

# An Evaluation of the Linguistic and Cultural Validity of the Spanish Language Version of the Children with Special Health Care Needs Screener

Debra Read · Christina Bethell · Stephen J. Blumberg ·  
Milagros Abreu · Clara Molina

Published online: 12 June 2007  
© Springer Science+Business Media, LLC 2007

## Abstract

**Objectives** The 2001 National Survey of Children with Special Health Care Needs (CSHCN) used the CSHCN Screener, a 5-item survey based tool, to identify children with special health care needs. The prevalence of special health care needs for Hispanic children was lower than that reported for all other ethnic and racial groups, with the exception of Asian children. To better understand the reasons for the lower prevalence rate, this study examined variations in CSHCN prevalence for Hispanic children according to whether parents responded to the National Survey of CSHCN screening interview in Spanish or English. The Spanish translation of the CSHCN Screener was further evaluated through a series of face-to-face interviews with parents with limited English proficiency (LEP).

**Methods** The 2001 National Survey of CSHCN screened 372,174 children ages 0–17 years for special health care

needs. Bivariate and multivariate analyses were conducted to examine the effects of interview language on the CSHCN prevalence rates for Hispanic children ( $n = 47,371$ ). Using a standardized protocol, cognitive interviews were conducted in Spanish with 19 LEP parents to elicit their comprehension of and reactions to the screening questions.

**Results** When parents were interviewed in English, 11.7% of Hispanic children were identified as CSHCN. When parents were interviewed in Spanish, 5.1% of Hispanic children were identified as CSHCN. Lower prevalence of the need for or use of prescription medications for chronic conditions made the largest contribution to the observed difference in CSHCN prevalence. Cognitive interviews with parents did not identify any linguistic or cultural deficiencies in the Spanish translation of the CSHCN Screener. Parents did express disinclination toward sharing details of their children's health in the context of a typical telephone survey.

---

D. Read (✉) · C. Bethell  
Department of Pediatrics, School of Medicine,  
The Child and Adolescent Health Measurement Initiative,  
Oregon Health and Science University, 707 SW Gaines Road,  
Mail Code CDRCP, Portland, OR 97239-2998, USA  
e-mail: readd@ohsu.edu

S. J. Blumberg  
National Center for Health Statistics, Centers for Disease  
Control and Prevention, 3311 Toledo Road, Room 2112,  
Hyattsville, MD 20782, USA

M. Abreu  
Prevention Research Center, Boston University School  
of Public Health, Boston, MA 02118, USA

C. Molina  
Private Consultant, Spanish Interpretation Services,  
Portland, OR, USA

**Keywords** Children with special health care needs ·  
Hispanic · Spanish language · CSHCN Screener

In the past 20 years, the percentage of Hispanic children in the US has increased faster than that of children in any other racial or ethnic group, growing from 9% of the child population in 1980 to 19% in 2003 [1]. By 2020, it is projected that nearly 1 in 4 children in the US will be of Hispanic origin [1]. Hispanic children are more likely to be uninsured, live in households with incomes below the poverty level, and to have lower levels of health care utilization and access compared to non-Hispanic children [2–5]. In addition, it is estimated that at least one half of Hispanic children in the US live in “mixed status” families

with at least one non-citizen parent [6]. In these families, children are often eligible for public health benefits and services but parents may avoid enrolling them because of their own concerns about deportation and other immigration related consequences [7, 8]. The barriers to accessing health care that Hispanic children and their families experience are well documented; however, little is known about linguistic and cultural effects on parents' responses on recent national surveys about children's health care.

The National Survey of Children with Special Health Care Needs (NS-CSHCN) was conducted for the first time in 2000–2001. Sponsored by the federal Maternal and Child Health Bureau (MCHB), the survey was designed to provide state and federal policymakers with population-based prevalence estimates of children with special health care needs (CSHCN) at the national and state levels for planning and policymaking purposes. The prevalence of special health care needs for Hispanic children found in the 2001 NS-CSHCN is lower than that observed for all other ethnic and racial groups, with the exception of Asian children [9]. Although other studies have also found lower rates of chronic conditions or disabilities in the Hispanic child population [10–13], it is not known whether the lower prevalence of special health care needs among Hispanic children in the 2001 NS-CSHCN is a valid estimate of the prevalence of special health care needs for that population. Concerns largely center on the validity of the translation from English to Spanish of the screener questions used to identify CSHCN and whether the screening questions are culturally appropriate and understood as intended when administered to Spanish speaking parents.

To identify CSHCN, the NS-CSHCN uses the CSHCN Screener, a 5-item survey tool specifically developed and validated to identify children who meet the federal MCHB non-diagnostic specific, health-consequences-based definition of special health care needs [14–15]. This screening tool asks children's parents about the presence of five different health consequences (see Appendix A.) Parents of children who experience one or more of the health consequences are then asked whether the specific health consequences are attributable to a medical, behavioral, or other health condition and whether this condition has lasted or is expected to last for at least 12 months. Research demonstrates that nearly all CSHCN (as identified by other parent reported methods, physician chart review studies, or classification approaches using medical claims and encounter data) experience at least one of these five health consequences regardless of the specific underlying conditions that are present [15–18]. Thus, any child with an affirmative response to one of the five consequences and to each of the two follow-up questions is considered to have special health care needs. The Spanish language version of the 2001 NS-CSHCN, including the CSHCN Screener ques-

tions, was produced by translating the English version into Spanish and then back translating into English. The translators resolved linguistic discrepancies identified through this process before finalizing the version used in the Spanish language interviews.

The purpose of this study is to explore the degree to which linguistic and cultural factors, and family preferences contribute to the lower CSHCN prevalence estimate for Hispanic children in the 2001 NS-CSHCN. Language, culture, level of acculturation, and preferences related to accessing and utilizing health care are all factors that may potentially influence how the parents of Hispanic children answer the CSHCN Screener survey items. Parents of nearly one half (48%) of all Hispanic children screened for the NS-CSHCN responded in Spanish, so there is also the possibility that the translation of the CSHCN Screener used in the survey was linguistically or culturally deficient in ways that conveyed the screening concepts differently to Spanish-speaking parents. In addition, it may be that parents of Hispanic children differ from other parents in their socio-cultural perceptions of children's health and criteria for what comprises a "health problem." As a result, the health consequences and problems asked about in the CSHCN Screener may have systematically missed Hispanic children who actually met the MCHB definition. Differences in the specific barriers to health care or health seeking patterns also may lead parents of Hispanic children to respond to questions differently than parents of non-Hispanic children with similar health issues. Finally, it may be that parents of Hispanic children are reluctant to report negative health consequences experienced by their children in the context of a telephone interview, or that they "censor" their answers in other ways.

In this study, we first examine the relationship between the language in which parents responded to the NS-CSHCN interview and CSHCN prevalence rates for Hispanic children, and then we report the results from a series of in-depth cognitive interviews conducted with Spanish-speaking, limited English proficient (LEP) parents of Hispanic children to explore the linguistic and cultural issues summarized above.

## Methods

### Quantitative analyses

The data used to produce CSHCN prevalence estimates for Hispanic and non-Hispanic child populations are from the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) screener interview file. MCHB was the primary sponsor of the survey, and the National Center for Health Statistics (NCHS) of the Centers for Disease

Control and Prevention (CDC) oversaw its administration. The 2001 NS-CSHCN was conducted from October 2000 to April 2002 using the sampling frame of the National Immunization Survey, a large random-digit-dial telephone survey that monitors vaccination coverage of children in the US [19]. The 2001 NS-CSHCN obtained CSHCN screening interviews with the parents of 372,174 children (48,690 with special health care needs) from 196,888 households with children in the US. The respondent was the parent or guardian most knowledgeable about the health and health care of the children in the household. About 5% of all households were interviewed in Spanish; less than 1% of interviews were administered in one of 10 languages other than English or Spanish [20].

