

About the Item Set for Children With Chronic Conditions

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Introduction

To better address the needs of children with chronic conditions (commonly referred to as children with special health care needs), the CAHPS Consortium decided in 2002 to integrate a new set of items into the CAHPS Health Plan Survey child questionnaires. This item set allows sponsors to:

- Identify children who have chronic conditions;
- Assess their experiences with the health care system; and
- Compare their experiences to those of similar children in other health plans and/or children without chronic conditions in the same plan.

This document explains why this information is useful, what is included in this set of items, and how sponsors and other organizations can use the survey results.

Note About the 4.0 Version: In 2007, the item set for children with chronic conditions was updated to make the items consistent with refinements made to the 4.0 version of the CAHPS Health Plan Survey. Please turn to *Appendix A: Comparison of the 3.0 and 4.0 Item Sets* to learn how the items have been changed.

Also, in the 4.0 version, the Children With Chronic Conditions Item Set is incorporated into the Child Medicaid Questionnaire. The Child Commercial Questionnaire consists of core items only. Sponsors using that questionnaire are free to add supplemental items, including those from the Children With Chronic Conditions Item Set.

How Does CAHPS Define Children With Chronic Conditions?

The CAHPS methodology uses the Maternal and Child Health Bureau's definition of children with special health care needs, which is based on consequences rather than specific conditions or diseases:

“Children with special health care needs are those who have a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that generally required by children.”¹

Research indicates that children with chronic conditions account for 15 to 18 percent of all children under 18, although some sponsors of the CAHPS Health Plan Survey may serve a relatively higher proportion of children with chronic conditions than is found in the general population.²

¹ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):137-40.

² Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. An epidemiologic profile of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):117-23. Stein RE, Silver EJ. Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. *Arch Pediatr Adolesc Med*. 1999 Jan;153(1):68-74.

Why Is This Information Important?

While the numbers of children with chronic conditions may be small, several factors point to the need to measure and report on quality of care for this segment of the population:³

- **Financial impact.** Children with chronic conditions consume a preponderance of the health care dollars spent on children, with estimates ranging from 80 to 90 percent.⁴
- **Evidence of poor quality.** Researchers have found that quality of care for children with chronic conditions is often inadequate. According to studies conducted by FACCT-The Foundation for Accountability, parents of children with chronic conditions rate their experiences with care at a level that ranges from 50 percent to 80 percent of what would be considered optimal.⁵

It is critical to assess and track quality of care for this vulnerable segment so that parents, health plans, and other survey sponsors can evaluate how well the needs of children with chronic conditions are being met and identify which aspects of care need to be improved.

- **Equity.** The experiences that children with chronic conditions have with health plans and providers are often different from those of healthy children, who primarily rely on the health care system for preventive and acute care. Families, health plans, and policymakers need to know if quality of care is not consistent for all children and which plans are best suited to meet the needs of children with chronic conditions.
- **The need for relevant information.** The continual needs of children with chronic conditions far exceed those of their peers, particularly with respect to the type, scope, and frequency of health care services they require. They also have a greater demand for health information, education, partnership with providers, and coordination of care. When reviewing their coverage options, the parents of these children need access to comparative performance information that is relevant to their circumstances.

³ For a more recent analysis, see: Shulman S, Ireys H, Peterson S. Children with Special Health Care Needs in Commercial Plans, Quality Care for Special Kids: Profiles of Children with Chronic Conditions and Disabilities, Update #1. Washington, DC: Mathematica Policy Research, Inc. 2006 Sep. Document No. PP06-75. Accessed at http://www.mathematica-mpr.com/publications/redirect_PubsDB.asp?strSite=PDFs/qualitycareupdate1.pdf.

⁴ Lewit EM, Monheit AC. Expenditures on health care for children and pregnant women. *Future of Children*, 2, 1992. 95-114 (David and Lucile Packard Foundation).

