The Children With Special Health Care Needs Consumer Quality Measurement Module

CAHPS/AHRQ Submitter's Kit

Prepared by the Child and Adolescent Health Measurement Initiative, FACCT—The Foundation for Accountability

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NOTE: Confidential data and research findings are presented in this submitters kit. Please do not cite or present any data or research findings presented here outside of the context of CAHPS and AHRQ deliberations.

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Background and Acknowledgements

The Children with Special Health Care Needs Consumer Quality Measurement Module (CSHCN Module) was developed under the auspices of the Child and Adolescent Health Measurement Initiative's (CAHMI) Living with Illness Task Force and in collaboration with the CAHPS research team. The development of the CSHCN Module has been largely funded by FACCT—The Foundation for Accountability through grant support from the David and Lucile Packard Foundation and The Robert Wood Johnson Foundation. The Agency for Healthcare Research and Quality (AHRQ) provided funding for the substantial participation by key members of the CAHPS® research team. The CSHCN Module has been formally endorsed by the National Advisory Committee of the Child and Adolescent Health Measurement Initiative (CAHMAC) and accepted by NCQA for inclusion in HEDIS, 2002.

The Child and Adolescent Health Measurement Initiative was founded in May of 1998 as a collaborative effort between FACCT and the National Committee for Quality Assurance (NCQA). The purpose of the CAHMI is to develop strategies and methods for both measuring and communicating the quality of child and adolescent health care provided by health care system, including health plans and provider groups. Three measurement task forces have focused on developing health plan quality measures in the following consumer-relevant quality categories: (1) Staying Healthy (2) Getting Better and (3) Living with Illness. These task forces also consider how such measures can be used for quality improvement, community-wide assessment and medical group evaluation.

The following individuals have provided substantial and ongoing input regarding the development and testing of the CSHCN Module screening tool, sampling strategy and supplemental survey items and measures (in alphabetical order):

- Julie Brown, RAND
- Paul Cleary, Harvard Medical School
- Susan Epstein, New England SERVE
- Shirley Girouard
- Jack Fowler, University of Massachusetts
- John Hochheimer, formerly of the National Committee for Quality Assurance
- Charles Homer, Boston Children's Hospital
- Debbie Klein Walker, Massachusetts Department of Public Health
- Peggy McManus, Maternal and Child Health Policy Research Center
- Merle McPherson, Maternal and Child Health Bureau
- John Neff, Center for the Study of Children With Special Health Care Needs
- Paul Newacheck, UCSF Medical Center
- James Perrin, Massachusetts General Hospital
- Joe Thompson, Arkansas Children's Hospital
- Ruth Stein, Albert Einstein College of Medicine
- Nora Wells, Family Voices

Christina Bethell, PhD, Senior Vice President at FACCT-The Foundation for Accountability, is Director of the CAHMI and principal investigator for the development and testing of the CSHCN Module. Debra Read, MPH is the senior research associate for the CSHCN Module. Debbie Levy provided administrative and research assistance.

Criterion 1 – Purpose:

Wide consensus exists among federal, state and local agencies, health plans, providers, and consumer organizations that children with chronic or special health care needs (CSHCN) represent an important focus for quality measurement (Ireys 1992, Newacheck et al. 1998, Perrin et al. 1997, HCFA 2001). On face value, the health care needs of children with and without chronic or special health care needs differ substantially, especially in terms of the type, scope and frequency of health care services required and the ongoing parent/child needs for health information, education, partnership with providers and coordination of care. Although CSHCN are the minority of children overall (15 – 21%), they consume 80 – 90% of health care dollars spent on children (Institute of Medicine 1998, Neff 1995, Lewit 1992). The lack of a simple, straightforward, standard approach to identifying CSHCN has been a major barrier to assessing care for this important group of children.

The Children with Special Health Care Needs (CSHCN) Module is a set of survey-based methods and tools designed to identify children with special health care needs and measure the basic aspects of health care quality for this group of children. Developing the capacity to score and report the consumer information collected with the CAHPS 2.0 Child Survey separately for children with special health care needs was one of the primary objectives guiding the development of the CSHCN Module.

The CSHCN Module is specifically designed for use in conjunction with the CAHPS 2.0 Child Survey and has four components:

1. A five-item screening tool, the CAHMI / CSHCN Screener, to identify children with chronic or special health care needs. (Appendix A)

2. The CSHCN question supplement with 31 survey items addressing topics especially relevant to CSHCN and their families. (Appendix A)

3. A diagnostic code-based algorithm for use with an optional enriched sampling strategy. (Appendix B)

4. Guidelines for scoring the four new CSHCN-specific measures collected through the CSHCN Module.

A copy of the CAHPS 2.0 Child Survey with the CSHCN Screener and CSHCN Question Supplement (final version) is included under Appendix C.

Results from the survey-based screening tool (CSHCN Screener) make it possible to calculate the standard composites and ratings derived from the core CAHPS 2.0 Child Survey for children who do and do not meet the criteria of having a special health care need. Four additional CSHCN-specific measures are calculated from data obtained through the CSHCN question supplement for children meeting the CSHCN criteria:

a) Getting Prescription Medicines
b) Getting Specialized Services
c) Family Centered Care and Decision Making
d) Coordination of Care

Development background

The CSHCN Module was developed as part of the Child and Adolescent Health Measurement Initiative (CAHMI). The CAHMI was established in 1998 by FACCT—The Foundation For Accountability—and the National Committee on Quality Assurance (NCQA) to provide leadership and resources for measuring and communicating relevant, actionable information about the quality of health care for children and adolescents to consumers, providers and policymakers.

The CAHMI brings together consumers, researchers, providers, policymakers and other stakeholders into four national advisory committees. One of these committees, the CAHMI Living with Illness Task Force, which included the members from the CAHPS research team, advised CAHMI research staff during the development, testing and refinement of the CSHCN Module. For a list of Task Force members, see Appendix D.

To ensure the relevance, soundness and feasibility of its measures, the CAHMI employs the same standard six-stage measure development and testing process used by FACCT. All CAHMI quality measures, including the CSHCN Module, go through the steps outlined in Table 1.

Table 1: Six-Stage FACCT/CAHMI Measurement Development and Testing Process

Stage 1: Conceptual Framework and Relevance

Develop conceptual framework for measurement within topical area, obtain consumer input, review available literature, measurement methods and tools, establish and obtain input from an expert advisory group. *Key Focus: Consumer & Professional Relevance, Usefulness & Face Validity*

Stage 2: Synthesize and Review

Develop starting point measurement proposal and conduct Phase I feasibility and stakeholder review. *Key Focus: General Feasibility & Content Validity*

Stage 3: Specify Methods and Testing Design

Specify viable measurement methods and tools and convene advisory group to select options for further development and design field test. *Key Focus: Applied Feasibility & Soundness of Measures*

Stage 4: Field Test

Conduct field testing (minimum 3 sites), conduct data analysis and engage advisory group in review and interpretation of findings. *Key Focus: Feasibility & Soundness of Measures*

Stage 5: Revise and Refine

Revise and refine quality measurement specifications for each application (e.g. health plan comparison) addressing each criteria. Obtain additional consumer input and specify scoring and reporting guidelines. *Key Focus: Relevance, Feasibility, Soundness & Interpretability*

Stage 6: Document and Disseminate

Develop scientific and technical documentation and begin large-scale implementation and dissemination. *Key Focus: Application, Generalizability & Usefulness*

The CAHMI process that ultimately produced the CSHCN Module included:

- 18 focus groups with parents (8 CSHCN-specific)
- 6 national in-person meetings of the Living with Illness Task Force
- Cognitive testing of the instruments involving families of children with and without special health care needs
- Field trials and pretests collecting over 36,000 cases of data across national, statewide and health plan settings
- Regular conference calls (25 – 30 total) involving the Living with Illness Task Force Advisory Group
- Innumerable emails and "real-time" review sessions among Task Force members at important junctures during the development and testing of the CSHCN Module.

Research goals

Three major questions guided the quantitative and qualitative research contributing to the CSHCN Module:

1. What is the most feasible, reliable and valid method to identify a cohort of children having special health care needs for the purpose of assessing their care?
2. What aspects of care are the most relevant and essential to assess for CSHCN?
3. Given the low prevalence of CSHCN in the child population overall, how can a survey of CSHCN be most efficiently and feasibly deployed?

The first priority in developing the CSHCN Module was to ensure the meaningfulness and relevance of the topics selected to families with children who have special health care needs. Early in the development process, focus groups conducted by FACCT/CAHMI confirmed the interest and need by families of children with special health care needs for information about quality of care specific to this group. These focus groups also served as the starting point for identifying crosscutting aspects essential to the care and management of children with special health care needs regardless of the specific nature or severity of their conditions. Summaries of the focus groups are provided in Appendix E.

One of the early decisions made by the CAHMI Living with Illness Task Force was to design an approach to assessing care for CSHCN that would be compatible with the CAHPS 2.0 Child Survey. This strategy had several advantages. The CAHPS 2.0 Child Survey is a standardized, widely-used survey. A number of the care topics identified by literature review, expert and family input as being particularly relevant and important for CSHCN were already assessed through the CAHPS survey. Instead of developing a new survey, the incorporation of a method to identify children with special health care needs and a set of supplemental items addressing additional aspects of care especially relevant for CSHCN would make it possible to use the CAHPS survey as the core for assessing care quality for children with and without special health care needs.

The number of factors were taken into account during the design and testing of a survey-based, CAHPS-compatible approach to identifying CSHCN and assessing relevant aspects of their care. Specifically, these included:

- A “gold standard” definition of CSHCN does not exist due to varying conceptualizations of this population and the nature of childhood chronic conditions.

- The epidemiology of childhood chronic conditions makes condition-specific assessment impractical for performance comparison. Relative to the adult population, children face a much larger array of potential conditions, most with very low prevalence.

- Condition checklists and/or diagnoses codes from administrative data have limited utility for prevalence and performance measurement as many chronically ill children, especially those with special health care needs, are not easily or reliably identified through such sources.

- The low overall prevalence of childhood chronic conditions or special health care needs (15 – 21%) has implications for sample sizes necessary to obtain a statistically adequate cohort of CSHCN through population-based methods.

- The capacity to maintain CAHPS trending data must be preserved by any method considered for integration into the core CAHPS 2.0 Child Survey.