The publicly released data file for the 2001 NS-CSHCN includes a derived variable indicating if the sampled child is of Hispanic or Latino origin [20]. Data from the multiple survey items used to derive this variable are suppressed to protect respondent confidentiality. For the same reason, data indicating the specific language in which “other than English” interviews were collected are not included in the publicly released NS-CSHCN data files. The public files do, however, include a variable indicating which households were interviewed in languages other than English. For the purposes of the findings presented in this paper, we developed a proxy indicator to identify children with interviews conducted in Spanish by combining information about children’s Hispanic ethnicity with that about interviews conducted in languages other than English. The approximate number of households interviewed in Spanish using this method ( $n = 9399$ ) is very close to the actual number of household interviews conducted in Spanish ( $n = 9604$ ) reported by NCHS [20]. Unknown values due to “don’t know” or “refused” responses on the Hispanic ethnicity question account for nearly all of the 238 discrepancies between the actual number of Spanish language interviews and those identified through the proxy method.

We conducted bivariate analyses to compare CSHCN prevalence and the proportion meeting each screening criterion for Hispanic and non-Hispanic child populations according to whether their parents responded to the 2001 NS-CSHCN screener interviews in English or Spanish. The data from the 2001 NS-CSHCN used to produce these prevalence estimates are weighted to be nationally representative of the non-institutionalized 0–17-year-old child population in the US [20]. Differences between percentages or rates were evaluated using two-sided significance tests at the .05 level. We used multiple logistic regression methods to estimate the relationship of 2001 NS-CSHCN interview language and children’s Hispanic ethnicity with the probability of meeting each of the five CSHCN screening criteria after controlling for children’s age, sex, and household poverty status. Point estimates, multiple

logistic regression models, and corresponding variance estimates for 2001 NS-CSHCN prevalence estimates were calculated using SPSS 14.0 Complex Samples Module [21] to account for the complex sample design of the NS-CSHCN.

#### Cognitive interview study design

To evaluate the current translation of the screening tool, we conducted face-to-face, semi-structured interviews in Spanish with LEP parents of children ages 0–17 using the Spanish language version of the CSHCN Screener from the 2001 NS-CSHCN. The interview protocol was designed to: (1) test parents’ general reaction to the screening questions and the subject matter; (2) assess parents’ ability to answer the CSHCN Screener questions; (3) examine concordance between researcher and parent interpretations of the screener questions, the intended concepts, and children’s current health status; and (4) evaluate the cultural validity of the questions about children’s health for Spanish-speaking parents. Interviews were conducted in two locations (Metro area of Portland, Oregon, and Boston, Massachusetts) to explore any cultural or regional differences in understanding the translation or responding to the screening questions. Spanish-speaking parents with limited proficiency in English were targeted for the interview as they represent the demographic group most likely to respond in Spanish to a national telephone survey interview.

Parents were recruited through Spanish-language flyers posted in community locations serving a high percentage of Hispanic families. The flyer text directed interested parents to telephone a Spanish-speaking recruiter. After confirming the presence of children ages 0–17 in the household, the recruiter asked parents two questions to identify those meeting the criterion of having LEP. The questions used to screen for LEP were drawn from items used in the 2002 National Survey of Latinos to assess household language preferences [22]. The recruiter scheduled interviews with interested parents who met the language criterion. All parents who met the limited English proficiency inclusion criteria agreed to participate in the interviews. A total of 19 interviews were scheduled. Parents were given the choice of being interviewed at home or at a conveniently located neutral location in the community. Parents, with one exception, opted to be interviewed in their homes and all interviews were completed as scheduled.

Each interview lasted 1 h. Participants were asked an initial set of standard demographic questions about themselves and the children in the household. Next, the CSHCN Screener was verbally administered using the format employed by the NS-CSHCN, which simultaneously screens

all children living in the household (see Appendix A). After completing the screening questions, participants were asked questions about specific child health problems of all children in the household. In households with more than one child, participants were asked to specify to which child or children any affirmative responses pertained. An open-ended question was included to ascertain the presence of health problems not explicitly covered. Information about children's current or past health problems was compared with parents' earlier answers on the CSHCN Screener questions, and follow up questions were asked to clarify any seemingly contradictory responses.

Standard cognitive interviewing methods, including "think aloud" exercises, paraphrasing, concurrent verbal probing, and debriefing questions, were used to elicit parents' comprehension of the screener questions and their cognitive decision processes when responding [23]. Parents received thirty dollars at the time of the interview for their participation. The NCHS Institutional Review Board approved the study procedures.

All interviews were conducted in Spanish by bi-cultural interviewers who learned Spanish as their first language. In Oregon, the interviewer (CM) was a professional interpreter who works with several health systems in the Portland area. A physician researcher (MA) in the process of completing a graduate degree in public health conducted the Boston interviews. A limited-Spanish-proficient researcher (DR) who conducted many of the original CSHCN Screener cognitive interviews with English-speaking parents was present at all interviews to assist in the "real time" development of follow-up probes based on parents' responses. The interviewers asked the follow-up probes in Spanish and interpreted parents' responses for the limited-Spanish-proficient researcher. The researcher also recorded parents' CSHCN Screener and child condition checklist responses on a standardized form and collected behavioral coding data regarding hesitations, confusion and requests to repeat questions. The interview team debriefed after each interview to confirm findings, to clarify points, and to discuss any implications for subsequent interviews.

Cognitive interview findings were later consolidated across each of the parent interviews. CSHCN Screener results were tabulated and scored for each child screened during the interviews. Parents' responses to the cognitive interview tasks and follow up questions were analyzed using qualitative assessment of responses on each of the key components of interviews: assessment of participant and child characteristics, overall reaction to screening questions, and performance of current translation. The standardized interview protocol questions and data collection instrument facilitated valid comparisons of participants' responses and CSHCN Screener results for each child.

## Key variables

### *CSHCN status*

We used CSHCN Screener responses to determine children's CSHCN status and identify children meeting each of five screening criteria. As noted earlier, for a child to be classified as having special health care needs, the child must currently experience one or more of five health consequences attributable to a medical, behavioral, or other health condition that has lasted or is expected to last for at least 12 months. These consequences include: (1) ongoing limitations in the ability to perform activities that other children the same age can perform; (2) ongoing need for prescription medications; (3) ongoing need for specialized therapies; (4) ongoing need for more medical, mental health, or educational services than are usual for most children of the same age; and (5) the presence of ongoing behavioral, emotional or developmental conditions requiring treatment or counseling (see Appendix A). A specific CSHCN Screener criterion is considered to be met if there are affirmative responses to the question about the consequence and to each of the two follow-up questions (i.e., attributable to a condition, and the condition has at least a 12-month duration) [15]. Children classified as CSHCN only need to meet one criterion, though many CSHCN meet multiple criteria.

### *Child and parent demographics*

During the cognitive interviews, information about the participating parents' ages and educational status and about the ages and gender of the children screened was collected on the standardized interview form. Because of its sensitive nature, the immigration and citizenship statuses of family members were not formally collected on the interview form. However, all participants either spontaneously mentioned their countries of origin and years of residency in the US during the course of the interview or volunteered this information when asked by the interviewer.

### *Chronic childhood conditions*

During the cognitive interviews, parents were asked if their children currently experienced any of 14 different health problems. Responses were recorded on the standardized interview form. The list of health problems asked during the interviews was adapted from a longer list currently being collected through the 2005–2006 administration of the NS-CSHCN [24].

## Results

### CSHCN prevalence and language

Nationally, 8.5% of Hispanic children were identified in the 2001 NS-CSHCN as having special health care needs [9]. The prevalence profile for Hispanic children, however, varied significantly by language of the interview (Table 1). The CSHCN prevalence for Hispanic children whose parents chose to complete the interview in Spanish was less than half that observed for Hispanic children whose parents chose to complete the interview in English (5.1% vs. 11.7%, respectively). Hispanic children with Spanish language interviews were less likely to meet each of the five CSHCN screening criteria relative to either Hispanic children with English language interviews or non-Hispanic children.

The CSHCN prevalence for Hispanic children whose parents chose to complete the interview in English was also lower than the prevalence for non-Hispanic children whose parents chose to complete the interview in English (Table 1). However, for three of the five screening criteria, the proportion of children meeting each criterion was the same for Hispanic and non-Hispanic children with English interviews (Table 1). The difference of 2 percentage points in the proportion of Hispanic and non-Hispanic children with English language interviews meeting the prescription medication criterion (8.4% vs. 10.5%, respectively) is particularly notable. The lower proportion of Hispanic children meeting this single criterion accounts for the majority of the 2.2 percentage points difference in overall CSHCN prevalence observed for these two groups.

