by the survey vendor for the National CSHCN Survey, the CSHCN Screener took an average of 2.1 minutes to administer by telephone when all children in the household were included (range = 1.1–4.5 minutes). When administered by telephone for a single target child in a household, administration time averaged 1 minute.

### Impact of Item Reduction of the CSHCN Screener

In the national and Medicaid managed care samples, respectively, 89.0% and 80.0% of children positively identified by the CSHCN Screener had positive responses

to either or both of the prescription medicine (Q1) or above routine service use (Q2) item sequences. Of these children, 40.5% and 54.0% also had positive responses to one or more of the remaining 3 Screener items in the national and Medicaid managed care samples, respectively. In the SSI sample, 90.5% of children positively identified by the CSHCN Screener had positive responses to either or both of the prescription medicine (Q1) or above routine service use (Q2) item sequences. Over 96.5% of these children also had positive responses to one or more of the remaining 3 Screener items.

Among the 11% of children in the national sample who were positively identified by the CSHCN Screener on the basis of questions other than the 2 highest frequency items, one third reported functional limitations and 57.0% had some type of ongoing emotional, developmental, or behavioral condition requiring treatment. This is a not an unexpected finding, particularly given that many functional disabilities and developmental or emotional problems do not necessarily require traditional medical services or medication. Such conditions might include mental retardation, learning disabilities, speech and other communication difficulties, blindness, deafness, autism, or post-traumatic stress syndromes. Children in this group would not be identified if the CSHCN Screener were further reduced to include only the 2 items on which children in this study were most often positively identified by the CSHCN Screener.

Reducing the CSHCN Screener to just the 2 highest frequency items may also limit the ability to identify subgroups of CSHCN based on their answers to one or more of the other 3 Screener items. For example, when compared to children with positive answers to one or both of the high-frequency items only, children qualifying on the functional limitations survey item in combination with one or both of these 2 survey items were significantly more likely to have visited the doctor 10 or more times during the time period previous to the survey (39% vs 16.9%), to have experienced health conditions that limited their ability to function significantly more often (91.1% vs 21.9%), and to have experienced health conditions that were more likely to be rated as being severe/very severe in nature by parents (31.9% vs 6.7%). Identification of other subgroups may be possible. However, an examination of the characteristics of all possible subgroups is beyond the scope of this article.

### **Feasibility of Self-Administration of the CSHCN Screener**

In the Medicaid managed care sample, over 98% of individuals who self-administered the CSHCN Screener completed each of the 5 items, and 94% appropriately followed the 7 skip patterns. These item completion rates and appropriate skip pattern completion rates are commensurate with or higher than those observed for other items included in the Survey of CAHPS. Finally, in both the statewide Medicaid managed care and SSI samples, rates of children positively identified by the CSHCN Screener did not differ according to whether the screening

instrument was administered by mail or telephone ( $P = .50$ ).

### **Rates of Positive Identification by the CSHCN Screener**

In the national sample, the CSHCN Screener positively identified 15.3% of children under the age of 18 years. This rate is not adjusted for noncoverage of households without telephone numbers and for other potential sampling, selection, and response biases. In the Medicaid managed care and the SSI samples, the CSHCN Screener positively identified 20.7% and 94.6% of children under the age of 13 years, respectively (Table 2).

As noted earlier, in the national sample and the Medicaid managed care sample, need or use of prescription medication for an ongoing condition was the CSHCN Screener criterion most frequently met by children (11.4% and 14.4%, respectively), followed by above-routine use of health or related services (6.5% and 9.7%, respectively). The proportion of children in these samples qualifying on the functional limitations criterion was low relative to other CSHCN Screener items (3.8% and 6.4%, respectively). However, among children in the statewide SSI sample, the CSHCN Screener item addressing functional limitations had the greatest frequency of positive responses (83.4%), and the prescription medication item had the lowest frequency of positive responses (54.4%) (Table 3).

In the national and Medicaid managed care samples, approximately one half of the children positively identified by the CSHCN Screener qualified on only one screening question. Just over 20% of the positively identified children in these 2 samples qualified on 2 out of the 5 screening questions, with the remaining positively identified children qualifying on the basis of 3 or more of the 5 questions. In contrast, in the SSI sample, over 85% of children positively identified by the CSHCN Screener qualified on 3 or more of the 5 CSHCN Screener items (Table 3).