The CSHCN screening tool, the CSHCN question supplement, the enriched sampling strategy and scoring components of the CSHCN Module were specifically developed in response to one or more of the issues described above. Table 2 presents a summary of these components in conjunction with the corresponding research objectives and methodologic challenges addressed by each.

Reporting the development and testing of the CSHCN Module

The CSHCN Module is an integrated set of survey-based methods and tools designed for use in conjunction with a core patient experience of care survey, such as the CAHPS 2.0 Child Survey, to identify children with special health care needs and to measure, report and improve the quality of care of their care. To achieve this goal, the survey-based CSHCN Screening tool, CSHCN Question Supplement and the enriched sampling strategy utilizing the administrative data-based prescreening algorithm were all developed as a result of the research leading to the final CSHCN Module. Each component underwent its own unique course of validation and testing. As such, the remaining criteria sections in this document are organized around these components with pertinent research findings reported separately for each.

Table 2: Overview of the CSCHN Module Components

Research Objective	***CSHCN Module Component***	***Issues Addressed***
OBJECTIVE #1: To identify a cohort of children having special health care needs in an efficient, flexible, valid & reliable manner for the purpose of assessing their care.	CSHCN Screener • 5 item survey-based screening tool • Based on the Maternal and Child Bureau (MCHB) definition of CSHCN • Uses health consequences-based, non-condition specific criteria rather than formal diagnosis or named condition to identify CSHCN • Self or interviewer administered to parents via mail or telephone	• Consensus-based MCHB definition increases potential for acceptability across broad range of users • Parent self-report avoids limitations & biases inherent to administrative data • Non-condition specific approach reduces probability of missing children who lack recorded dx's or access to health care • Consequences-based criteria avoids the demonstrated unreliabilities of condition-specific checklists, asking parents to name child's health condition or to indicate whether child has an ongoing health problem • Flexibility & efficiency maximized by dual administration modes & brevity of the screening tool
OBJECTIVE #2: To identify, assess & communicate the aspects of care most relevant and essential to families of children with special health care needs.	CSHCN Question Supplement & Scoring Guidelines • 31 items total, including filter questions to identify appropriate responders to questions • Addresses topics of care highly relevant or essential for CSHCN and their families • Data collected by CSHCN Question Supplement used to calculate 4 new quality measures specific to CSHCN	• Includes aspects of care NOT previously assessed by the core CAHPS 2.0 Child Survey but which were identified through parent focus groups, literature review & expert input as being essential or highly relevant for CSHCN • Allows non-condition-specific assessment of care by addressing crosscutting aspects of care essential for all CSHCN, regardless of the nature or severity of their health conditions • Wording, formatting & scoring are congruent with other CAHPS items & composites to allow compatibility with standard CAHPS scoring & presentation protocols
OBJECTIVE #3: To minimize the burden and maximize the feasibility & efficiency of deploying a survey of children with special health care needs.	Prescreen & Enriched Sampling Strategy (optional) • ICD-9 code-based prescreening algorithm uses administrative records to identify a cohort of children with a higher likelihood of meeting the survey-based CSHCN Screener criteria • Starting sample for CAHPS survey is stratified to include random samples from both the general population and the group meeting prescreen criteria	• The relatively low overall prevalence of CSHCN is addressed by increasing the number of children in a survey starting sample having a higher potential of meeting the CSHCN Screener criteria • Stratifying the starting survey sample to include children who meet the prescreening criteria dramatically reduces the sample size required when a targeted number of CSHCN are needed for statistical or other purposes • Maintaining the standard CAHPS random population-based sample allows CAHPS trending data to be preserved

Criterion 2 – Building on existing research

A. *CSHCN Screener*

An in-depth review and comparison of existing consequences-based definitions and survey-based methods for identifying CSHCN were conducted. Definitions and classification frameworks set forth by the federal Maternal and Child Health Bureau (MCHB) (McPherson et al. 1998), the Research Consortium on Chronic Illness in Childhood (RCCIC) (Perrin et al. 1993) and the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) (Stein et al. 1997) were reviewed, as were survey items used by the National Health Interview Survey (NHIS) and the Consumer Assessment of Health Plans Survey (CAHPS) (AHCPR 1998). Although similar in their use of consequences-based criteria, the definitions reviewed varied in terms of the type, scope and intensity of health and health service needs required to qualify a child as having a special health care need and the specific types and duration of conditions required (e.g. medical, mental, behavioral or developmental conditions; duration of 3 vs. 12 months). The three survey-based methods considered (NHIS, QuICCC and CAHPS) also varied a great deal in the number, wording, content and formatting of survey items used.

Based upon the review, the MCHB definition of CSHCN and elements of both the RCCIC and the QuICCC frameworks for identifying CSHCN were selected to guide the development of the CSHCN Screener. The MCHB definition of CSHCN states that for a child to qualify as having a special health care need, he or she should (1) have a physical, developmental, behavioral or emotional condition and (2) require health or related services of a type or amount beyond that required by children generally. This definition was specifically chosen because it moves beyond disability and functional impairment conceptualizations of children with special health care needs to include children whose health conditions do not involve impairments to a child's day-to-day functioning or whose conditions are well managed such that functional consequences are minimized or eliminated.

The MCHB definition draws closely on the conceptual framework created by the developers of the Questionnaire for Identifying Children with Chronic Conditions (Stein et al. 1993, ibid. 1997). In the interviewer-administered QuICCC instrument, parents are first asked if their child experiences a specific functioning, compensatory mechanism or service use consequence. If the answer is 'Yes', parents are next asked two follow-up questions to determine if the consequence is due to a medical, behavioral or other condition lasting or expected to last at least 12 months. To qualify as having a chronic condition, the specific consequence experienced by a child must be attributable to a medical, behavioral or other condition lasting or expected to last at least 12 months.

The developers of the QuICCC found the sequence of asking if a child experiences a specific consequence first, followed by whether it was due to a medical, behavioral or other condition lasting or expected to last at least 12 months, to be the most reliable method of employing consequences-based criteria in the context of an interviewer-administered survey. This format, along with other elements of the QuICCC conceptual framework served as a starting point for the development of a brief set of self-administered, consequences-based survey items to identify children with special health care needs.

Key References for the CSHCN Screener

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998:102:137-140

2. Perrin EC, Newacheck PW, Pless IB, Drotar D, Gortmaker SL, Leventhal J, et. al. Issues involved in the definition and classification of chronic health conditions. *Pediatrics.* 1993;91:787-793

3. Stein REK, Bauman LJ, Westbrook LE, Coupey SM, Irey HT. Framework for identifying children who have chronic conditions: the case for a new definition. *J Pediatrics*. 1993;122:342-347

4. Stein REK, Westbrook LE, Bauman LJ. Questionnaire for identifying children with chronic conditions (QuICCC): a measure based on a noncategorical approach. *Pediatrics*. 1997;99:513-521

5. Harvard Medical School, RAND, Research Triangle Institute. *CAHPS 2.0 Surveys.* Agency for Health Care Policy and Research; October, 1998

B. *CSHCN Question Supplement*

Using the CSHCN Screener in conjunction with the CAHPS 2.0 Child Survey allows the standard CAHPS composite measures and ratings to be calculated separately for children who meet the screening criteria for having a special health care need. The relevance of the core CAHPS Child Survey content for families with children in managed care is already well established. If anything, the basic aspects of care assessed by the core CAHPS Child Survey are even more relevant for CSHCN—a group whose ongoing parent/child needs for partnership and communication with health care providers, access to specialty care and responsive customer service exceed that of other children.

The ability to identify children with special health care needs using the CSHCN Screener also makes it possible to assess additional care topics important to families of these children. Practice guidelines, existing surveys focused on special needs populations and published literature were reviewed to identify baseline aspects of care essential for the successful treatment, management, and support of children with chronic conditions. Particular attention was paid to areas where significant need for improvements in quality have been noted or where evidence exists linking provision of care to desirable outcomes.

The measurement concepts reflected in the CSHCN Question Supplement represent important aspects of care suggested by existing research to pertain to nearly all children with chronic conditions regardless of the nature or severity of the specific condition or special need. The final set of supplemental items represents a consensus set of survey questions agreed upon by the CAHMI Living with Illness Task Force in collaboration with the CAHPS research team. Four conceptual areas not already addressed by the core CAHPS 2.0 Child Survey are represented:

e) Getting Prescription Medicines: includes ease of accessing child’s new prescriptions and refills.

f) Getting Specialized Services: includes access to medical equipment, special therapies, treatment or counseling for emotional, developmental or behavioral problems.

g) Family Centered Care and Decision Making, includes having a personal doctor or nurse who knows and understands child & family, involvement of the family by child’s providers in shared decision making and provision of necessary information related to child’s health condition or special needs.

h) Coordination of Care: includes level of help family receives coordinating child’s care among multiple health providers and services.

The face validity of each of the conceptual areas addressed by the CSHCN Question Supplement is well supported by current research (Garwick 1998, Hill 1999, American Academy of Pediatrics 1997, Newacheck 1996, McManus 1996, Kuhlthau 1998, FACCT 1999, Family Voices 2000). It is worth noting, however, that the empirical evidence linking the measurement concepts to improved outcomes is strongest for what is described as a “family centered” model of care incorporating good communication, shared decision making and support and education for self management (Von Kroff 1997, DiMatteo 1994, Wagner 2000, Lorig 1999, Braddock 1997, Sobel 1995). The area of family/child communication with doctors and other health providers is addressed through the core CAHPS Child Survey content. The CSHCN Question Supplement adds the dimensions of family involvement in decision making, provision of information addressing family’s questions and concerns about child’s health and whether the child’s personal doctor or nurse knows and understands how the child’s health impacts the child and family.

In particular, the strength of the research linking shared decision making with improved outcomes for patients spurred the inclusion of an expanded set of “shared decision making” items in the final version of the CSHCN Question Supplement. A shared decision making scale already extensively tested in the adult population was adapted for use with families and children. Earlier versions of the supplemental questions had included only one item addressing parents’ involvement in decisions related to their children’s health.

Concerns about the performance of managed care often revolve around the care of people with chronic conditions (Neff 1995, Newacheck 1996, Kuhlthau 1998, McManus 1996). Not only do the topics included through the CSHCN Question Supplement allow managed care organizations to demonstrate performance in areas having particular relevance for children with chronic conditions, they also provide information useful for tracking and improving performance. Improvements in functioning, reductions in negative health events such as days lost from school or acute events requiring emergency care for conditions such asthma and diabetes, and improved adherence to medical advice are expected to result from improvements in aspects of care measured by the CSHCN Module (Clark 1986, Lewis 1984, Hughs 1991, Charron-Prochownik 1994, Geller 1985, Sinnock 1984).