After controlling for children's age, gender, and household poverty status, language of the interview remained a significant and strong predictor of whether Hispanic children met any of the five CSHCN screening criteria. Compared with non-Hispanic children, the adjusted odds that a Hispanic child met any of the five screening criteria were much lower when the parent responded to the interview in Spanish rather than English (Table 2). In contrast, when parents' responded to the survey in English, Hispanic ethnicity contributed only modestly to the probability of meeting the screening criteria. Compared with non-Hispanic children, Hispanic children with English interviews had only slightly lower odds of meeting the prescription medicine, specialized therapies, or emotional, developmental or behavioral conditions screening criteria. Hispanic ethnicity did not significantly affect the odds of children meeting the elevated services need/use or functional limitations screening criteria when parents responded in English (Table 2).

### Results of the cognitive interviews

#### *Participant and child characteristics*

We conducted 19 parent interviews, resulting in 37 children screened for special health care needs. All participating parents were the mothers of children screened during the interviews. Eight interviews took place in Portland, OR; the rest were conducted in Boston, MA. Table 3 summarizes the demographic characteristics of participating parents and the children screened during the course of the interviews. About one third of the mothers

**Table 1** Prevalence of children 0–17 years with special health care needs and proportion meeting each screening criterion by child ethnicity and language of survey interview—US, 2001

Language of NS-CSHCN interview	Child ethnicity		
	Hispanic		Non-Hispanic
	Spanish	English	English
Number in sample	20,280	27,091	320,155
Number of CSHCN identified	927	3,375	44,117
% CSHCN <sup>a</sup>	5.1 <sup>b</sup> (4.6–5.7)	11.7 <sup>c</sup> (11.0–12.5)	13.9 (13.6–14.1)
% meeting each CSHCN Screener criterion <sup>a</sup>			
Prescription medication criterion	2.4 <sup>b</sup> (2.0–2.7)	8.4 <sup>c</sup> (7.7–9.0)	10.5 (10.3–10.7)
Elevated service needs/use criterion	2.6 <sup>b</sup> (2.2–3.0)	5.9 (5.3–6.4)	6.2 (6.1–6.4)
Functional limitations criterion	0.9 <sup>b</sup> (0.7–1.2)	2.8 (2.5–3.2)	2.9 (2.8–3.0)
Specialized therapies criterion	1.1 <sup>b</sup> (0.9–1.4)	2.1 (1.8–2.4)	2.4 (2.3–2.5)
Emotional, developmental or behavioral problem(s) criterion	1.8 <sup>b</sup> (1.5–2.2)	3.2 <sup>c</sup> (2.9–3.7)	4.0 (3.8–4.1)

<sup>a</sup> All estimated percentages are weighted to represent the US non-institutionalized child population ages 0–17; (95% CI)

<sup>b</sup> Results differ significantly from Hispanic children with English interviews,  $P < .05$

<sup>c</sup> Results differ significantly from non-Hispanic children with English interviews,  $P < .05$

**Table 2** Adjusted odds ratios for meeting each screening criterion—US, 2001

CSHCN Screener criteria	Prescription medications	Elevated service use/needs	Functional limitations	Need/use of specialized therapies	Emotional, developmental or behavioral health problems
	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)
<i>Ethnicity and language of interview</i>					
English/non-Hisp child	1.00	1.00	1.00	1.00	1.00
English/Hisp child	.79 (.72–.87) <sup>††</sup>	.89 (.79–.99)	.88 (.76–1.01)	.78 (.67–.92) <sup>†</sup>	.77 (.67–.90) <sup>†</sup>
Spanish/Hisp child	.19 (.16–.23) <sup>††</sup>	.29 (.25–.36) <sup>††</sup>	.21 (.16–.28) <sup>††</sup>	.30 (.23–.39) <sup>††</sup>	.28 (.22–.35) <sup>††</sup>
<i>Age</i>					
0–5 years	1.00	1.00	1.00	1.00	1.00
6–11 years	2.15 (2.03–2.27) <sup>††</sup>	1.96 (1.83–2.10) <sup>††</sup>	1.76 (1.59–1.93) <sup>††</sup>	1.45 (1.32–1.60) <sup>††</sup>	3.68 (3.32–4.08) <sup>††</sup>
12–17 years	2.38 (2.25–2.53) <sup>††</sup>	2.04 (1.89–2.18) <sup>††</sup>	2.10 (1.90–2.31) <sup>††</sup>	.95 (.85–1.06)	4.11 (3.69–4.57) <sup>††</sup>
<i>Sex</i>					
Female	.68 (.65–.70) <sup>††</sup>	.58 (.56–.61) <sup>††</sup>	.61 (.57–.66) <sup>††</sup>	.56 (.52–.61) <sup>††</sup>	.53 (.49–.57) <sup>††</sup>
Male	1.00	1.00	1.00	1.00	1.00
<i>Household income (relative to poverty)</i>					
< 100% FPL	1.08 (1.00–1.16)	1.76 (1.61–1.93) <sup>††</sup>	2.35 (2.07–2.65) <sup>††</sup>	2.98 (1.74–2.28) <sup>††</sup>	2.54 (2.27–2.84) <sup>††</sup>
100%– < 200% FPL	.98 (.92–1.04)	1.44 (1.33–1.56) <sup>††</sup>	1.79 (1.61–2.01) <sup>††</sup>	1.64 (1.44–1.85) <sup>††</sup>	1.74 (1.54–1.98) <sup>††</sup>
200%– < 400% FPL	.88 (.84–.93) <sup>††</sup>	1.09 (1.01–1.17) <sup>*</sup>	1.16 (1.04–1.29) <sup>†</sup>	1.09 (.97–1.22)	1.13 (1.02–1.25) <sup>*</sup>
400% FPL and above	1.00	1.00	1.00	1.00	1.00
Survey sample size	316543	316543	316543	316543	316543

\**P* < .05; † *P* < .01; †† *P* < .001

**Table 3** Characteristics of cognitive-interview participants and their children

	(n)	(%)		(n)	(%)
Child characteristics (n = 37)					
Age			<i>Met any CSHCN criterion</i>	15	41.0
< 1 year	4	11.0	Male	6	46.2
1–4 years	11	30.0	Female	9	37.5
5–8 years	10	27.0			
9–12 years	6	16.0	<i>Met each CSHCN criterion</i>		
13–16 years	6	16.0	Prescription medicine	4	10.8
			Elevated service need/use	12	32.4
Sex			Functional limitations	5	13.5
Male	13	35.0	Special therapies	7	19.0
Female	24	65.0	Emotional, developmental, or behavioral conditions	9	24.3
Participant Characteristics (n = 19)					
Age			<i>Educational level</i>		
18–24 years	0	0.0	Less than HS	6	31.6
25–34 years	10	52.6	High school	6	31.6
35–44 years	7	36.8	Some college/tech school	4	21.1
45–54 years	1	5.3	4 year college degree or more	3	15.8
55–64 years	1	5.3			
<i>Years residing in US</i>			<i>Country of origin</i>	8	42.1
5 years or less	11	58.0	Mexico	10	52.6
6–10 years	5	26.0	Colombia	1	5.3
More than 10 years	3	16.0	Guatemala		

reported less than high school education, and approximately another third had education beyond high school. The majority of participants reported residing in the US for 5 years or less. Mexico was the country of origin for all eight of the mothers interviewed in Portland, OR. A total of 10 of the 11 mothers interviewed in Boston were originally from Colombia, and the remaining mother was from Guatemala.

#### *Overall reaction to screening question*

Parents' reactions to the content and purpose of the screening questions were uniformly positive. They described the questions as "very clear," "easily answered," and "things a mother of course knows about her children." Parents of children identified as having special health care needs noted that the health consequences in the CSHCN Screener reflected concepts that were both familiar to them and relevant to their children's health. Both interviewers independently confirmed that the tone and content of parents' responses during the course of interviews were consistent with their favorable comments when asked directly about their overall reactions to the subject matter.