### **Variation in Positive Identification by the CSHCN Screener According to Child Characteristics**

As summarized in Table 2, variations in rates of positive identification on the CSHCN Screener were observed according to a child's demographic characteristics for all 3 samples. As shown in Table 4, the adjusted odds were 1.48 times greater that male children were positively identified in both the national and Medicaid managed care samples. The adjusted odds were 2.25 to 5.83 times greater (across the 3 samples) that older children were positively identified by the CSHCN Screener (Table 4). The adjusted odds were .61 to .84 times less that Hispanic children were positively identified in the national and Medicaid managed care samples, respectively, compared to White, non-Hispanic children. However, the Hispanic sample includes only children from households responding in English and therefore cannot be generalized to all Hispanic families. In the national sample, for example, just over half (55.2%) of all Hispanic children were from

**TABLE 2.** Percentage of Children Identified by Children With Special Health Care Needs (CSHCN) Screener Overall and By Age, and Sex, Race/Ethnicity By Study Sample

	National Sample (n = 17 985)*	Statewide Medicaid Managed Care Sample (n = 3894)†	Statewide SSI Sample (n = 1550)
% Meeting CSHCN Screener criteria	15.3	20.7	94.6
% Meeting CSHCN Screener criteria by sex, age, and race/ethnicity			
Female	12.8	18.4	94.6
Male	17.7 ( <i>P</i> < 0.001)	25.6 ( <i>P</i> < 0.001)	94.5 (NS)
Under 1 y to 4 y old	8.0	12.5	93.6
5–9 y old	17.2	22.6	95.7
10–14 y old	17.9	31.1 ( <i>P</i> < 0.001)	94.0 (NS)
15 y old and over	18.4 ( <i>P</i> < 0.001)	n/a	n/a
Mean age			
CSHCN	10.0 y	8.3 y	8.7 y
Non-CHSCN	8.5 y ( <i>P</i> < 0.001)	6.5 y ( <i>P</i> < 0.001)	8.8 y (NS)
Race/ethnicity-specific rates among children 0–13 y old‡			
	CSHCN rate	CSHCN rate	CSHCN rate
Hispanic child	12.8	16.3	94.2
White/non-Hispanic child	15.1	23.3	95.7
Black/non-Hispanic child	14.6	24.1	91.3
Other/non-Hispanic child	9.7 ( <i>P</i> < 0.001)	14.4 ( <i>P</i> < 0.001)	87.1 ( <i>P</i> < 0.001)

SSI, Supplemental Security Income.

\*Data from surveys collected in English only.

†Data from surveys collected in English only; non-multi-child responders only.

‡To allow comparability across samples, race/ethnicity-specific rates include only children from 0 to 13 years of age.

households responding in English and 44.2% were from households responding in Spanish.

We also investigated the effect of parent-reported utilization of care and child health status on the probability of positive identification in the Medicaid managed care and SSI samples. As expected, children with more outpatient visits to a health care provider in the past 6 months and children whose parents rate their child's health as less than excellent or very good were significantly more likely to be positively identified by the CSHCN Screener (Table 4).

## DISCUSSION

The CSHCN Screener was developed to be an instrument for the comprehensive, efficient, and flexible identification of CSHCN. Because of its brevity and flexible administration, the CSHCN Screener is more viable than existing screening instruments for standardized use in identifying CSHCN for a variety of purposes, including public health monitoring, health care quality assessment, and program planning and evaluation. In addition, the consensus-based process used to develop this instrument contributes to its acceptability across the range of potential users.

The results presented above indicate that the CSHCN Screener requires minimal time to administer and is acceptable for use as both an interviewer- and self-administered survey. Findings also indicate that limiting the CSHCN Screener to the 2 items with the highest frequency of positive responses would eliminate many children with current health problems and health care needs, especially those with problems of an emotional, mental, or

developmental nature. Hence, we do not recommend further item reduction at this time. The interest in parsimonious screening instruments is high, given the costs of survey administration. Further evaluation regarding the impact of item reduction is underway.