Survey instruments reviewed

1. Providence General Children's Center. *Child Health Survey*. Partnerships for Improved Community Care Project. Everett, WA

2. Family Voices & Heller School, Brandeis University. *Your Voice Counts*. The Family Partners Project, 1998.

3. New England SERVE. *Family Survey: Shared Responsibilities Tool Kit, Version 1.0*. November 1998.

4. King S, Rosenbaum P, King G. *MPOC: the measure of processes of care. A means to assess family-centered behaviours of health care providers.* Neurodevelopmental Clinical Research Unit, McMaster University; Hamilton, Ontario, Canada. 1995.

5. Harvard Medical School, RAND, Research Triangle Institute. *CAHPS 2.0 Surveys.* Agency for Health Care Policy and Research; October, 1998 (specifically, the Child Supplemental Questions for Chronic Conditions; draft versions of CAHPS / CSN survey were also reviewed).

6. Oregon Department of Human Resources. *Satisfaction Survey: Your Child's or Foster Child's Health Care.* Office of Medical Assistance Programs, 1997.

Key References for the CSHCN Question Supplement

1. American Academy of Pediatrics. *Guidelines for Health Supervision III*. Illinois: American Academy of Pediatrics. 1997;3

2. Braddock CH, et al. How doctors and patients discuss routine clinical decision. *J Gen Intern Med*. 1997;12:339-345

3. Clark NM, Deldman CH, Evans D, et al. The impact of health education on frequency and cost of health care use by low income children with asthma. *J Allergy Clin Immunology.* 1986;78:104-114

4. Charron-Prochownik D, Kovacs M, Obrosky DS, Stiffler L. Biomedical and psychosocial predictors of early rehospitalization among children with insulin dependent diabetes mellitus: a longitudinal study. *Diabetic Medicine*. 1994;11:372-377

5. Diehl SF, Moffit KA, Wade SM. Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings. *Child Health Care*. 1991;20:170,178

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8. FACCT—The Foundation for Accountability. *Summary of focus groups with families with children with chronic conditions: Interim Report on the Living with Illness Field Trial*; 1999

9. Family Voices. *The Health Care Experiences of Families of Children with Special Health Care Needs: Summary Report of Findings from a National Survey.* New Mexico: Family Voices. 2000

10. Garwick AW, Kohrman C, Wolman C, Blum R. Families' recommendations for improving services for children with chronic conditions. *Arch Pediatr Adolesc Med.* 1998;152:440-448

11. Geller J, Butler K. Study of educational deficits as the cause of hospital admission for diabetes mellitus in a community hospital. *Diabetes Care*. 1981;4;4;487-489

12. Hill I, Schwalberg R, Zimmerman B, Tilson W. *Achieving service integration for children with special health care needs: an assessment of alternative Medicaid managed care models, Health Resources and Services Administration*. Maternal and Child Health Bureau, United States Department of Health and Human Services; 1999

13. Hughs DM, McLeod M, Garner B, Goldbloom RB. Controlled trial of a home and ambulatory programme for asthmatic children. *Pediatrics.* 1991;87:54-61

14. Kuhlthau K, Klein Walker D, Perrin JM, et al. Assessing managed care for children with chronic conditions. *Health Affairs.* 1998;17:4:42-52

15. Lewis CE, Rachelesfsky GS, Lewis MA, Del la Sota A, Kaplan M. A randomized trial of A.C.T. (asthma care training) for kids. *Pediatrics.* 1984;74:478-486

16. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Medical Care.* 1999;37:5-14

17. McManus MA, Fox HB. Enhancing preventive and primary care for children with chronic or disabling conditions served in health maintenance organizations. *Managed Care Quarterly.* 1996;4:3:19-29

18. Neff J, and Anderson G. Protecting children with chronic illness in a competitive marketplace. *JAMA.*. 1995;274:1866-1869

19. Newacheck PW, Stein REK, Klein Walker D, et al. Monitoring and evaluating managed care for children with chronic illnesses and disabilities. *Pediatrics.* 1996;98:952-958

20. Prochaska JO, et al. Stages of change and decisional balance for 12 problem behaviors. *Health Psychology*. 1994;13:39-46

21. Sinnock, P. The use of hospitalization data to evaluate patient education programs. *The Diabetes Educator*, Special. 1984:43-45

22. Sobel DS. Rethinking medicine: improving health outcomes with cost-effective psychosocial interventions. *Psych Med*. 1995;57:234-44

23. Solloway M. *Developing a framework for pediatric measures of accountability: executive summary*. Prepared for the Foundation for Accountability; 1997

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25. Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness: essential elements. *Ann Intern Med.* 1997;127:1097-1102

26. Wagner EH. The role of patient care teams in chronic disease management. *BMJ*. 2000;320:569-572

C. *Prescreening Algorithm and Enriched Sampling Strategy*

Because no published research exists, the prescreening algorithm using ICD-9 codes from administrative records drew on unpublished diagnoses code lists developed by researchers from the Research Consortium on Chronic Illness in Childhood and others. Using these lists as a starting point, additional expert review and input were obtained from health services researchers familiar with administrative record data methods. A number of diagnosis codes were added to the original list and several code types known to have high false positive rates were subset to require two or more outpatient visits with the code in order to qualify. CAHMI research staff developed the ACCESS look up tables and other analysis programs required to apply the prescreening algorithm to health plan administrative records.

Criterion 3 – Coordinating questionnaire and reports development

The primary impetus for developing the CSHCN Module was to generate quality information for reporting to consumers. Achieving this goal in a feasible and efficient manner led to the initial decision to design a set of supplemental items that could be used in conjunction with the core CAHPS 2.0 Child Survey and which would provide data compatible for use with the standard CAHPS consumer reporting formats.

As described under Criterion #1, when used in conjunction with CAHPS 2.0 Child Survey, the CSHCN Module allows the standard CAHPS composites and ratings to be calculated separately for children with and without special health care needs. In addition, data collected through the CSHCN Question Supplement is used to calculate four new composite measures for the group of children identified as having special health care needs by the CSHCN Screener:

1. Getting Prescription Medicines
2. Getting Specialized Services
3. Family Centered Care and Decision Making
    a) Part A: Personal Dr / Nurse who Knows Child
    b) Part B: Shared Decision Making
    c) Part C: Getting Needed Information About Child's Health
4. Coordination of Care

To ensure compatibility with CAHPS consumer reporting formats, the CSHCN Question Supplement items use the same response sets as the core CAHPS survey. The CSHCN items are scored into consumer reporting composites using the same scoring approaches used to construct standard CAHPS composites. Table 3 on the next page provides an overview of the CSHCN measures derived from the final version of the CSHCN Question Supplement used in conjunction with the CAHPS 2.0 Child Survey. Appendix F provides an item by item list of the final version of the CSHCN questions comprising each of the CSHCN composite measures.

Table 3: Summary of the CSHCN consumer reporting measures derived from the CAHPS® 2.0 Child Survey with the final version of the CSHCN Question Supplement included

I. *Standard CAHPS consumer reporting composites calculated separately for children meeting CSHCN Screener criteria*

Measure	Content	Response task
How Well Drs Communicate	Parent/family reports of how often doctors/providers spend enough time, show respect, listen, & explain things clearly.	Never, sometimes, usually, always
Getting Care Quickly	Parent/family reports of experiences with scheduling appointments and wait times and getting phone advice, emergency or urgent care when needed.	Never, sometimes, usually, always
Getting Needed Care	Parent/family assessments of problem level finding a personal dr/nurse; getting referrals to specialists; getting necessary care or delays in care by health plan.	Big problem, small problem, no problem
Courteous & Helpful Office Staff	Parent/family reports on experiences with respectfulness and helpfulness of the office staff from their child's doctors/providers offices.	Never, sometimes, usually, always
Customer Service	Parent/family assessments of problem level with customer service, written plan materials and paperwork	Big problem, small problem, no problem

II. *CSHCN consumer reporting composites calculated separately for children meeting CSHCN Screener criteria*

Measure	Content	Response task
Getting Prescription Medicines	Parent/family assessment of problem level getting medication prescribed for their child.	Big problem, small problem, no problem
Getting Specialized Services	Parent/family assessment of problem level getting medical equipment, devices, or specialized therapies needed by child	Big problem, small problem, no problem
Family Centered Care		
• Part A: *Personal Dr / Nurse who Knows Child*	Parent/family report on whether child's personal dr or nurse knows child/family and impact of child's condition on the child and family	Yes / no*
• Part B: *Shared Decision making*	Parent/family report on experiences being actively involved in decisions about child's health and health care by child's doctors/providers	Never, sometimes, usually, always**
• Part C: *Getting Needed Information about Child's Health*	Parent/family report on experiences getting information from doctors/providers about their child's condition	Never, sometimes, usually, always**
Coordination of Care & Services	Parent/family report on whether they receive help from child's providers to coordinate child's care among multiple providers and/or the school system.	Yes / no*

* The versions of these questions tested in the Phase III field test used the 'never, sometimes, usually, always" response task.

** Earlier versions of these questions were tested in the Phase III field test. Data for the final versions of the questions in these composites will be available for analysis Summer 2001.

CSHCN consumer reporting measures

As with the standard CAHPS composites, conceptual and empirical criteria were both taken into account when organizing the CSHCN Question Supplement items into consumer reporting measures. Conceptual organization served as the primary basis for the Getting Prescription Medicine, Getting Specialized Services, and Coordination of Care composites. The items included in each of these composites assess conceptually related experiences or needs for services that are independent of each other. For example, the need for medical equipment; the need for physical, occupational or speech therapy and the need for treatment or counseling for an emotional, developmental or behavioral problem are distinct service needs, yet related conceptually by being highly important services to the individual children who need them.

About 50% of CSHCN in the Phase III field test needed at least one of these specialized services (vs. 9% of non-CSHCN) and 75%of the CSHCN that had a need for specialized services only needed one of these three services during the six months previous to the survey. On the other hand, prescription medication was needed or used by 80% of the CSHCN group during the six months preceding the survey. One option considered was to combine prescription medicines with the other specialized services. However, when examined empirically, the large proportion of CSHCN reporting on prescription medicines tended to obscure performance information specific to other specialized services. Consumer focus group input and review of the literature both emphasized the importance placed by families of CSHCN on information about access to the specific specialized services assessed through the CSHCN Question Supplement. As a result, getting prescription medicine was separated from the other specialized services content as a reporting measure of its own.