The majority of parents, however, did not view the relative anonymity of a telephone interview as conducive

to speaking candidly about issues related to their children's health. When probed on this point, parents expressed a reluctance to talk about their children's health with a stranger—especially when they had concerns in this area or were facing barriers to getting care and services for their children. Several parents suggested adding introductory statements to the survey acknowledging how emotionally difficult it might be for parents to answer questions about their children's health and explaining how children in general would benefit from the information being collected. Two of the parents indicated that they would not respond to a telephone interview of any type because of confidentiality concerns related to their immigration status.

#### *Performance of the Spanish language translation*

No issues related to the current Spanish translation of the CSHCN Screener emerged during the interviews. Although given multiple opportunities, including specific verbal probes to elicit suggestions for better words or terms, parents did not offer any revisions or changes to current wording or translation of the screening questions. Parents' responses on the "think aloud" and paraphrasing tasks consistently aligned with their assertions that the current Spanish translation was clear and easily understood.

**Table 4** Health needs of Hispanic children not identified as CSHCN during cognitive interviews

Child's age	Parent comments about child's current need for or use of medicine "prescribed by a doctor"*	Parent-reported child health problems from condition checklist	Parent comments about child's current and past health problems
3 months	"Only vitamins"	None	n/a
3 months	(No medication use reported)	None	n/a
3 months	(No medication use reported)	None	n/a
4 months	(No medication use reported)	None	n/a
1 year	(No medication use reported)	None	n/a
1 year	Recent pneumonia; still taking antibiotics	Asthma or breathing problems	"Breathing problems" = lingering cough due to recent bout of pneumonia; doctor says child will be fine in 2–3 months.
2 years	(No medication use reported)	None	Only things that children get such as colds or fevers; nothing serious—just "normal."
2 years	(No medication use reported)	Learning, understanding or paying attention	"He does not pay attention but that is just because he is a child and is hyperactive."
2 years	"Fluoride only"	None	n/a
3 years	(No medication use reported)	Heart or blood circulation problem	Heart/blood problem = 2 years ago hospitalized child was for "red eyes;" tested for potential blood issues but no disease found; no further problems
3 years	(No medication use reported)	None	n/a
4 years	"Only fluoride"	None	n/a
4 years	(No medication use reported)	Seeing or hearing	Lots of ear infections; mom does not think child needs or uses more medical care than normal for most children
5 years	"Only vitamins"	Migraines or other headache problems	Complained of occasional headaches last summer; doctor checked child and confirmed these are not chronic
5 years	(No medication use reported)	None	"Sometimes gets cold or fever and I take them to the doctor. But that is normal."
5 years	(No medication use reported)	None	"Very healthy."
6 years	(No medication use reported)	Asthma or breathing problems	Breathing problems = "not asthma really, but bronchitis in the winter."
7 years	"Just vitamins"	Allergies	Teacher has mentioned that child needs to pay more attention in school; allergic to Tylenol
8 years	(No medication use reported)	No health issues	n/a
9 years	(No medication use reported)	Depression, anxiety, eating disorder or other emotional problems	Does very well in school; can get anxious/stressed about school work and pressure from peers; taking a special class at school to increase self esteem; mom does not consider this to be a problem that will last
9 years	(No medication use reported)	Asthma or breathing problems	Breathing problems = "Adenoids sometimes can cause problems"
11 years	Currently taking Isoniazid to prevent TB infection	Seeing or hearing; depression, anxiety, eating disorder or other emotional problems	Tantrums/acting out at home; excels academically/no behavior problems at school; mom is waiting to see if child outgrows behaviors

Interviewers specifically asked parents to define the following terms using their own words: (a) emotional; (b) developmental; (c) behavioral; (d) mental health; and (e) educational services. In every case, the definitions that parents gave reflected the intended meanings of the terms. Examples of parents' responses include:

Emotional: "nervous," "crying" "depression," "sad heart," "lack of confidence" (referring to an autistic child's inability to socially interact with peers)

Developmental: "stages of growth," "normal growth." Parents of children with Down syndrome, autism, or complex neurological problems were very familiar with the term and used it spontaneously earlier in the interview to describe their children's conditions.

Behavioral: "something not normal for a kid," "emotional outbursts," "problems getting along with other people," "strong temper," "acting out."

**Table 5** Health needs of Hispanic children identified as CSHCN during cognitive interviews

Child's age	CSHCN Screener criteria on which child qualified				Parent comments about child's current need for or use of medicine "prescribed by a doctor":*	Parent comments about child's current and past health problems
	Prescription medication	Elevated service use/need	Functional limitations	Specialized therapies		
2 years	No	Yes	Yes	Yes	No	Undiagnosed muscular weakness (e.g., child unable to climb stairs; marked turning in of feet/atrophy of leg muscles); currently undergoing diagnostic testing but doctors have not made a formal diagnosis yet; allergic to penicillin
4 years	Yes	No	No	No	Takes Rx meds daily to control seizures	Diagnosed w/ epilepsy; takes medication daily to control seizures; no functional limitations at present time; regularly sees a pediatric neurologist
5 years	Yes	Yes	Yes	Yes	Takes two Rx meds daily to control seizures	Anoxia at birth; blind/deaf; does not speak; peritoneal feeding tube; uses wheelchair; has cerebral palsy, other issues; needs OT/PT/Speech but does not get these services because of immigration status
8 years	No	Yes	No	No	Last prescription inhaler expired without being used. Mom got a refill "just in case child might need it"—but indicates that child has not needed or used this medication for several years	Gets blood transfusions every 6 months for hemolytic anemia; Mom describes child as hyperactive—school urges medication but family refuses because they know a child who takes ADHD medication and "he acted like a dummy,"
8 years	Yes	Yes	No	No	Rx pimrolimus cream (Elidel) for severe eczema	Moderately severe eczema; cracking/bleeding causes child great discomfort, especially around eyes/nose/mouth
8 years	Yes	Yes	Yes	Yes	Levothyroid daily for hypothyroidism associated w/ Down syndrome	Down syndrome; uses diapers; hearing aids; glasses; gets OT/PT & Speech therapy
10 years	No	Yes	No	Yes	(No medication use reported)	Depressed; explosive outbursts; anxiety; cries easily/very emotional; teased/bullied at school; excellent student but no friends. Family unable to access mental health care for child
11 years	No	No	Yes	Yes	Currently taking antibiotic for ear infection	Mom concerned about child's behavior and emotions due to traumatic experience; unable to access mental health care for child due to lack of insurance
11 years	No	Yes	Yes	Yes	(No medication use reported)	Autism; needs OT, PT, & Speech therapy but school does not provide
13 years	No	No	No	Yes	(No medication use reported)	Mom describes child as depressed and anxious; needs mental health care due to confidential traumatic event; unable to access mental health care because family does not have health insurance
14 years	No	Yes	Yes	Yes	Only Tylenol for fever or cold	Down syndrome; gets speech therapy at school; needs OT/PT but funding cutbacks eliminated services; metabolic issues related to DS
15 years	No	Yes	No	No	(No medication use reported)	Depressed, cries a lot; mom very worried; school contacted parent because of adolescent's weight loss; child is seeing social worker at school but no medical care to-date for problems, family does not have insurance or Medicaid

Table 5 continued

Child's age	CSHCN Screener criteria on which child qualified				Parent comments about child's current need for or use of medicine "prescribed by a doctor":*	Parent comments about child's current and past health problems
	Prescription medication	Elevated service use/need	Functional limitations	Specialized therapies		
15 years	No	No	No	No	(No medication use reported)	Attention problems; protein in urine but no follow up; mom says child needs treatment/counseling for behavior & learning problems
15 years	No	Yes	No	No	(No medication use reported)	Depressive episodes for the past 3 years; suicide attempt; extreme mood swings; severe acne, currently receiving counseling at school from social worker; does not receive medical or mental health care for problems because no insurance coverage
16 years	No	Yes	No	No	Rx meds in past for kidney condition; currently takes Rx medication for acne—mom does not consider this to be a health problem	Sees doctor every 3 months for tests to monitor kidney function—condition present since early childhood

One mother distinguished the school based counseling for suicide attempts and mood swings her adolescent daughter is receiving from the types of treatment and services her younger child gets for behavioral issues related to Down syndrome.