⁵ Bethell, C, Lansky, D, Hendryx, M. The Robert Wood Johnson Foundation National Strategic Indicators Survey: RWJF Priority and Program Area Performance Indicators Summary Report. 2006 Sep. Portland, OR: FACCT-The Foundation for Accountability. Bethell, C. *Measuring patient centered care across consumer relevant domains of quality: A report prepared for the Institute of Medicine Committee on the National Quality Report on Health Care*. 2006 Jul.

Contents of the Children's Chronic Conditions Set

The chronic condition set for children consists of two groups of items:

- A set of **24 supplemental questions** that ask about the health care experiences of children with chronic conditions. [Note: The 3.0 version had 31 questions.]
- A five-item **screeener** that classifies children with chronic conditions during the analysis stage after the survey has been administered.

What Are the Supplemental Questions?

The supplemental questions focus on topics with special relevance to children with chronic conditions. These topics are reflected in the following reporting measures for this item set:

- Access to prescription medicines.
- Access to specialized services.
- Family-centered care:
 - Having a personal doctor or nurse who knows the child.
 - Shared decisionmaking.
 - Getting needed information.
- Coordination of care and services.

What Are the Screener Items?

The five-item screener is a tool used during the analysis of the data to determine which responses to the questionnaire reflect the experiences of children with chronic conditions.

The Problem: Children with Chronic Conditions Are Hard to Find

To identify children with special health needs, it is not sufficient to look for categories of children, i.e., those with specific conditions or diseases.

- First, the prevalence of any given chronic condition among children is relatively low.
- Second, there are a large number of applicable diagnoses, many of which are very rare.
- Third, identification strategies that rely on diagnoses have been known to miss children who should qualify as having chronic conditions. Reasons for this problem include coding errors, misdiagnoses, lack of access to care, and the global or developmental nature of some childhood problems.
- Finally, there are many definitions of children with chronic conditions (or special health care needs), and each results in a different set of conditions and/or codes to operationalize the definition.

Our Approach: Focus on Consequences

The CAHPS methodology addresses this problem by classifying children as having a chronic condition if they report one or more of the consequences associated with such conditions.

The screener is designed to identify children who meet three criteria.

- Criteria #1: The child currently experiences a specific consequence.
- Criteria #2: The consequence results from a medical, behavioral, or other health condition.
- Criteria #3: The duration or expected duration of the condition is at least 12 months.

What Does the Screener Ask?

The screener consists of five main questions, each of which has three parts. The questions cover the following five health consequences:

- Use or need of prescription medication;
- Above average use or need of medical, mental health, or education services;
- Function limitations compared with others of the same age;
- Use or need of specialized therapies (e.g., occupational therapy, physical therapy, speech); and
- Treatment or counseling for emotional, behavioral, or developmental problems.

If the answer to the first part of the question is "yes," the respondent moves on to the second part to say whether the consequence is due to any kind of health condition. If so, the respondent continues to the third part, which asks whether the condition has lasted or is expected to last for at least 12 months. (The one exception to this pattern is the last screener question, which has only two parts.)

A child who meets all three criteria for one or more of the five main questions would qualify as having a chronic condition. On average, 16 to 20 percent of the general population of children meets these criteria. When you analyze the data, the number of children who meet the screener criteria will be the denominator for calculations of quality measures for children with chronic conditions.

Can I Add Other Items?

Sponsors of the CAHPS Child Questionnaire are free to add other supplemental questions from the CAHPS Health Plan Survey (not related to chronic conditions) as well as their own questions. In particular, you may be interested in three communication items from the 3.0 version of the Children with Chronic Conditions Set that were moved into the more general set of supplemental items for the child questionnaires:

- In the last 6 months, did you have any questions or concerns about your child's health or health care?
- In the last 6 months, how often did your child's doctors or other health providers make it easy for you to discuss your questions or concerns?
- In the last 6 months, how often did you get the specific information you needed from your child's doctors or other health providers?

Please note that any additional questions contribute to the time required of respondents. However, while a lengthy survey sometimes affects the response rate, the CAHPS Consortium's research indicates that this is unlikely with respondents for children with chronic conditions.