The variation observed in the proportions of children positively identified by the CSHCN Screener across the 3 study samples was expected given the different age, socioeconomic, and health status characteristics of children represented in each sample. The overall rates in the national and Medicaid managed care samples and observed variation in the proportion of children positively identified by the CSHCN Screener in these samples are consistent with the findings from other research on CSHCN. In particular, higher rates for male children, older children, and children who regularly utilize health services are consistent with findings from other studies on the epidemiology of CSHCN.<sup>23,24,30,31</sup> In addition, the CSHCN Screener identified nearly all children in the SSI sample, a group whose special health care needs are presumably well-verified. Taken together, these findings support the face validity of this instrument. Additional findings on the validity of the CSHCN Screener are reported on in Bethell et al.<sup>33</sup> Studies are also underway to assess the use of the CSHCN Screener for a wider range of settings and purposes than are reported here.

The lower CSHCN screening rates observed among Hispanic children in the national and Medicaid managed care samples were anticipated based on prior studies of CSHCN, however, these differences are not fully understood and merit further investigation. Caution is necessary in interpreting these findings as the Hispanic sample in-

**TABLE 3.** Percentage of Children Positively Identified By Children With Special Health Care Needs (CSHCN) Screener, By Screener Question and According to the Type and Number of CSHCN Screener Questions

	National Sample (n = 17 985)*	Statewide Medicaid Managed Care Sample (n = 3894)†	Statewide SSI Sample (n = 1550)
A) Percentage of children overall positively identified by each CSHCN Screener question			
Q1: Need/use of prescription medicines	11.4	14.4	54.5
Q2: Above-average need/use of services	6.5	9.7	80.5
Q3: Functional limitations	3.8	6.4	83.4
Q4: Need/use of specialized therapies	2.7	3.4	75.9
Q5: Need/use of emotional, behavioral, or developmental treatment/counseling	4.2	9.7	65.4
B) Percentage of children positively identified by CSHCN Screener according to type or number of screening questions			
Number of children in sample positively identified by CSHCN Screener	n = 2753	n = 808	n = 1466
Highest yield questions;			
% of CSHCN who qualified on prescription, medication and/or above-routine service use, alone or in combination with other questions	89.4%	80.0%	90.5%
% CSHCN qualifying on 1, 2, or 3+ questions:			
On 1 screening question (%)	53.3	46.4	5.5
On 2 screening questions (%)	21.2	23.5	8.9
On 3 or more screening questions (%)	25.5	30.1	85.6

SSI, Supplemental Security Income.

\*Data from surveys collected in English only.

†Data from surveys collected in English only; non-multi-child responders only.

**TABLE 4.** Odds Ratios from Multivariate Logistic Regression Models Assessing the Impact of Child Characteristics on the Probability of Positive Identification on the Children With Special Health Care Needs (CSHCN) Screener\*

Characteristic	National Sample (n = 17 985)†		Statewide Medicaid Managed Care Sample (n = 3894)		Statewide SSI Sample (n = 1550)	
	Odds ratio	P value	Odds ratio	P value	Odds ratio	P value
Age of child						
0–3 y	1.00	—	1.00	—	1.00	—
4–7 y	2.25	<0.001	2.50	<0.001	5.17	<0.001
8–11 y	2.75	<0.001	4.56	<0.001	5.83	<0.001
12–13 y	3.03	<0.001	5.19	<0.001	3.56	<0.001
14–17 y	2.84	<0.001	n/a	n/a	n/a	n/a
Sex of child						
Male	1.48	<0.001	1.48	<0.001	1.23	<0.001
Race/ethnicity of child						
Hispanic	0.84	<0.05	0.61	<0.001	0.61	(NS)
White/non-Hispanic	1.00	—	1.00	—	1.00	—
Black/non-Hispanic	0.92	(NS)	1.12	(NS)	0.66	(NS)
Other/non-Hispanic	0.67	<0.001	0.48	0.001	0.29	0.001
Doctor’s office or clinic visits, past 6 mo						
No visits			1.00	—	1.00	—
1–2 visits		n/a	2.73	<0.001	1.64	(<0.10)
3–4 visits			4.38	<0.001	3.69	0.001
5 or more visits			6.69	<0.001	17.35	<0.001
Parent rating of child’s health						
Excellent, very good			1.00	—	1.00	—
Good		n/a	3.12	<0.001	1.76	<0.05
Fair, poor			6.85	<0.001	2.34	0.05

SSI, Supplemental Security Income.