*Prescription medications*

Particular attention was paid to this concept during the interviews because of the low proportion of Hispanic children meeting the prescription medication criterion in the NS-CSHCN. All the parents interviewed demonstrated a clear understanding of the term “prescription medicine.” Their responses to the Spanish language version of this screening criterion were congruent with their children’s current medication scenarios (Tables 4, 5). Many parents brought out their children’s prescription medicines during the interview to illustrate their understanding and show the interviewers exactly what medicines their children were currently taking. In their comments, parents spontaneously distinguished “medicine prescribed by a doctor” from over-the-counter medications such as Tylenol, vitamins, fluoride, homeopathic products, and alternative therapies. They also made clear distinctions between prescription medicines taken for an acute illness (e.g., ear infection; “la gripe”) and those taken for chronic health conditions (e.g., epilepsy; severe eczema; thyroid condition).

The follow-up questions to the initial prescription medication item screened out children who were currently taking prescription medications for non-chronic conditions (Table 4). These included two children taking antibiotics for acute conditions (ear infection; pneumonia) and one child taking prescription medication prophylactically to prevent tuberculosis infection. In the latter case, the mother replied affirmatively when asked if the child was currently taking prescription medication, but gave a negative response to the first follow-up question about the presence of a health condition, stating “my child does not have a medical condition—rather, she is taking the medicine to keep her from getting one!” Another mother responded negatively to the prescription medicine question even though she had recently refilled her child’s prescription for an asthma inhaler, which had expired without being used (Table 5). From her perspective, the child did not need or use this medicine any more because he had not experienced asthma symptoms for several years. She refilled the prescription “just in case” his symptoms should reoccur.

The child health questions asked after the CSHCN Screener was completed for the children in the household included an item about the use of traditional or alternative treatments for children’s health problems. Parents were

asked, in Spanish, “Do you currently use any traditional methods of healing for your children such as *hierbas curativas*, *acupuntura*, *lo llevó a ver a curanderos*, *santiguadoras o salvadoras*, (medicinal herbs, acupuncture, or take them to see faith healers, santiguadoras, or salvadoras)?” Parents who responded affirmatively were asked to describe the methods. Only three of the 19 mothers interviewed gave affirmative replies. One described taking her child off all prescription medications and using only homeopathic therapies to treat the child’s asthma and behavioral issues related to autism. Another parent was currently using lemon and honey and a mixture of radishes and garlic to clear mucus and to help alleviate the cough that lingered after her child’s recent bout of pneumonia. The last mother reported that upon advice from relatives she had tried rubbing her young child’s legs with egg whites to relieve symptoms of muscular weakness. Two mothers who replied negatively to this question stressed that they would never use such methods because it would be contrary to their religious beliefs. Several mothers laughed out loud when they heard the question because they found the idea of using such approaches to treat their children to be absurd.

#### *Elevated service need/use*

Parents’ responses to this screening criterion were consistent with their children’s current health statuses and child health checklist results (Tables 4, 5). Parents accurately distinguished between medical, mental health and educational services and did not have any difficulty assessing whether each of their children needed or used more of these services than usual compared to children of the same age. Several parents indicated that their child met this screening criterion based on their children’s need for services—mental health care predominately—that they were not able to access.

The stem question for this screening criterion is the only one that parents asked to have repeated after hearing it for the first time. During the Portland interviews, one parent of the eight interviewed asked to have the question repeated. In Boston, however, three of the four parents interviewed on the first day reacted with puzzled looks when they first heard the question and requested to have it read to them again. Upon hearing it a second time, they all comprehended and responded appropriately. When probed, all three parents reported that the question was too long and wordy, which caused them to lose track of what was being asked. They also explained that being asked about what seemed to them to be three disparate services (medical, mental health, and educational) in the same question was unexpected and confusing.

Based on this input, the interview team revised the stem question to ask about medical care separately from mental health and educational services—in effect, creating two questions out of the original one. During the next four interviews, parents immediately understood and answered the revised questions the first time asked with no confused looks or need to have the questions repeated. The interview team also tested the effects of revising the order and emphasis of the original stem question wording on parents’ comprehension of a single screening question on elevated service need/use. The phrase asking parents to “compare your child to others the same age” was moved to first place and a phrase “any of the following services” was added:

Original screener question on elevated need/use of services (English version): “Does your child (Do any of your children) need or use more medical care, mental health, or educational services than are usual for most children of the same age?”

Revised screener question on elevated need/use of services (English version): “Think about your child (each one of your children) in relation to other children of the same age(s). Does your child (do any of your children) need or use more of ANY of the following services than other children do: medical care, mental health care or educational services?”

The last four parents interviewed in Boston appropriately answered this version of the screening question without hesitation or need for repetition. Their responses to the “think aloud” and paraphrasing tasks indicated that the revisions did not alter the intended meaning of this question.

#### *Functional limitations*

Parents’ responses on the “think aloud” and “re-state the meaning in your own words” paraphrasing tasks were consistently aligned with the intended meaning of functional limitations screening question. A total of five of the 37 children screened met the functional limitations screening criterion (Table 3). Diagnosed health conditions in this group included Down syndrome, autism, severe eczema, and complex neurological disorders. In every case, parents’ responses were congruent with children’s current health and functioning. This was even true for the child who met this criterion although the ongoing evaluation of her musculoskeletal weakness by specialist doctors had not yet resulted in a formal diagnosis (Table 5). Parents were clearly familiar with the concept of using other children of the same age as a normative standard for comparing their own children. In both their elicited and spontaneous com-

ments, parents indicated using same age peers as the comparison base for a child's functioning rather than older or younger siblings or peers. Several parents explicitly used the term "normal" to describe their children's functioning when responding to the screening question.

### *Specialized therapies*

Parents consistently understood and appropriately answered the screening question about their children's need or use of physical, occupational, or speech therapies because of health problems lasting or expected to last at least 12 months. Parents who reported their children did not currently need any of these services offered explanations such as "he has no troubles with his body and does not need physical therapy" or "they do not need these things now, but if after a certain age they are not able to talk—then a child might need speech therapy."

Parents also distinguished the concept of need for specialized therapies from that of using such therapies. Parents of children affected by budget cutbacks that reduced or eliminated specialized therapies their children had previously received gave affirmative answers to all three parts of this screening criterion based on children's need for services they no longer were able to get. The mother of a young child whose physical therapy sessions were recently discontinued by Medicaid because doctors had not yet settled on a formal diagnosis also replied affirmatively to the questions about specialized therapies.

### *Emotional, developmental, and/or behavioral health conditions*

The stem question for the last screening criterion asks whether a child has any emotional, behavioral, or developmental conditions for which he/she needs or gets treatment or counseling. Parents giving affirmative answers to the stem question are asked if the condition is expected to last or has lasted 12 months or longer. The parents interviewed in this study not only consistently understood the intended meaning of the question but also spontaneously distinguished conditions they perceived as being emotional or behavioral from those they considered to be developmental. As with the other screening questions, parents accurately distinguished the concept of needing treatment or counseling from care that children were currently getting. Responses to the interview tasks demonstrated that parents took into account treatment/counseling services children were currently receiving and those for which they had unmet needs when answering the stem question for this criterion. For example, a child using a wheelchair whose complex neurological problems included seizures, hearing loss and vision impairment had not resided in the US long

enough to have Medicaid coverage for the health care and therapies he needed. Currently, he was receiving minimal services through the school system. His mother responded affirmatively to both parts of this screening criterion on the basis of her child's current use of services and his unmet needs for treatment.

### **Discussion**

The overall prevalence of CSHCN for Hispanic children in the 2001 NS-CSHCN was substantially lower than for non-Hispanic children (8.5% and 13.9%, respectively). However, the language in which parents responded to the screening interview had a substantial impact on the probability of Hispanic children being identified as CSHCN. Hispanic children were less than half as likely to have positive screening results when their parents were interviewed in Spanish rather than English (5.1% and 11.7%, respectively).