The Family Centered Care composite has three separate components assessing different aspects of family centered care. The three components are organized according to focus of evaluation (part A: Child’s personal dr/nurse vs. parts B & C: Child’s drs or other health care providers) and conceptually by care topic (e.g. shared decision-making vs. information pertinent to a child’s health issues). Earlier versions of these components were tested in the Phase III field test. The inter-item correlation for the items making up each component ranged from .49 to .79. When examined together as a composite, the three Family Centered Care components exhibited strong internal consistency (standardized Cronbach's alpha = .77). Data for the final version of the Family Centered Care composite components will be available in early Summer 2001. Similar results are expected based the findings from the earlier versions and those reported by researchers who have used similar questions in other studies.

In both the Phase I and III field tests, the consumer reporting quality of care information contributed by the CSHCN composites was unique and not highly redundant of that provided through the standard CAHPS composites. In the Phase III field test, correlation between the CSHCN composites and the CAHPS composites that assess experience of care (how well drs. communicate, getting care quickly, getting needed care) ranged from .17 to .65. (See Table 4 on under Criterion #5 for more detail).

CSHCN consumer reporting measures and testing with target audiences

As a part of the Phase III state-wide Medicaid managed care field test, a health plan quality report based on the data collected through CAHPS 2.0H Child Survey with CSHCN Module included was prepared and sent to Medicaid clients throughout the State. The standard CAHPS composites and a version of the CSHCN composites were reported separately for children identified as having special health care needs by the CSHCN Screener (a copy of the health plan quality report can be found in Appendix G). An independent contractor using the Control 21 scoring program available to CAHPS users prepared the report. The standard CAHPS scoring program was easily adapted to create the version of the CSHCN composites included in the report.

The health plan quality report was distributed statewide to Medicaid clients during the Fall 2000 open enrollment period. During late spring of 2001, the State Medicaid Administration conducted focus groups with Medicaid clients that included getting feedback on the health plan quality report. The findings from these groups are still being analyzed and should be available soon.

Remaining issues

Even though progress continues in terms of the accurate, meaningful scoring and presentation of the quality information to consumers, much more remains to be learned. This is the case for consumer-reporting information generated by the CSHCN Module, as well. A number of issues are relevant and with noting:

- More work remains to determine the most meaningful ways to present health care quality information to consumers. The health plan report generated as a result of the Phase III field test used a relative scoring approach which does not take into account the overall level of performance. For example, all the health plans in the report received a “two star” or average rating in terms of performance in coordination of care. In reality, overall performance by plans in this area was dismally low; a factor not communicated by the presentation format and scoring approach.

- Conversely, the performance by many plans was high and relatively uniform in other areas such as “getting needed care.” The report did not capture this information. Instead, a plan’s performance was only presented in relation to others in the group without providing the important context about where all the plans fell relative to the “best” performance possible.

- It was a tremendous accomplishment to have information about care received by CSHCN distributed to actual consumers using real data about performance. However, as is often the case, success raises more issues. These include:

    a) The Phase III field test collected data for an earlier version of the Family Centered Care components. The final version of the components will be confirmed when data becomes available during Summer 2001.

    b) The earlier versions of the items in part A of the Family Centered Care composite and the Coordination of Care composites used either “never, sometimes, usually, always” or problem assessment response tasks. As a result of the consensus process with CAHPS researchers, these items now use “yes/no.” How these revisions perform in the field and how results ultimately should be scored will be determined once data are available this summer.

    c) The final version of the CSHCN Question Supplement includes questions about shared decision making and getting needed information about children’s health that are relevant to all families, not just those with CSHCN. Because the filter or ‘gate’ questions included in the final version make it possible to more accurately identify respondents to whom these topics apply, it maybe appropriate to report these measures for all children to whom they apply and not just CSHCN. Again, data will be available soon to examine this option.

Criterion 4 – Simplifying the cognitive task of responding to questionnaire items

In February and March of 1999, a round of cognitive testing and a readability assessment were conducted prior to the Phase I field test of the draft versions of the CSHCN Module and the CSHCN Question Supplement (see Table 4 under Criterion #5). The results of each are summarized below.

I. Cognitive Testing

The goals for the cognitive testing of the draft versions of CSHCN Screener and the CSHCN Question Supplement included determining whether respondents understood the items, response choices and skip pattern instructions as intended and whether answers given by respondents reflected what the questions were designed to measure. As previously described, the CSHCN Screener and CSHCN Question Supplement were developed for use in conjunction with the core CAHPS 2.0 Child Survey. Determining how the screening tool and supplemental questions performed when integrated into the standard CAHPS 2.0 Child Survey was an additional testing objective.

Design and Methods:

A) Nine in-depth one-on-one interviews completed.

- The local chapter of “Family Voices”, a national organization representing families of children with special health care needs, identified potential interviewees from among its membership and made the initial phone contacts.
- Nearly every family contacted agreed to the interviews and supplied phone numbers. CAHMI research staff made the follow up contact to schedule the interview.
- 7 interviewees were mothers of children with an established chronic or special health need representing a range of cognitive, physical and developmental conditions varying in level of severity and functional impact (children’s ages ranged from 18mos. to 14 years old).
- 2 interviewees were mothers of children, both 6 years old, who did not have any chronic or special health needs.
- A range of SES backgrounds and reading abilities were represented.

  - All children had HMO coverage either through Medicaid or private insurance. Some of the children also had additional benefits through Medicaid/SSI.

B) Each interviewee completed a paper and pencil version of the CAHPS 2.0H Child Questionnaire with the CSHCN Screener and Supplemental Questions integrated at appropriate places throughout the survey.

  - In the interest of time, only the sections of the CAHPS survey in which supplemental or screener items had been integrated were tested.

  - The following sections of the CAHPS 2.0H Child Questionnaire were omitted from the cognitive testing version as no new questions had been integrated:
    “Getting Health Care from a Specialist”
    “Calling Doctor’s Offices”
    “Your Child’s Health Plan.”

  - The time taken by interviewees to complete the cognitive interview version of the survey ranged from 10 to 23 minutes.

  - All but two of the interviews were conducted in the homes of the interviewees. The interviews lasted from 11/2 to 2 hours and participants were paid $40.00 in appreciation for volunteering

C) Once the survey was completed, the interviewer went over each question with the respondent using “think aloud” techniques accompanied by a series of specific probes to gain an understanding of the interviewee’s interpretation of the questions and thought processes used to arrive at the answers chosen.

    - The “think aloud” process and question probes were used for all survey questions, including the items from the core CAHPS 2.0H Child Survey.

An in-depth summary of the interview findings and a copy of the instrument used during the cognitive tests are included in Appendix H. Also included under Appendix H is the February 22, 1999 memo from CAHMI researchers to CAHPS research team outlining a series of recommendations based on findings from the cognitive interviews conducted prior to the Phase I testing of the CSHCN Screener and CSHCN Question Supplement.

A. *CSHCN Screener*

The CSHCN Screener tested in the cognitive interviews conducted by CAHMI researchers was the pilot version of the tool comprised of three, two-part questions, one of which utilized a checklist format. This version represented a second iteration of the screening tool, incorporating refinements based on two small pilot studies fielding an earlier version by telephone and mail.

Key cognitive interview findings–pilot version of CSHCN Screener

(The question numbers referenced are from the cognitive testing instrument included in Appendix XX)

- The seven children in the sample whose health profiles qualified them as having chronic or special health needs were positively identified based on parent responses to the screening tool. Conversely, the two children in the sample without histories of chronic or special health needs screened negatively on the screener questions.
- Interviewees described the screening questions as "clear, to-the-point, easy to answer." Several interviewees made comments such as "finally, something about my child!" or " this is describes (child's name) to a tee."
- All interviewees correctly followed the skip pattern format used by the three, 2-part questions and were able to answer all the screening questions without assistance.
- The "check list" approach used in Q80 appeared to work well and interviewees did not have problems understanding the terms used in the list. The terms: IFSP, IEP or IWRP were immediately recognized by parents whose child had one of these special education plans. Parents whose children did not have one of these plans also had no trouble recognizing that to be the case.
- When probed regarding how they arrived at their responses for Q79 and Q82, all interviewees described arriving at their answers about their children's functional status and service use by comparing their child along these dimensions using other children the same age as their child as the reference point. This appeared to be a familiar way of thinking as all interviewees readily and easily described exactly in what ways their child was similar or different from others of his or her own age in the specific areas of functional limitations and the need or use of medical, educational or mental health services.
- The need for a response option for those who did not check "YES" to any of the items listed in Q80 became apparent, and it was added before the screener was fielded in the Phase I studies.

More recently, the final version of the CSHCN Screener fielded in the Phase II and III field tests (see Table 4 under Criterion #5) was cognitively tested in a study conducted by Westat. Key findings reported by Westat in an April 9, 2001 memo to the Agency for Healthcare Research and Quality (AHRQ) are summarized below.

Key cognitive interview findings–Final version of CSHCN Screener

- Based on the findings described in the memo, respondents appeared to interpret the screening questions as intended and were able to appropriately follow the "gate" questions and skip patterns used by the screener.

- The final version of the CSHCN Screener was easily and appropriately answered by the respondents in both English (n = 8) and Spanish (n = 9).

B. *CSHCN Question Supplement*

As with the CSHCN Screener, the version of the CSHCN Question Supplement tested in the CAHMI cognitive interviews was the draft version subsequently piloted in the Phase I field test. The goal was to develop a set of questions able to be easily integrated into the CAHPS 2.0 Child Survey. Consequently, the wording, response options and formatting of the draft CSHCN Question Supplement followed as often as possible the conventions already used by the CAHPS survey. In some cases, the questions included in the draft version of the CSHCN Question Supplement were items taken from the CAHPS 2.0 Child Supplemental Questions and revised or reworded on the basis of expert input and review.

Because of the close adherence the standard CAHPS wording and response formats, findings from the cognitive interviews for items comprising the CSHCN Question tended to fall into two categories: (a) those directly related to the standard CAHPS wording or response option conventions, and thus, not open to revision and (b) findings specific to the content or formatting of the CSHCN questions, which could be used as the basis for revisions or refinements.
The key findings from the cognitive interviews with the draft CSHCN questions are organized around these categories.