For More Information About the Screeners

If you are interested in using the screener on its own to identify children with chronic conditions, please contact the Child and Adolescent Health Measurement Initiative (CAHMI) at cahmi@ohsu.edu, or visit their Web site: <http://www.cahmi.org/>.

Gathering, Analyzing, and Reporting the Data

Sponsors of the CAHPS Child Questionnaire should consider the full range of opportunities and challenges in the process of gathering, analyzing and reporting their data. Below are some factors to bear in mind for those interested in conducting this survey.

Fielding the Survey

Since less than one-fifth of all children have chronic conditions, you have to make a special effort to ensure that you obtain a sufficient number of responses from that segment to report statistically valid results.

To maximize the number of usable responses, follow the sampling protocol explained in *Fielding the CAHPS Health Plan Survey: Medicaid Version* [Doc. No. 13a] in the *CAHPS Health Plan Survey and Reporting Kit*.

Analyzing the Data

If you obtain a sufficient number of responses, you can analyze the data for children identified as having chronic conditions separately from the data for the general population of children. For guidance in conducting this analysis, please contact the CAHPS User Network by e-mail (cahps1@ahrq.gov) or by telephone: (800) 492-9261.

Reporting the Data

With the data you collect from the Child Questionnaire, you can provide parents, providers, health plans, and purchasers with useful information about the care provided to an important segment of the child population. Parents and caregivers can incorporate these quality measures into their health care coverage decisions. Other potential

audiences for the reports include accrediting agencies, Medicaid agencies, SCHIP programs, children's advocacy groups, and Federal agencies.

You can use the information in two ways:

- **Report the standard CAHPS composites (getting needed care, getting care quickly, etc.) for two separate groups:**

- The general population of children
- The children with chronic conditions

This will allow you to identify the ways in which the experiences and perceptions of these two groups differ as well as the ways in which they are consistent.

- **Report only the measures for children with chronic conditions:**

- Access to prescription medicines
- Access to specialized services
- Family-centered care
 - Having a personal doctor or nurse who knows the child.
 - Shared decisionmaking.
 - Getting needed information.
- Coordination of care and services

These measures are designed to capture the domains of care that are especially important for this segment of the population.

For help in reporting the composites resulting from this analysis, see the guidelines in the Reporting Resources section of the CAHPS Web site (https://www.cahps.ahrq.gov/content/resources/report/RES_REPORT_Intro.asp). You may also contact the CAHPS User Network at cahps1@ahrq.gov for further assistance.

What If I Do Not Want Results for Children with Chronic Conditions?

If you are only interested in gathering and reporting basic information on the health care of children age 17 and under (i.e., no information on the specific experiences of those with chronic conditions), you can field the 4.0 version of the Child Medicaid Questionnaire without the chronic condition items.

- **Finding the items.** The chronic condition items are highlighted in yellow for easy identification and removal.
- **Reviewing remaining items.** After you delete the chronic condition items, carefully renumber the remaining items and the skip instructions associated with those items.

The remaining questionnaire consists of the required core items, along with any other supplemental questions you may have added.

Developers of the Children's Chronic Condition Set

The chronic condition set for children was developed through the Child and Adolescent Health Measurement Initiative (CAHMI), with substantial input from the CAHPS research team and the Agency for Healthcare Research and Quality (AHRQ).

What is CAHMI?

Primarily funded by the David and Lucile Packard Foundation and The Commonwealth Fund, the CAHMI is a national collaboration of more than 80 organizations. First established by FACCT-The Foundation for Accountability and the National Committee for Quality Assurance (NCQA), it is now housed at Oregon Health & Science University in the Department of Pediatrics.

CAHMI receives guidance from four national advisory committees comprised of consumers, researchers, providers, policymakers, and other stakeholders. The Living with Illness Task Force advised the CAHMI research staff during the development, testing, and refinement of the children's chronic conditions set.

For More Information

See CAHMI's Web site at <http://www.cahmi.org/>.