Although these findings are suggestive of possible linguistic or cultural deficiencies in the current Spanish language translation of the CSHCN Screener, the results from our Spanish language cognitive interviews with LEP parents did not support this explanation. The Spanish translation of the CSHCN Screener performed well during the cognitive interviews with parents. In every case, parents understood and appropriately answered the current Spanish translation of the screening questions when verbally administered during the interviews. Their responses to the "think aloud" tasks, verbal probes, and additional questions about children's current and past health issues confirmed the relevancy of the health consequences-based screening concepts for Spanish-speaking parents with regards to their children. The interviews did not identify any revisions or additions to the health concepts asked about in the current translation. Several parents, however, asked to have the screening question addressing elevated need/use of medical, mental health, or educational services repeated a second time in order to fully comprehend its meaning. Minor modifications to the ordering of the words and concepts in the question appeared to resolve this issue when tested during subsequent interviews.

### The prescription medication criterion

Our analyses of data from the 2001 NS-CSHCN identified differences in the proportion of Hispanic children meeting the prescription medicine screening criterion as a significant factor in the lower CSHCN prevalence for the Hispanic child population. The greatest differential in the proportion meeting any of the five screening criteria for Hispanic children with Spanish language interviews was on

the prescription medication criterion. When parents were interviewed in English, the lower proportion of children meeting the prescription medicine screening criterion accounted for the preponderance of the 2 percentage-points difference in CSHCN prevalence for Hispanic and non-Hispanic children. These findings are particularly relevant because the prescription medicine criterion is the most prevalent criterion among CSHCN—especially in the group of CSHCN identified by a single screening criterion. Variations in the proportion of children meeting this specific criterion would be expected to have a substantial influence on overall CSHCN prevalence.

Previous studies have found a similarly lower prevalence of prescription medication use by Hispanic children, especially those with Spanish language interviews. Analyses of the 1997 Medical Expenditure Panel Survey (MEPS) data showed Hispanic children were significantly less likely than either non-Hispanic white or black children to use prescription medications of any kind [25]. Hispanic children with Spanish language MEPS interviews were significantly less likely than those with English interviews to use any type of prescription medications. Analyses from another survey—the Third National Health and Nutrition Examination Survey (NHANES)—revealed that the use of prescription medications by Mexican American children increased dramatically in relation to their families' language acculturation and length of residency in the US [7]. In this survey, nearly all the parents of first generation Mexican-American children were interviewed in Spanish, and fewer than 1 in 12 of these children used prescription medications of any kind during the previous month. In contrast, the parents of only 7% of third-generation Mexican American children responded to the NHANES in Spanish. One in 5 of these third-generation Mexican-American children used prescription medication during the month previous to the survey—a rate nearly equal to that for non-Hispanic white children. In addition, CDC recently reported that Hispanic children were significantly less likely than non-Hispanic children to be taking medication for Attention Deficit Hyperactivity Disorder (ADHD). Hispanic children whose primary household language was Spanish were nearly 5 times less likely than other Hispanic children to be using medication for this condition [11].

Particular attention was given to parents' conceptual and linguistic understanding of prescription medicine screening questions during the Spanish language cognitive interviews. The parents we interviewed demonstrated an unequivocal understanding of the intended meaning of the concepts addressed by the prescription medicine screening questions in a number of ways, including voluntarily bringing out any prescription medications their children were taking for chronic or acute conditions to illustrate their comprehension. Based on the findings from these

interviews, the lower proportion of Hispanic children with Spanish-language NS-CSHCN interviews meeting the prescription medication criterion does not appear to be due to problems with current translation or the concepts asked about in the questions.

During the course of the cognitive interviews, participants were informed about the lower rates of affirmative responses when Hispanic parents are asked the prescription medicine screening question in national surveys. Interviewers asked parents what they thought might be the reasons for this finding. The most common explanation offered was “maybe we Latinos just take better care of our children.” Some mothers offered the opinion that Hispanic women take better care of themselves during pregnancy and that this might be an explanation. A number of parents, however, mentioned that Hispanic parents might respond negatively to such a question because they do not want to tell a stranger about their children's health problems.

#### Factors contributing to the lower CSHCN prevalence rate for Hispanic children

It is beyond the scope of 19 cognitive interviews with Spanish-speaking LEP parents to provide definitive answers regarding the lower CSHCN prevalence in the 2001 NS-CSHCN for Hispanic children in general or for those with Spanish language interviews specifically. However, information shared by parents during the interviews offers insight on some of the factors that may be involved. Nearly every parent we interviewed expressed some degree of disinclination and reluctance related to speaking candidly about their children's health issues with anonymous telephone interviewers. From the perspective of these parents, the fact that the interviewers did not know them was a compelling reason to not disclose such information. Needless to say, the theoretical assumptions that underpin confidential telephone survey methodology derive from the opposite premise. Several parents indicated that they would not respond to such a survey at all, especially if sponsored by the government, because of concerns about immigration and citizenship status. These factors clearly present challenges for obtaining valid, reliable responses to national telephone surveys on children's health from this population.

Barriers to accessing health care and appropriate treatment may also contribute to the lower proportion of children meeting the screening criteria when parents responded to the NS-CSHCN in Spanish. The mothers of school age CSHCN identified during the cognitive interviews specifically mentioned the lack of public insurance coverage for mental health treatment, including medication, as a significant barrier to accessing the care their children needed. Several of the adolescent-age CSHCN identified by the

screening questions had significant emotional and behavioral health problems that included depression, anxiety, eating disorders, and suicide ideation. Although most of these adolescents were receiving counseling in the school setting, none were currently taking medicine for these conditions. Parents explained that the cost of such medications was prohibitive and the programs available to their families did not cover the cost of mental health treatment or medication.

Culturally based perceptions of need for treatment may interact with barriers to care and how parents interpret information from doctors, teachers or counselors. The parents we interviewed expressed deep concerns about not being able to afford or access treatment and medications that they strongly felt their CSHCN needed. On the other hand, the mother of the one school age child reported to have ADHD during the cognitive interviews described the pressure she perceived from school officials to place the child on medication for attention deficit/hyperactivity disorder. Despite this pressure, the family staunchly refused to do so because, as the mother explained, they did not perceive their son's behavior to be a problem. Rather, they were proud of his academic achievements and were concerned that medication would interfere with his ability to do school work.

Another potential explanation for differences in prevalence of CSHCN when parents of Hispanic children are interviewed in Spanish is that parents of children with less severe or undiagnosed conditions are not familiar with the terminology used in the screening questions due to limited experience with the health care system. The "think aloud" and paraphrasing tasks during the cognitive interviews did not reveal any deficiencies in parents understanding of the terminology used in the screening questions, regardless of children's health status. Based on parent responses to the chronic condition checklist items asked for all children in the sample, the screening questions did not appear to systematically miss children with ongoing chronic health conditions of lesser severity (Table 4). The screening questions did, however, successfully identify children whose current health issues were not yet formally diagnosed or were not being treated because their families were not able to access health care (Table 5).

The lower prevalence of special health care needs among Hispanic children in the 2001 NS-CSHCN is in alignment with the significantly lower prevalence of chronic conditions reported for Hispanic children in other studies. Recent population-based estimates show the prevalence of parent-reported ADHD diagnoses for Hispanic children in US is less than half that reported for non-Hispanic children, with even lower rates reported for Hispanic children whose primary household language is Spanish [11]. Children of Mexican heritage comprise

nearly two-thirds of the Hispanic child population in the US [26]. As a group, these Hispanic children have the lowest rates of parent-reported lifetime asthma diagnoses and asthma attack prevalence compared with all other children, including Hispanic children of other national origins [13]. As with ADHD, parent-reported prevalences of asthma and asthma attacks are even lower when a parent responds in Spanish. The lower parent-reported rates for these conditions in the Hispanic child population are particularly significant because ADHD and asthma are among the most highly prevalent childhood chronic conditions in the US child population. They are also chronic conditions with a high likelihood of being managed through prescription medication. A lower prevalence of either or both conditions in the Hispanic child population would definitely be expected to reduce the rate of positive identification by the CSHCN Screener, and more specifically, the proportion of children meeting the screening criterion which assesses the use of medicine prescribed by a doctor for chronic medical, emotional, behavioral, or other health problems.