Key cognitive interview findings–pilot version of CSHCN Question Supplement

1) Findings related to standard CAHPS wording or response option conventions also used by the CSHCN Question Supplement items: (In order to maintain compatibility with the CAHPS surveys, no revisions were made to CSHCN items based on these findings).

    (The question numbers referenced are from the cognitive testing instrument included in Appendix H)

    - Although most interviewees initially found the terms “personal doctor or nurse” in the section “Your Child’s Personal Doctor or Nurse” (questions #5-11) to be confusing or ambiguous, they eventually were able to arrive at a correct interpretation.

        a) When probed, 7 of the 9 interviewees preferred the wording “primary doctor”, indicating that it was less confusing and more clear about who was being asked about. Interviewees may have been more familiar with this concept or term because of having HMO coverage.

    - Six of the nine interviewees indicated the “big problem; small problem; no problem” sequence used by many CAHPS questions (and also used by a number of CSHCN questions, as well) did not capture their experience adequately and that an “in-between” choice was needed.

        a) When probed, interviewees who had what they considered to be an in-between big and small problem experience consistently defaulted downward to the “small problem” response rather than upward, suggesting that actual plan performance may not be reliably reflected by the response choices offered.

    - When answering the CAHPS questions (and similarly worded CSHCN questions) asking respondents to report about “your child’s doctors or other health providers” (Q32-38), 8 of the 9 interviewees expressed confusion over WHO to focus on or answer the questions about. This was especially the case for those interviewees whose children had multiple providers including specialists, OTs, PTs, speech therapists, etc.

        a) Interviewees took one of two approaches to solving this dilemma: they either averaged across ALL the providers who saw their child (dr, OT, PT, hospital, ER staff, nurses) OR they picked one of these providers to focus on when answering a specific question.

        b) Interviewees, however, did not consistently choose the same focus of evaluation for each question but went back and forth between averaging across providers and focusing on one provider depending upon the content of the question, its relationship to and saliency vis a vis other recent experiences.

- Respondents interpretations of the “gate” question (Q36) asking respondents whether .” . . . your child (is) old enough talk with doctors about his or her health care” were varied and inconsistent, leading to some respondents inappropriately answering or not answering question 37 that followed concerning how often the child’s doctors or other health providers explained things in a way that the child could understand.

    a) One respondent answered Q36 “NO” and skipped Q37 even though her son was a normal 6 year old because “she is the one who talks to the dr about the care given to her child.”

    b) Other mothers whose children were “old enough to talk” but who had disabilities that prevented verbal communication answered “NO” to Q36 but also ignored the skip pattern and answered Q37 as “YES” “because the doctor did explain things in way their child could understand” even though the child could not communicate verbally.

2) Findings related to content or formatting specific to the CSHCN Question Supplement items, all of which were open to revision or refinement:

(The question numbers referenced are from the cognitive testing instrument included in Appendix H)

- Based on LWI Task Force input, other expert review and revisions suggested by CAHPS/CSN researchers, new wording and response set options were tested for Q8 and Q9: Child’s personal doctor or nurse’s understanding of affect of child’s health conditions on child’s and family’s day-to-day life:

    a) Original “YES/NO” response options replaced with: “Not at all; Some; A great deal.”

    b) About half of interviewees chose the “Some” responses, often giving the explanation that “people can really try, but no one, not even my child’s doctor can REALLY understand what it is like for my child or me or our family on a day-to-day basis. You have to live it to do that.”

    c) The “Not at all; Some; A great deal” response set was tested in the Phase I studies. However, the final version of the CSHCN Question Supplement returned to the YES/NO response options for these questions in order to maintain response set congruency with other items in the “Personal dr or nurse who knows child and family” composite measure score. The cognitive findings in “b” helped guided this revision.

- Based on LWI Task Force input, other expert review and revisions suggested by CAHPS/CSN researchers, new wording and response set options were tested for Q34: Reassurance and support by child's doctors or other health providers about care parent/caregiver provides for child:

    a) Original "YES/NO" response options replaced with: "Never; Sometimes; Usually; Always" and wording changed from : "does your child's personal dr offer….?" to "how often did your child's personal dr/nurse offer…."

    b) On the basis of the item reduction analysis conducted with Phase I test data, this item was eliminated from the final version of the CSHCN Question Supplement.

- Based on LWI Task Force input, other expert review and revisions suggested by CAHPS/CSN researchers, new wording and response set options were tested for Q44-46: Coordination of care between school and child's health providers.

    a) Original "YES/NO" response options replaced with: "No problem; Small problem; Big problem" and wording changed from : "does your child's doctor's ….?" to "how much of a problem was getting your child's doctors. . . ." The term "child care" was added since many children often spend as much of their day in childcare as they do in school.

    b) Of the 6 interviewees whose children fit the criteria for answering Q46 (getting the dr. to work w/ child's school/childcare to understand their child's special health needs), ALL chose the response option "not a problem" <u>because it was they, themselves</u>, not their child's doctor, who helped the teachers, school, child care understand their child's health related needs.

    c) This pattern of response suggests that this question may not be measuring actual provider performance either a "NO" or "NO PROBLEM" answer could be interpreted as either "NO: not a problem because parent is the one who does this" or "NO: the doctor doesn't help and it is a problem."

    d) Findings from these interviews help guide the final version of this question which includes the addition of a 'gate' question asking parents if they needed a doctor or other health provider to contact a school or daycare center about their children's health or health care, and if YES, whether they received the help they needed from their children's doctors to do so.

- Wording in Q49 changed from “written directions” to “written care plan.”

    a) This item was not retained in the final version of the CSHCN Question Supplement because of the current lack of evidence linking written care plans to health outcomes for children other than those having asthma.

- The use of the CAHPS wording: “How often do your child’s doctors or other health providers . . . . “ in the CSHCN items asking about family/patient education (Q39-51) led to the same issues concerning the focus of evaluation as described under the CAHPS-specific findings. (see the third bullet under the Findings #1 above).

- A new series of questions asking about access to specialized services (Q53-60: Access to special medical equipment, therapies, home health services and/or treatment or counseling for emotional, developmental or behavior) were tested with respondents.

    a) Although they easily understood the content of the specialized services questions, interviewees did not always limit their evaluation to services obtained through their child’s health plan (“How much of a problem getting _____ through your child’s <u>health plan</u>”), especially when a child received multiple services from a number of sources.

    b) When probed, interviewees were very able to distinguish between what was covered by their child’s health plan and what was not (e.g. durable medical equipment vs. diapers for older children). However, they did not always make this distinction when answering the questions and sometimes corrected their answers during the de-briefing interview.

    c) These findings, in combination with many rounds of expert input by NCQA’s Technical Advisory Committee and other measurement experts, led to the revisions and rewording of these items included in the final CSHCN Question Supplement.

    d) The strong expert and family consensus around the importance of providers and/or health plans being accountable at the very least for making an attempt to help families link up with community or other resources to obtain the services needed by their CSHCN, regardless of the underlying benefit structure covering such services, is reflected in the final version of the Getting Specialized Services question sequences. The wording “from your child’s health plan” has been dropped and respondents indicating they experienced either a big or small problems are asked if anyone from their child’s health plan, doctor’s office or clinic tried to help them with this problem.

II. Readability Assessment

The overall reading level and word complexity of the draft versions of CSHCN Screener and the CSHCN Question Supplement fielded in the Phase I studies were assessed by an independent consultant specializing in health and health care related documents. The draft versions of CSHCN Screener and the CSHCN Question Supplement exhibited an overall eighth grade reading level or “good for average adults.” Overall, 5 percent of the words used in the draft versions of CSHCN Screener and the CSHCN Question Supplement were classified as “complex”, contributing to the eighth grade reading level. For the most part, these complex words were related to health issues (e.g. conditions, behavioral, emotional, etc.) or health care-related experiences (e.g. appointment, treatment, equipment, medicines, etc.). Less complex substitutes do not exist for most of these terms. Use of words such as these in a survey about children’s health and health care helps to lessen the cognitive burden by placing their meaning within that context. A summary of the assessment results is included in Appendix I.

The consultant conducting the readability assessment suggested the single follow up question used by the draft CSHCN screener might be split into two parts to further minimize the cognitive task. This recommendation was incorporated into the final mail and telephone versions of the CSHCN Screener fielded in the Phase II and III field tests.

Criterion 5 – Employing a field test

The development of the CSHCN Module involved several phases of field-testing resulting in a grand total of 36,561 cases of data. In over 14,000 of these cases, the CSHCN Screener and Question Supplement were administered by mail and telephone in conjunction with the core CAHPS 2.0H Child Survey (Medicaid and commercial versions). Table 4 provides an overview of the field-testing conducted.

Table 4: CSHCN Screener and Question Supplement — Summary of fielding testing

PHASE I: Field trials in 4 health plans (mail & phone)

- 2 commercial HMOs; 1 Medicaid HMO, 1 mixed model MCO
- Administered in conjunction with the CAHPS 2.0H Child Survey
- 1,995 surveys collected
- 52.7% response rate*

PHASE II: Validation of CSHCN screening tool (phone only)

- 1 mixed model MCO; 2 national samples
- 22,423 cases collected
- CASRO rate: 68.4%

PHASE III: WA State Medicaid Pilot Study (mail & phone)

- 9 Medicaid HMOs; 1 FFS/SSI sample
- Administered in conjunction with the CAHPS 2.0H Child Survey
- 12,143 surveys collected
- 57.7% overall response rate (range across the nine health plans in the study: 44% to 57% , unadjusted; 49.5% to 61% , adjusted*)

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* Standard HEDIS/CAHPS response rate calculation (complete surveys / total eligible sample) HEDIS 1999, Vol. 3

The following provides a high level summary of the key field-test findings for each component of the CSHCN Module. More extensive descriptions and in-depth results from the field testing can be found in Bethell, Read, Stein et al. 2001 and Bethell, Read, Neff et al. 2001.

A. *CSHCN Screener*

At the outset of the CSHCN Module's development, a brief, survey-based method for identifying CSHCN for the purposes of quality assessment and reporting was not available. One of the major goals of the CSHCN Module field studies was the testing and validation of a short screening tool, administerable by either mail or telephone, with the capacity to identify the range of children having chronic or special health care needs while minimizing the number of "false positives."