\*Odds ratios and P values are for the sample indicated compared to the children in the sample who were not identified by the CSHCN Screener.

†Number of doctor’s office/clinic visits was only obtained for children identified by CSHCN Screener. Parent rating of child’s health was not included in this study.

— = Reference category.



cludes only children from households responding in English and therefore cannot be generalized to all Hispanic families. The observed differences in rates of positive identification by the CSHCN Screener by race/ethnicity are also not attributable to artifacts of language or translation as only data from cases where the CSHCN Screener was administered in English were included in the analysis.

The CSHCN Screener was fielded in a national sample that sought to be representative of all 50 states and 28 metropolitan areas. Still, results may not be generalizable to subpopulations of children not included in this sample, such as homeless and migrant children or children in institutional settings. The rate of CSHCN identified in the national sample should be interpreted cautiously. Roughly equivalent-sized samples were drawn from each state and each of the 28 metropolitan areas, and no sampling weights were used to adjust for potential selection biases. Caution is also necessary in interpreting the rate of identification of CSHCN for the Medicaid managed care sample, as this sample included only children under the age of 13 years with at least 6 months' continuous enrollment in a Medicaid health plan. The proportion of children positively identified by the CSHCN Screener would likely be different in a random sample that included all Medicaid-enrolled children under the age of 18 years, regardless of health plan enrollment, because older children are more likely to be identified by the CSHCN Screener and because those continuously enrolled in a health plan may be different from those with less-stable coverage. In addition, incomplete response rates to the CAHPS survey may affect results in unknown ways.

Findings regarding differences in rates of positive identification by the CSHCN Screener for mail versus telephone survey administration should not be taken as conclusive until a more careful study examining the effect of survey administration mode is conducted. In addition, we did not test face-to-face interview administration nor did we administer the screening instrument across a variety of health care or community settings. Work is underway to evaluate the use of the CSHCN Screener in alternate settings.

All data used in this study were collected with assurances of confidentiality; consequently, we do not have information on how parent responses to the CSHCN Screener may vary under circumstances where this is not the case. In the national sample, the CSHCN Screener was administered to the parents of adolescents. There are concerns about whether parents or adolescents themselves are the more reliable responders to these types of questions, especially regarding mental health and substance abuse problems. The question related to parents serving as proxy respondents for adolescents will be evaluated in future studies. Finally, this study did not attempt to fully examine the concurrent or convergent validity of the CSHCN Screener. Results of a study further evaluating the validity of the CSHCN Screener can be found in a separate article in this issue of *Ambulatory Pediatrics*.

The CSHCN Screener is the product of a broad collaborative process that built upon a quarter century of pro-

gress toward developing a shared understanding of how best to define and identify CSHCN. The CSHCN Screener is currently being used in the National Medical Expenditures Panel Survey to develop national estimates of the prevalence of CSHCN.<sup>33</sup> In addition, the Screener has been incorporated into the National Survey of CSHCN to allow both national- and state-level prevalence estimates.<sup>26</sup> Moreover, it has been formally integrated in the CAHPS Child Survey 2.0H, which is a part of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set. This application allows for the identification and measurement of basic aspects of health care quality for CSHCN enrolled in managed care health plans and is expected to be used in many states' Medicaid quality assessment initiatives during the coming years. The use of the CSHCN Screener in these and other applications will contribute to the creation of a common understanding of the health, health care needs, and health care quality provided to this important population of children.

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**Appendix. Children With Special Health Care Needs (CSHCN) Screener**

All 3 Parts of at Least One Screener Question (or, in the case of question 5, the 2 parts) Must Be Answered “Yes” In Order for a Child to Meet CSHCN Screener Criteria for Having a Special Health Care Need.

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 receive **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 receives **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
-