All these prevalence estimates, however, share in common the limitation of being based on the parent-reported survey data with all its inherent potential for respondent recall and survey selection biases, as well as other types of response errors. Although the results of our cognitive interviews did not identify any linguistic or cultural issues that interfered with parents' understanding of the intended meaning of Spanish version of the CSHCN Screener questions, it is not known how Hispanic parents interpret survey questions asking about specific diagnoses, especially when translated into Spanish. Taking all the potential sources of bias into consideration, the pattern of lower diagnosis-specific, parent-reported rates of highly prevalent chronic childhood conditions for Hispanic children found by other studies is remarkably congruent with the lower prevalence of affirmative responses in the 2001 NS-CSHCN to the non-diagnosis specific, health-consequences-based CSHCN Screener questions for Hispanic children—especially with regard to the prescription medicine criterion.

#### Limitations

In addition to being based on parent-report survey data, the findings of this study are subject to other limitations. We were not able to include important adjusters such as health insurance status and mother's educational level in our multivariate models using NS-CSHCN data to compare the effects of interview language and Hispanic ethnicity on the probability of children being identified by the CSHCN Screener criteria. Information about insurance status and maternal education was only collected for children who

were identified as CSHCN. This factor limits the interpretation of the multivariate findings; however, additional multivariate analyses of the in-depth CSHCN interview data by the authors (available upon request) show that the inclusion of insurance status and maternal education level does not alter the pattern of findings or conclusions described in this paper.

Parents participating in the cognitive interviews were self-selected and the sample size was relatively small. The percentage of children identified as CSHCN through these interviews is considerably greater (41%) than would be expected in a random sample—indicating that parents of children with on-going health problems were more likely to volunteer to be interviewed. It is also possible that parents of children with complex health needs or more severe conditions may be more likely to volunteer to participate. Five of the 15 Hispanic CSHCN identified in this study qualified on three or more of the screening criteria. By comparison, about 24% of Hispanic CSHCN identified by the 2001 National Survey of CSHCN met three or more of the screening criteria. Although a higher than expected proportion of CSHCN were identified through the cognitive interviews, the relative severity or complexity of their conditions appears similar to that for Hispanic CSHCN nationally.

The mothers we interviewed had an education level higher, on average, than that reported for mothers of Hispanic CSHCN in the 2001 NS-CSHCN. This finding is not unexpected as parents were recruited for the cognitive interviews through printed flyers posted in community locations. Parents with literacy levels associated with higher levels of education would likely have a greater propensity to read such flyers. The self-selection bias and higher levels of education in the group of parents participating in the cognitive interviews are limiting factors if the results are meant to be generalized to the population of Spanish speaking parents sampled for the national interview. However, cognitive interviews are not meant to produce generalizable findings of this type. The higher level of education of the participants we interviewed does mean we would be less likely to identify issues that interfere with respondents' comprehension of the intended meaning of the screening questions and is a limiting factor in this study. On the other hand, participants' self selection provided a much larger sample of children with chronic health conditions than if we had relied upon random methods—an outcome which actually worked in favor of the goals for the interviews because we were able to collect a wider range of information about how parents understood and responded to the Spanish version language version of health concepts included in the CSHCN Screener.

The cognitive interview participants were recruited in only two locations (Massachusetts and Oregon). Compre-

hension difficulties could be more pronounced for parents living in other states. Nationally, Hispanic children with English language interviews were about 2 times as likely as those with Spanish language interviews to be identified as CSHCN, based on data from the 2001 NS-CSHCN. In Oregon, Hispanic children with English language interviews were more than four times as likely as those with Spanish language interviews to be identified as CSHCN (15.4% vs. 3.4%, respectively). In Massachusetts, Hispanic children with English language interviews were only somewhat more likely than those with Spanish language interviews to be identified as CSHCN (15.8% vs. 10.2%, respectively). These findings suggest that the two states chosen for this study represent scenarios that are better and worse nationally in terms of the differences in prevalence of Hispanic CSHCN associated with the language of the NS-CSHCN interview.

With one exception, all participants in our study reported either Mexico or Colombia as their country of origin. We did not observe any differences in how Hispanic parents from these two countries understood and responded to the screening questions. However, the lack of Hispanic cultural diversity in our sample limits our ability to explore the question of whether parents from a wider range of Hispanic heritages share a common understanding of the Spanish translation and intended meaning of the CSHCN Screener questions.

### Implications

The dramatically lower prevalence of CSHCN in the 2001 NS-CSHCN for Hispanic children with Spanish language interviews has implications for interpreting both overall and Hispanic-specific prevalence of CSHCN, especially at the state level. The percentage of children whose parents responded to the NS-CSHCN interview in Spanish ranged from 23% to less than 1% across the 50 states and District of Columbia. In California and Texas, more than 1 in 5 children screened for the 2001 NS-CSHCN had Spanish language interviews. When Spanish language screening results are not included, the prevalence of CSHCN can increase by as much as 2–3% points in some states with a high proportion of Spanish language NS-CSHCN interviews. In such instances, states may want to examine the influence of the lower rates of positive screening results for children with Spanish language interviews on overall and Hispanic-specific CSHCN prevalence. Stratifying CSHCN prevalence by language of the NS-CSHCN interview at the state level may also provide information to program planners, clinicians, and policy makers that is useful for understanding the characteristics and needs of the Hispanic child population in their states.

The cognitive interviews identified reluctance on the part of the participating parents to disclose information about their children’s health to anonymous telephone interviewers. The contribution that such reticence makes to the lower positive identification rates of CSHCN in the NS-CSHCN when parents respond in Spanish cannot be determined from our study. Parents participating in the cognitive interviews suggested adding a tailored introduction to the survey that explains its purpose and acknowledges the sensitivity of sharing information about children’s health with strangers. They felt that such an addition would help to establish trust and overcome parents’ reluctance to be candid when contacted for telephone national interviews.

Findings from the cognitive interviews also suggested that minor modifications to the order of the concepts in the screening question addressing elevated need/use of medical, mental health, or educational services might improve some parents’ comprehension when they hear the question for the first time. Further work is needed to determine whether these issues are Spanish-language-specific or related to the wording of the question in general. It is important that additional in-depth, comprehensive testing in both English and Spanish be undertaken before making any modifications to the ordering and wording of any questions in the standardized screening tool.

The 19 cognitive interviews on the Spanish translation of the CSHCN Screener described in this study are the first of this type ever conducted. The level of consistency and congruency in how the 19 parents we interviewed comprehended and responded to the Spanish language translation of the CSHCN Screener was both unexpected and highly informative. These interviews are a first step in understanding how language, cultural perceptions, race/ethnicity, parent education levels, access barriers to adequate care and treatment interact with how parents of Hispanic children respond to the CSHCN Screener questions when administered in the context of national surveys on children’s health. Future work includes additional testing with parents of different educational levels and Hispanic heritage. The inclusion of tools such as the CSHCN Screener and condition-specific questions about children’s health in national surveys such as the National Survey of Children’s Health, the National Health Interview Survey, and the MEPS increases the need to understand variations in parent-report of children’s health consequences and chronic conditions. More study is needed to help elucidate the complex interactions among language, culture, access to care, and parents’ interpretation of their children’s health and health care needs.