The CSHCN Screener underwent three phases of validation and testing (see Table 4). Results from the first fielding of the pilot version of the screening tool in four health plan samples led (Phase I) led to the following modifications:

- To improve readability and reliability, the “checklist” format was removed and two service use items added in its place.
- To reduce cognitive burden and allow consistency during mail and telephone administration, the single follow-up item asking about the presence and duration of a health condition was split into two questions.
- Final wording and formatting edits were made to ensure compatibility with the CAHPS 2.0 Child Survey.

The final version of the CSHCN Screener, consisting of five survey items addressing specific health consequences, was fielded during the Phase II and III studies. Testing included:

- Comparison with the Questionnaire for Identifying Children with Chronic Conditions–Reduced version (QuICCC-R) in a nationally representative sample during the first SLAITS CSHCN Survey pretest (n = 2,420).
- Comparison with the administrative data-based 3M-Clinical Risk Groups system (CRG’s) and the QuICCC-R in a mixed model managed care sample (n = 496).
- Fielding in a second nationally representative sample during the final pretest for the SLAITS CSHCN Survey (n = 19,507) and in a statewide sample of children either enrolled in Medicaid managed care (n = 10,560) or receiving Medicaid through SSI eligibility (n = 1,583).
- Administration in conjunction with the CAHPS 2.0H Child Survey (English and Spanish) in nine different managed care plan samples.

Key findings–CSHCN Screener

As expected, significant variations were found in the proportion meeting the CSHCN screening criteria according to the age, gender, race/ethnicity and insurance status of the child. Differences observed were similar to those found by other researchers. Overall, the CSHCN Screener identified:

- 15.3 – 16% of children age 0-17 in the population-based national samples
- 21% of children age 0 – 12 yrs enrolled in Medicaid managed care health plans through TANF (range across nine health plans sites: 17% – 25%)
- 95% of children age 0 - 12 yrs enrolled in Medicaid through SSI

Compared with other methods, the CSHCN Screener agreed with both the QuICCC-R and the CRG algorithm approximately nine out of ten times on whether or not a child was identified as having a special health care need (PPV = .93 and .67, respectively). The brief CSHCN Screener discriminated among children with and without chronic conditions, those with poorer parent-reported health status and higher and more complex health services needs. It did not appear to systematically miss children with special health care needs according to the type or severity of health conditions or demographic characteristics of children when compared with other recognized methods.

The CSHCN was found to be both a feasible and an efficient method for identifying CSHCN in the context of a large-scale mail or telephone survey:

- The CSHCN Screener takes approximately 1-2 minutes to administer.
- No differences in proportion of children identified were noted according to whether the screening tool was self-administered by mail or interviewer-administered by telephone.
- The addition of the CSHCN Screener to the CAHPS 2.0H Child Survey did not have an adverse effect on response rates. In fact, the overall response rate for the state-wide Medicaid managed care study (57.7%) exceeded by 7 - 9 percentage points the statewide response rates obtained in previous years using the core CAHPS Child Survey alone.

Means scores on the standard CAHPS composite measures were compared for children within the same health plans who met and not meet the CSHCN Screener criteria. Significantly poorer performance on one or more measures of care for CSHCN was observed within each of the nine health plans participating in the study. These findings support the hypothesis that children identified by the CSHCN Screener represent a group for which separate quality assessment is appropriate (for a summary of these findings, see Appendix K).

B. *CSHCN Question Supplement*

As previously described, the CSHCN Question Supplement is comprised of 31 questions assessing four new quality domains highly relevant to CSHCN and their families. The use of filter or gate questions identifying the appropriate respondents for each item or set of items allow the questions to be included in the core CAHPS 2.0 Child Survey. After data collection is completed, survey responses to the CSHCN Screener are scored and children meeting the CSHCN criteria identified. The CSHCN-specific measures based on data collected through the CSHCN Question Supplement are calculated for this group only.

During the Phase I testing, assessments of the convergent and divergent validity of the CSHCN Module survey items were guided by several hypotheses. Expectations for how families of children with chronic conditions would answer the survey versus those whose children did not have a chronic condition were examined, as were hypotheses concerning how parents answering one question a certain way would be expected to answer a different question. Where hypotheses were not confirmed or only weakly supported, survey items were deleted (e.g. written care plan items; level of symptom management; partnership with provider) or reconstructed and reevaluated (e.g. coordination of care items). Correlation among items within scales and between scales and items across scales was reviewed and informed the final selection of the minimum set of survey items for the next phase of testing.

In addition to re-assessing the divergent and convergent validity and reliability of the survey questions, Phase III testing also examined the capacity of the CSHCN-specific measures to discriminate performance across health plans and to indicate opportunities for improvements in performance.

Key findings–CSHCN Question Supplement

- Incorporating the 31-item CSHCN Question Supplement into the core CAHPS 2.0H Child Survey did not adversely effect overall response rates or response rates in English or Spanish:

  a) About 10% of the surveys in the Phase III field test were collected in Spanish. Response rates for the English and Spanish versions of the survey were nearly equal, with overall adjusted response rates of 57.6% and 58.6%, respectively.

  b) Response rates in English and Spanish for the CAHPS 2.0H Child Survey with the CSHCN Question Supplement included exceeded by 7 – 9 percentage points the previous statewide response rates obtained using the core CAHPS Child Survey alone.

  c) Reliability as measured by Cronbach's alpha was well within an acceptable range (.65 or above) for all survey scales represented in the CSHCN-specific measures.

- The "new" CSHCN-specific quality information calculated from the CSHCN Question Supplement is not highly redundant with existing CAHPS composites (Table 5).

Table 5: Correlation (Pearson r): CAHPS composites and CSHCN measures

	CAHPS: How Well Drs Communicate	CAHPS: Getting Care Quickly	CAHPS: Getting Needed Care
CSHCN: Getting Rx Medicines	.17**	.17**	.27**
CSHCN: Getting Specialized Services	.31**	.26**	.46**
CSHCN: Family Centered Care Components	.58 - .65**	.38 - .50**	.28 - .38**
CSHCN: Coordination of Care & Service	.46**	.35*	.35**

* p≤.01; ** p≤.000 Statewide Medicaid Managed Care Study, CAHMI 2000

- Significant variations in care quality for CSHCN on both the CAHPS composites and CSHCN-specific measures were found across the nine health plans in the Phase III field test (Table 6 below; for a more detailed summary, see Appendix K).

Table 6: Variations in care quality for CSHCN across health plans
(Anova results for mean scores across 9 health plans)

	F value ranges (9 sites)
Standard CAHPS composites	12.6 – 4.4 (p's $\leq$ .000)
CSHCN measures	7.3 – 3.6 (p's $\leq$ .001)

- Although within-plan performance for children with and without a chronic or special health care needs often varied significantly in the Phase III statewide Medicaid study, a consistent pattern of poorer performance for CSHCN was not observed.

  a) The CSHCN groups in some health plans reported significantly better performance for certain measures.

  b) In some plans, no significant differences in care between CSHCN and non-CSHCN were found on measures for which significant differences were observed in other plans. See Appendix K for summary tables.

- The margin of health plan controllability and the opportunity for improvement at the health plan level concerning the aspects of care quality assessed by the CSHCN-specific measures are supported by the following:

  a) Care quality for CSHCN was not found to be uniformly lower in every plan and, some cases, care for CSHCN actually outperformed that for non-CSHCN in the same plan.

  b) Demographic and health-related variables made a relatively small contribution to the individual variations in performance observed for the CSHCN group on both the CAHPS composites and CSHCN-specific measures (average adjusted R^2 across all measures = .04; see Appendix K for summary tables).

C. *Prescreening Algorithm and Enriched Sampling Strategy*

The low overall prevalence of children with chronic or special health care needs (15 – 21%) in the general child population has implications for sample sizes necessary under some applications, such as HEDIS, to achieve the numbers of CSHCN targeted for statistical or other purposes. An optional enriched sampling strategy with the capacity to reduce the overall sample sizes required under such circumstances by increasing the number of children in the sample with a higher potential of meeting the CSHCN Screener was developed and tested as part of the CSHCN Module field testing.

Administrative encounter records from each health plan participating in the Phase III field test were used to identify a cohort of children having a higher potential of meeting the CSHCN screening criteria. Using a pre-specified list of ICD-9 codes, administrative data over a 24-month period for all CAHPS survey eligible child members were examined for the presence of diagnostic codes indicative of a probable chronic or special health need (See Appendix B for list of diagnostic codes used in the prescreening algorithm).

Based upon the prescreening results, each CAHPS survey-eligible child member was assigned one of three statuses:

1) No encounter records found
2) Encounter records DO NOT MEET criteria for having a probable chronic or special health need
3) Encounter records MEET criteria for having a probable chronic or special health need.

After prescreening statuses were determined, a stratified sample was randomly drawn in each plan. First, the standard CAHPS starting sample of 1,050 eligible Medicaid child members per plan was selected. After the standard CAHPS sample had been drawn, the remaining eligible Medicaid child members in each plan were subset to ONLY the group who met the prescreening criteria for having a probable chronic or special health need (Prescreen Status Group #3). A second random sample of up to 1,500 per plan was selected from this group. The CAHPS 2.0H Child Survey with the CSHCN Screener and Question Supplement included was administered to all households in both samples (see Appendix M). Diagrams in Appendix J illustrate the standard CAHPS sampling protocol and the enriched sampling approach used in the Phase III field test.

Key findings–CSHCN Prescreening Algorithm and Enriched Sampling Strategy

- 8 – 11% of CAHPS survey eligible children across the 9 health plans participating in the Phase III field test met the "prescreen" criteria (1 or more dx codes from list)

- No differences were found in mail or telephone survey response rates according to whether the child did or did not meet the prescreening criteria.

- The most commonly occurring diagnoses among the group meeting the prescreen criteria were: asthma (31%), ADHD/ADD (12%), congenital anomalies (11%), hearing loss (10%), mental health issues including depression, neuroses, eating disorders, substance abuse (9.8%) and developmental delay (8%)

- The prescreen algorithm successfully and reliably identified children with a higher potential of meeting the survey-based CSHCN Screener criteria across the different health plans in the study:
  a) Overall, 52% of children identified by the ICD-9 code prescreening criteria as having a probable chronic or special health need met the survey-based CSHCN screening tool.

  b) The percentages of children in the prescreen group meeting the survey-based CSHCN Screener criteria were fairly consistent across the nine health plans in the study (range: 51% to 58%).

- Use of the prescreen algorithm and the enriched sampling strategy did not appear to create a bias in the specific criteria on which children from different health plans qualified on the CSHCN Screener (Table 7):

Table 7: Percentage of children in the prescreened sample having qualifying answers to specific CSHCN Screener questions / criteria

CSHCN Screener question / criteria	% overall of prescreen group having qualifying answers to specific CSHCN Screener criteria (range across 9 plans)
Q1: Prescription medication	27..3 – 30.8%
Q2: Service use/need above routine	19.4 – 22.6%
Q3: Functional limitations	11.7 – 13.6%
Q4: Need/ use of specialized therapies	5.0 – 7.5%
Q5: Tx or counseling for emotional, behavioral or developmental problems	15.5 – 18.2%

Criterion 5 – Provide an explicit reference period or event

A. *CSHCN Screener*

Conceptually, the CSHCN Screener uses consequences-based criteria to screen for children with chronic or special health needs (see Appendix A for a copy of the screening tool). To qualify as having chronic or special health needs, a specific health consequence experienced by a child must be due to a medical or other health condition having a duration or expected duration of the condition of 12 months or longer.

Options considered regarding the reference period for the duration or expected duration of a reported health consequence included three, six and twelve months. No research comparing these options or supporting a specific length of duration was found in the literature. After a series of deliberations, the Living With Illness Task Force Advisory Group recommended the 12 months or longer time period used by the CSHCN Screener for two reasons:

- The well-tested Questionnaire for Identifying Children with Chronic Conditions (QuICCC) upon which the shorter CSHCN Screener is conceptually based uses a 12 month reference period for the duration of a child's health condition.

- The pediatrician developers of the QuICCC explicitly chose the 12 month reference period based on clinical experience that suggested a shorter reference period would tend to over-identify children with injuries, surgeries and other self-limiting conditions.

In addition, findings from the cognitive testing and from field tests comparing CSHCN Screener results to chart review and administrative record data and parents' verbatim naming of children's health conditions, all strongly supported the validity and sensitivity of using a 12 months duration as the criteria for having a chronic or special health care need.

B. *CSHCN Question Supplement*

As described in previous sections, the CSHCN Question Supplement was explicitly designed for compatibility with and integration into the CAHPS 2.0 Child Survey. As such, all the CSHCN supplement items use the same 6 or 12-month reference period used by the version of the CAHPS survey into which they have been inserted. The CSHCN Question Supplement was tested in the contexts of both the privately insured and Medicaid versions of CAHPS 2.0H Child Survey during the Phase I and Phase III field testing.

Criterion 7 – Explicitly identify persons to whom particular questions apply

A. *CSHCN Screener*

Respondents' answers to the CSHCN Screener are used to identify the group of children for whom the CSHCN measures apply. The CSHCN Screener is included in the CAHPS 2.0 Child Survey and all survey respondents answer the five of the screening questions. After data collection has been completed, respondents' answers to the CSHCN Screener are scored and children meeting the CSHCN criteria are identified.

The CSHCN Screener uses consequences-based criteria to screen for children with chronic or special health needs. To qualify as having chronic or special health needs, the following set of conditions must be met:

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

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

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

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

All three parts[1] of at least one screener question (or in the case of question 5, the two parts) must be answered "yes" in order for a child to meet CSHCN Screener criteria for having a chronic condition or special health care need. Any child qualifying on one or more of the five screening questions becomes part of the denominator for which the CSHCN measures apply.

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[1] CSHCN screener question 5 is a two-part question. Both parts must be answered "yes" to qualify.

In addition to the number of qualifying screener items, children can also vary as to the type and combinations of screening criteria upon which they qualify. A description of these variations and a discussion of using such information can be found in Bethell, Read, Neff et al. 2001.

Skip pattern analysis — CSHCN Screener

Because the skip pattern wording and format of the CSHCN Screener differ somewhat from the standard conventions used in the core CAHPS 2.0 Child Survey, there were concerns about respondents' ability to correctly follow the 'gate' or filter question directions for these items. The patterns of appropriately and inappropriately answered or skipped responses and the missing values rates to the CSHCN Screener items were examined and compared with those for the items comprising three of the standard CAHPS composites. As can be seen in Table 8, respondents successfully followed the skip pattern format and wording of the CSHCN Screener as often or more often (94.3% vs. 90- 92.3%) than for items using standard CAHPS 'gate' or filter question wording and formats.

Table 8: Comparison of "skip pattern" performances for items from the CSHCN Screener and the CAHPS composites

Phase III Statewide Medicaid Study — 1st Interim dataset
(n = 841)

	CAHPS: How well drs communicate	CAHPS: *Getting care quickly*	CAHPS: *Getting needed care*	*CSHCN Screener*
(Mean % across all items in composite)	5 items	4 items	4 items	5 items / 14 components
% responding appropriately *(appropriately answered or skipped items)*	90.0%	92.3%	91.0%	94.3%
% responding inappropriately *(inappropriately answered items)*	2.5%	1.8%	3.1%	2.4%
% skipping inappropriately *(inappropriately skipped items)*	3.0%	3.5%	3.0%	1.8%
% missing values *(no response to item)*	3.6%	2.3%	3.2%	3.7%

B. *CSHCN Question Supplement*

In keeping with the conventions used in the core CAHPS 2.0 Child Survey, the CSHCN Question Supplement uses ‘gate’ or filter questions to identify and direct respondents who have had a particular experience to answer to a question or series of questions applying specifically to that experience. All the filter questions used in the CSHCN Question Supplement follow the format and wording established in CAHPS 2.0 Child Survey. Appendix L lists the CSHCN Question Supplement filter questions in the order they appear when integrated into the core CAHPS 2.0 Child Survey. The item or items for which it is meant to identify appropriate respondents follow each filter question.

Criterion 8 – Provide for multiple administration modes

During the Phase III field test, the CSHCN Screener and CSHCN Question Supplement were integrated into the CAHPS 2.0H Child Survey and administered by mail or telephone to over 10,000 parents of children enrolled in Medicaid managed care. The standard CAHPS 2.0H survey administration protocols were used for both the mail and telephone data collection (NCQA 1998). The survey vendor contracted by the State in which the Phase III study was conducted had undergone the CAHPS survey administration and data collection certification process required by the National Committee on Quality Assurance (NCQA). A copy of the survey instrument used in the Phase III field test is included under Appendix M.

Approximately 80% of the surveys were collected by mail, the remainder through telephone interview. Households listing Spanish as the first language were given the option of responding in either English or Spanish. Surveys for about 10% of the sample were collected in Spanish.

The Phase III field test provided the first opportunity to examine mode effect for the final version of the CSHCN Screener. Analyses of this type focused on the performance of the screening tool according to mode of administration.

C. *CSHCN Screener*

To examine the effect of mail versus telephone administration of the screening questions, the proportions of children identified by the CSHCN Screener according to administration mode were compared for three groups: (a) the standard CAHPS sample with surveys collected in English (b) the prescreened sample with surveys collected in English (c) the standard CAHPS and prescreen samples with surveys collected in Spanish.

As shown in Table 9 on the following page, the proportions of children identified by the CSHCN Screener did not vary significantly by mail or telephone for either the English or Spanish versions of the tool (p = .50 – ..98). No differences were found as well in the performance of the CSHCN Screener by mode of administrative in the sample of children who met the administrative data-based prescreening criteria for having a probable chronic or special health care need (p = .84).

Table 9: Percentage of children identified by the CSHCN Screener by mode of administration

	MAIL % identified by CSHCN Screener	TELEPHONE % identified by CSHCN Screener	(P value)
a) Standard CAHPS / English (n = 3,894)	22.2	21.1	(.50)
b) Prescreened sample / English (n = 4,987)	47.1	47.5	(.84)
c) Regular CAHPS & prescreened samples combined / Spanish (n = 1,102)	16.0	16.2	(.98)

D. *CSHCN Question Supplement*

Although the data are available, a mode effect analysis has not yet been conducted for the items in the CSHCN Question Supplement. However, the CSHCN items were explicitly designed using the same wording, formatting and response tasks as the CAHPS 2.0 Child Survey. These similarities to the core CAHPS instrument are expected to minimize or eliminate any significant mode effect.

Criterion 9 – Reports and ratings

The CSHCN Question Supplement and the CSHCN Screener do not depart from the “report type” question design utilized by the CAHPS survey. All items in the CSHCN Question Supplement were explicitly designed to use the same “yes/no”, “problem assessment” or “how often something happened” response option sets used in the core CAHPS survey. Copies of the CSHCN Screener and the CSHCN Question Supplement are found under Appendix A.

Criterion 10 – Comparability of Scales:

The CSHCN Screener and CSHCN Question Supplement items are intended for use with the core CAHPS 2.0 Child Survey and use formats and response scales that are the same or as close as possible to those used in the core CAHPS instrument. None of the CSHCN questions have response tasks that are new or not found among the core CAHPS 2.0 Child Survey questions. The following describes the response scales used by the items in each of the CSHCN consumer reporting composites and compares them with those used in the core CAHPS 2.0 Child Survey.

1. <u>Getting Prescription Medicines</u>
2. <u>Getting Specialized Services</u>

The design and scoring of these measures were among the most challenging of issues faced during the development of the CSHCN Module. The importance of these services and treatments to the well-being and health of the CSHCN who depend upon them is strongly supported in the literature and emphasized by their families. Despite this importance, the variability that exists in benefit design and structure make uniform attribution of responsibility and accountability for delivery of such services difficult or, in some cases, impossible.

After much discussion and input from various stakeholders, including public and private health plan representatives from NCQA's Technical Advisory Group and Committee on Performance Measurement, a minimum performance standard was identified and agreed upon. Even in the settings where benefits packages do not cover such services or where they are "carved-out" by the purchaser, health plans and providers are at the very least expected to try to help families whose children need such services connect with community programs or other resources that may offer them.

Because benefit design and coverage varies depending upon the context of the measurement project, the items comprising the Getting Prescription Medicines and Getting Specialized Services offer the flexibility of being able to be used in two ways:

- For measurement contexts having integrated and uniform benefits design, such as the Medicaid managed care programs in many states, the Getting Prescription Medicines and the Getting Specialized Services are scored in the same way as other CAHPS composites using a problem assessment scale.