**Appendix A: Children with Special Health Care Needs (CSHCN) Screener as Used in the National Survey of CSHCN**

English language version <sup>a</sup>	Spanish language version <sup>a</sup>
(1) Does your child (Do any of your children) need or use medicine prescribed by a doctor, other than vitamins?  (1_a) Is (CHILD 1, CHILD 2...)’s need for prescription medicines because of ANY medical, behavioral or other health condition?  (1_b) Is this a condition that has lasted or is expected to last 12 months or longer?	(1) Actualmente, ¿necesita o usa su niño/a (alguno de sus niños) medicamentos recetados por un doctor, aparte de vitaminas?  (1_a) Con respecto a [CHILD #1, Child #2]: ¿Es la necesidad por medicina recetada debido a algún problema médico, de comportamiento o otro problema de salud?  (1_b) ¿Eséste un problema que ha durado o se piensa que dure 12 meses o más?
(2) Does your child (Do any of your children) need or use more medical care, mental health or educational services than are usual for most children of the same age?  (2_a) Is (CHILD 1, CHILD 2...)’s need for medical care, mental health or educational services because of ANY medical, behavioral or other health condition?  (2_b) Is this a condition that has lasted or is expected to last 12 months or longer?	(2) ¿Su niño/a (Alguno de sus niños) necesita o usa más servicios de atención médica, salud mental, o educativos de lo que es común para la mayoría de los niños de la misma edad?  (2_a) Con respecto a [CHILD #1, Child #2]: ¿Es la necesidad por atención médica, salud mental o educativos debido a algún problema médico, de comportamiento o otro problema de salud?  (2_b) ¿Eséste un problema que ha durado o se piensa que dure 12 meses o más?
(3) Is your child (Are any of your children) limited or prevented in any way in his or her (their) ability to do the things most children of the same age can do?  (3_a) Is (CHILD 1, CHILD 2...)’s limitations in abilities because of ANY medical, behavioral or other health condition?  (3_b) Is this a condition that has lasted or is expected to last 12 months or longer?	(3) ¿Está su niño/a (alguno de sus niños) limitado(a) o impedido(a) de alguna manera en su habilidad de hacer cosas que la mayoría de niños de la misma edad pueden hacer?  (3_a) Con respecto a [CHILD #1, Child #2]: ¿Es este limitado(a) o impedido(a) el de debido a algún problema médico, de comportamiento o otro problema de salud?  (3_b) ¿Eséste un problema que ha durado o se piensa que dure 12 meses o más?
(4) Does your child (Do any of your children) need or get special therapy, such as physical, occupational, or speech therapy?	(4) ¿Su niño/a (Alguno de sus niños) necesita o recibe terapia especial, como terapia física, ocupacional o del habla?

continued	
English language version <sup>a</sup>	Spanish language version <sup>a</sup>
(4_a) Is (CHILD 1, CHILD 2...)’s need for special therapy because of ANY medical, behavioral or other health condition?	(4_a) Con respecto a [CHILD #1, Child #2]: ¿Es la necesidad el de por terapia especial debido a algún problema médico, de comportamiento o otro problema de salud?
(4_b) Is this a condition that has lasted or is expected to last 12 months or longer?	(4_b) ¿Eséste un problema que ha durado o se piensa que dure 12 meses o más
(5) Does your child (Do any of your children) have any kind of emotional, developmental, or behavioral problem for which he/she (they) need(s) treatment or counseling? <sup>b</sup>	(5) ¿Tiene su niño/a (alguno de sus niños) algún tipo de problema emocional, de desarrollo o de comportamiento, por lo que necesita tratamiento o terapia/consejería?*
(5_a) Has (CHILD 1, CHILD 2...)’s emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?	(5_a) Con respecto a [CHILD #1, Child #2]: ¿Es este un problema de emocional, de desarrollo o de comportamiento que ha durado o se piensa que dure 12 meses o más?

<sup>a</sup> Affirmative responses to the initial question about the health care consequence and to each of the two follow-up questions are necessary for a child to meet a specific screening criterion

<sup>b</sup> Question 5 has a single follow up question asking about duration of child’s emotional, developmental, or behavioral health conditions. Affirmative responses to the initial question about the need for treatment and counseling and to the follow-up question about the duration of the condition are required for a child to meet this screening criterion

## References

- Federal Interagency Forum on Child and Family Statistics. (2005). *America’s children: Key national indicators of well-being*, Washington, DC: U.S. Government Printing Office.
- Flores, G., Abreu, M., Olivar, M. A., & Kastner, B. (1998). Access barriers to health care for Latino children. *Archives of Pediatrics and Adolescent Medicine*, *152*, 1119–1125.
- Weinick, R. M., & Krauss, N. A. (2000). Racial/ethnic differences in children’s access to care. *The American Journal of Public Health*, *90*, 1771–1774.
- Ku, L., & Waidmann, T. (2003). *How race/ethnicity, immigration status, and language affect health insurance coverage, access to care and quality of care among the low income population*. Washington, DC: The Henry J Kaiser Family Foundation.
- Kataoka, S. H., Zhang, L., & Wells, K. B. (2002). Unmet need for mental health care among US children: variation by ethnicity and insurance status. *The American Journal of Psychiatry*, *159*, 1548–1555.
- Ojeda, V. D., & Brown, E. R. (2005). Mind the gap: parents’ citizenship as predictor of Latino children’s health insurance. *Journal of Health Care for the Poor and Underserved*, *16*, 555–575.
- Burgos, A. E., Schetzina, K. E., Dixon, B., & Mendoza, F. S. (2005). Importance of generational status in examining access to and utilization of health care services by Mexican American children. *Pediatrics*, *115*(3), e322–e330.
- Capps, R., Fix, M. E., Ost, J., Reardon-Anderson, J., & Passel, J. S. (2004). *The health and well being of young children of immigrants*. Washington DC: The Urban Institute.
- US Department of Health and Human Services. (2004). Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville, Maryland: U.S. Department of Health and Human Services.
- Newacheck, P., & Halfon, N. (1998). Prevalence and impact of disabling childhood chronic conditions. *The American Journal of Pub Health*, *88*, 610–617.
- Centers for Disease Control and Prevention. (2005). Mental health in the United States: Prevalence of diagnosis and medication treatment for attention-deficit/hyperactivity disorder—United States, 2003. *MMWR*, *54*, 842–847.
- Mendoza, F. S., & Fuentes-Afflick, E. (1999). Latino children’s health and family-community health promotion model. *The Western Journal of Medicine*, *170*, 85–92.
- Lara, M., Akinbami, L., Flores, G., & Morgenstern, H. (2006). Heterogeneity of childhood asthma among Hispanic children: Puerto Rican children bear a disproportionate burden. *Pediatrics*, *117*(1), 43–53.
- McPherson, M., Arango, P., Fox, H., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*, 137–140.
- Bethell, C. D., Read, D., Stein, R. E. K., Blumberg, S. J., Wells, N., & Newacheck, P. W. (2002). Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics*, *2*, 38–47.
- Stein, R. E., Bauman, L. J., Westbrook, L. E., Coupey, S. M., & Ireys, H. T. (1993). Framework for identifying children who have chronic conditions: The case for a new definition. *The Journal of Pediatrics*, *122*, 342–347.
- Stein, R. E., Westbrook, L. E., & Bauman, L. J. (1997). Questionnaire for identifying children with chronic conditions (Qu-CCC): A measure based on a noncategorical approach. *Pediatrics*, *99*, 513–521.
- Bethell, C. D., Read, D., Neff, J., Blumberg, S. J., Stein, R. E. K., Sharp, V., & Newacheck, P. (2002). Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambulatory Pediatrics*, *2*, 49–57.
- Zell, E. R., Ezzati-Rice, T. M., Battaglia, M. P., & Wright, R. A. (2000). National immunization survey: the methodology of a vaccination surveillance system. *Public Health Reports*, *115*, 65–77.
- Blumberg, S. J., Olson, L., Frankel, M., Osborn, L., Becker, C. H., Srinath, K. P., & Giambo, P. (2003). Design and operation of the national survey of children with special health care needs, 2001. National Center for Health Statistics. *Vital and Health Statistics*, *41*, 1–136.
- SPSS Complex Samples 14.0. (2006). Copyright SPSS Inc. 2006. Chicago, IL.
- The Pew Hispanic Center/Kaiser Family Foundation. (2002). *National Survey of Latinos*. Available at: <http://www.kff.org/kaiserpolls/20021217a-index.cfm>. Accessed September 2005
- Willis, G. B. (1999). *Cognitive interviewing: Reducing survey error through research on the cognitive and decision processes in surveys*. Research Triangle Park, NC: Research Triangle Institute.
- National Center for Health Statistics. *National survey of children with special health care needs, 2005–2006*. Survey instrument

- available online at: [http://www.cdc.gov/nchs/about/major/slraits/cshcn\\_05\\_05.ht](http://www.cdc.gov/nchs/about/major/slraits/cshcn_05_05.ht).
25. Weinick, R. M., Jacobs, E. A., Stone, L. C., Ortega, A. N., & Burstin, H. (2004). Hispanic healthcare disparities: challenging the myth of monolithic Hispanic population. *Medical Care*, 42(4), 313–20.
  26. Guzman, B. (2001). *The Hispanic population 2000 census brief*. US Census Bureau. C2KBR/01–3.