- For measurement contexts with ‘carve-outs’ and other non-uniform benefits design, such as many privately insured settings, responses to the problem assessment scale question and responses to the question about whether the respondents experiencing problems received any help are combined into a constructed variable used to score the Getting Prescription Medicines and the Getting Specialized Services (See the table in Appendix F for information).

3. Family Centered Care and Decision Making

Part A: Personal Dr / Nurse who Knows Child:

All the items in this component use “Yes/No” response tasks. Earlier versions of the items assessing a child’s personal doctor or nurse used the “Never to Always” scale.
During the August 2000 review meeting between FACCT/CAHMI, NCQA and CAHPS researchers, it was strongly argued that it was not appropriate to ask how often a child’s personal doctor or nurse asked about how the child was feeling, growing or behaving. Whether this is occurs or not depends on how long it has been since the provider last saw the child. Taking this into consideration, a response of “sometimes” may actually reflect good care under circumstances where a child comes in for frequent visits. As a result, the response scale for this question was changed to “Yes/No.” The response scales for the other Part A questions assessing the child’s personal doctor or nurse were also changed to “Yes/No” to maintain consistency for scoring purposes. The table found in Appendix F describes the scoring for the “Personal Dr or Nurse who Knows Child” component of the Family Centered Care composite.

Part B: Shared Decision Making:

The items in this component use the same “Never to Always” scale used by other core CAHPS questions to allow respondents to summarize experiences across all their child’s doctors or other health providers. The “Shared Decision Making” component is scored according to the same method used for CAHPS composites with a “Never to Always” scale.

Part C: Getting Needed Information About Child's Health:

The items in this component use the same "Never to Always" scale used by other core CAHPS questions to allow respondents to summarize experiences across all their child's doctors or other health providers. The "Getting Needed Information About Child's Health" component is scored according to the same method used for CAHPS composites with a "Never to Always" scale.

4. <u>Coordination of Care</u>

The questions used by the CSHCN Question Supplement to assess the provision of care coordination among multiple providers and services went through several iterations. Arriving at appropriate wording and response scales for assessing this important dimension of care for CSHCN has been an ongoing challenge for many researchers. In particular, whether to assess if families received help coordinating care versus whether a case manager was assigned by the child's health plan were issues that received much discussion. It was decided to focus on "help with coordinating care among multiple providers or services" because the use of case managers varied widely across plan settings.

The earlier versions of the items comprising the "Coordination of Care" composite used a variety of response scales including problem assessment and "Never to Always". During the August 2000 review meeting between FACCT/CAHMI, NCQA and CAHPS researchers, all the items were assigned "Yes/No" response tasks in an effort to align the response scales across the items making up the composite. Whether this was an appropriate decision or not deserves further attention. Findings from the recent cognitive interviews conducted by the Westat research team suggest that the "Yes/No" response scale may not appropriately or sufficiently allow respondents to report heterogeneous experiences. Interviewees' comments also suggest that the wording of the coordination of care gate question should be re-visited to see if the term "case manager" could or should be added.

The table found in Appendix F describes the currently recommended scoring for the Coordination of Care composite.

Criterion 11 – Translation Process:

The Phase III field test entailed a statewide survey of families with children enrolled in Medicaid managed care. As part of this study, the CSHCN Screener and the CSHCN Question Supplement were translated into Spanish and integrated into the Spanish language version of the CAHPS 2.0H Child Survey.

Pacific Interpreters, a Portland, OR based organization employing translators certified through the American Translators Association, did the initial translation of the CSHCN materials. Pacific Interpreters was chosen because its experience translating health plan information into Spanish language. Once this initial translation was completed, FACCT/CAHMI staff worked with Pacific Interpreters, native Spanish speakers, and Spanish-speaking representatives from the survey research firm contracted by the State where the survey was to be conducted to revise and refine the Spanish language version of the CAHPS 2.0H Child Survey with CSHCN Screener and Question Supplement administered in the Phase III field test. Copies of the English and Spanish language versions of the survey administered during the Phase III field test are found in Appendix M.

Description of translation process

1. To ensure that a consistent tone and writing style would be maintained throughout the translated survey, the untranslated CSHCN Screener and Question Supplement items were inserted into the Spanish version of the CAHPS 2.0 Child Survey. This was done to supply the translators with a guide for an appropriate tone and wording conventions. In keeping with this goal, all subsequent reviews were based on the complete survey including both CAHPS and CSHCN questions.

2. A CAHMI research staff member having a BA in Spanish reviewed the translations and corrected many of the grammatical and spelling errors.

3. A cognitive interview was conducted with a native Spanish speaker whose child has a special health care need. The interviewee suggested several changes to improve the readability of the questions and also suggested several more common words.

4. The edited and revised translations were reviewed by several Spanish-speaking members of the survey research firm's staff and native Spanish-speaking staff from the Medicaid Administration in the State where the survey would be conducted.

5. Several conference calls between Spanish-speaking CAHMI research staff, survey research firm employees and native Spanish speaking representatives from the State Medicaid Administration were held to discuss and correct linguistic and cultural problems with the translated documents.

6. Agreed-upon edits and refinements were made to Spanish version of the survey including the word changes involving several of the CAHPS items.

Results

In the Phase III field test, households indicating Spanish as the first language were given the option of responding to the survey in English or Spanish. In previous years, CAHPS survey projects in the State that was the site for the Phase III test had experienced discrepancies exceeding 10 percentage points in the response rates between those replying in English and Spanish. This was not the case in the Phase III study. The response rates in both English and Spanish well exceeded those of past years and did not differ according to the language in which the survey was collected (English response rate = 57.6%, adjusted; Spanish response rate = 58.7%, adjusted). The improvements made in the clarity, readability and cultural competency of the Spanish version of the CAHPS 2.0 Child Survey with the CSHCN Screener and Question Supplement undoubtedly played an important role in this success. Overall, in the Phase III field test:

- 10% of surveys in the statewide Medicaid sample were collected in Spanish (n = 1,102).
- 46% of all respondents answering “Yes, my child is Hispanic” responded to the survey in Spanish.
- Nearly 100% of those who responded in Spanish described their child as being Hispanic.

In the Phase III field test, children described as being Hispanic tended to be identified as having special health care needs by the CSHCN Screener at lower rates than non-Hispanic children. The Hispanic CSHCN rates also varied according to the language in which the survey was collected:

- 18% of Hispanic children whose parents completed the survey in English met the CSHCN Screener versus 21% non-Hispanic children.
- 10% of Hispanic children whose parents completed the survey in Spanish met the CSHCN Screener.

The age distribution in the Spanish language group may explain some of the CSHCN rate differences as children in the youngest age groups have lower CSHCN rates than do older children (mean age for the Spanish group: 6 years; mean age for the English group: 8 years)

The reading level of the screener did not appear to be implicated in the differences observed as the mode of administration did not significantly effect CSHCN screening rates in Spanish. However, a mix of cultural and translation factors may account to some extent for the rate differences:

- Children described as being Hispanic were more likely to meet the CSHCN criteria if the survey was collected in English.
- Spanish speakers appear more reluctant to use the health care system than English speakers:
    a) Parents whose surveys were collected in Spanish reported more than twice the rate of NO doctor/clinic visits by their children during the past 6 months (35% Spanish, 18% English) compared to parents whose surveys were collected in English.
    b) Despite less outpatient contact by the Spanish-speaking group, the level of emergency room utilization was the same for children in both language groups.
- Culturally, Spanish speakers may be more hesitant to declare that their child has a medical or mental health condition.

Interestingly, despite significantly lower CSHCN rates for the group responding in Spanish, 20% of parents who responded in Spanish rated their “child’s health now” as ‘fair’ compared to 6% in the group responding in English. A more detailed comparison of Hispanic and non-Hispanic CSHCN can be found in Bethell, Read, Stein et al., 2001.

One of the ongoing challenges for all survey-based methods concerns the cultural competency and validity of the instruments themselves. More work is being conducted by FACCT/CAHMI staff and others to identify and understand the issues related to the socio-cultural construction of special health care needs. Additional work is also underway by FACCT/CAHMI, Westat and others to ensure the cultural and cognitive appropriateness of the Spanish language version of the CSHCN Screener. Spanish translation of the final version of the CSHCN Question Supplement is currently underway by Westat.

Criterion 12 – Stakeholders input:

The CSHCN Module was developed as part of the Child and Adolescent Health Measurement Initiative (CAHMI). The main goal of the CAHMI is to measure and communicate to consumers, providers and policymakers relevant, actionable information about the quality of health care for children and adolescents. To accomplish this, the CAHMI brings stakeholders together into four national advisory committees. Included are consumers, researchers, clinicians, health plan representatives, policymakers and others. These committees provide on-going input and review throughout the measurement development process.

All CAHMI measures go through the six-stage measure development and testing process described in Table 1 under Criterion #1. Formal stakeholder review and input are explicitly included as part of the process. Opportunities for input include national meetings, regular conference calls, and numerous real-time review sessions by email at important junctures.

The CAHMI Living with Illness Task Force advised FACCT/CAHMI staff during the development, testing and refinement of the CSHCN Module. For a list of Task Force members, see Appendix D. In addition, the Children and Adolescent Health Measurement Advisory Committee (CAHMAC) meets twice a year to review and formally approve all CAHMI measures. A list of CAHMAC members is included at the end of this section.

One of the Living with Illness Task Force's goals was to submit the CSHCN measures to the National Committee on Quality Measurement (NCQA) to be considered for inclusion as part of HEDIS. As a result, both the NCQA Technical Advisory Group and the Committee on Performance Measurement provided extensive review and input throughout the development and testing of the CSHCN Module components.

The CAHPS research team also provided extensive input on the CSHCN Module during its development and testing. FACCT/CAHMI, NCQA and CAHPS researchers met formally in May 2000 and August 2000 to review work to-date and finalize the wording and content of the CSHCN Screener and CSHCN Question Supplement.

In April 2001 the Committee on Performance Measurement formally adopted the HEDIS application of the CSHCN Module. The CSHCN Screener and CSHCN Question Supplement are now integrated into the CAHPS 2.0H survey, which is a part of the National Committee for Quality Assurances' Health Plan Employer Data and Information Set (HEDIS). In addition, the CSHCN Screener is currently being used as part of the National CSHCN Survey and in the National Medical Expenditures Panel Survey (MEPS).

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