Related Resources

- The Child Health Tool Box – <http://www.ahrq.gov/chtoolbx/>
- The Foundation for Accountability (FACCT) – <http://www.markle.org/resources/facct/index.php>
- National Committee for Quality Assurance (NCQA) – <http://www.ncqa.org>

Appendix A. Comparison of the 3.0 and 4.0 Item Sets

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
<p>9. Does your child have <u>any medical, behavioral, or other health conditions</u> that have lasted for more than 3 months?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC19. Does your child have any medical, behavioral, or other health conditions that have lasted for more than 3 months?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>10. Does your child’s personal doctor or nurse <u>understand</u> how these medical, behavioral, or other health conditions affect your child’s day-to-day life?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC20. Does your child’s personal doctor understand how these medical, behavioral, or other health conditions affect your child’s day-to-day life?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Reworded item to be consistent with focus on “personal doctor” in Health Plan Survey 4.0.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>11. Does your child’s personal doctor or nurse <u>understand</u> how your child’s medical, behavioral, or other health conditions affect your <u>family’s</u> day-to-day life?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC21. Does your child’s personal doctor understand how your child’s medical, behavioral, or other health conditions affect your family’s day-to-day life?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Reworded item to be consistent with focus on “personal doctor” in Health Plan Survey 4.0.</p> <p>Changed visual emphasis.</p>
<p>40. In the last 6 months, did you have any <u>questions or concerns</u> about your child’s health or health care?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>		<p>Deleted item from this item set; moved it into supplemental item set for children under “Communication.”</p>
<p>41. In the last 6 months, how often did your child’s doctors or other health <u>providers make it easy</u> for you to discuss your questions or concerns?</p> <p>¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always</p>		<p>Deleted item from this item set; moved item into supplemental item set for children under “Communication.”</p>

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
<p>42. In the last 6 months, how <u>often</u> did you get the <u>specific information</u> you needed from your child's doctors or other health providers?</p> <p> ¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always </p>		Deleted item from this item set; moved item into supplemental item set for children under "Communication."
<p>43. In the last 6 months, how <u>often</u> did you have <u>your questions</u> answered by your child's doctors or other health providers?</p> <p> ¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always </p>	<p>CC1. In the last 6 months, how often did you have your questions answered by your child's doctors or other health providers?</p> <p> ¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always </p>	Removed underlining in order to comply with CAHPS rules for visual emphasis.
<p>44. In the last 6 months, were <u>any decisions</u> made about your child's health care?</p> <p> ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No </p>		Replaced items 44- 48 with "child" versions of HEDIS supplemental items on shared decision-making. The new item set (CC5-CC7) represents a refinement of the terms used to describe shared decision making.
<p>45. When <u>decisions</u> were made in the last 6 months, how <u>often</u> did your child's doctors or other health providers <u>offer you choices</u> about your child's health care?</p> <p> ¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always </p>	<p>CC2. Choices for your child's treatment or health care can include choices about medicine, surgery, or other treatment. In the last 6 months, did your child's doctor or other health provider tell you there was more than one choice for your child's treatment or health care?</p> <p> ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No </p>	Replaced items 44-48 with "child" versions of HEDIS supplemental items on shared decision-making. The new item set (CC5-CC7) represents a refinement of the terms used to describe shared decision making.

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
<p>46. When <u>decisions</u> were made in the last 6 months, how <u>often</u> did your child's doctors or other health providers <u>discuss</u> with you the good and bad things about each of the different choices for your child's health care?</p> <p> <input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always </p>	<p>CC3. In the last 6 months, did your child's doctor or other health provider talk with you about the pros and cons of each choice for your child's treatment or health care?</p> <p> <input type="checkbox"/> ¹ Yes <input type="checkbox"/> ² No </p>	<p>Replaced items 44-48 with "child" versions of HEDIS supplemental items on shared decision-making. The new item set (CC5-CC7) represents a refinement of the terms used to describe shared decision making.</p>
<p>47. When <u>decisions</u> were made in the last 6 months, how <u>often</u> did your child's doctors or other health providers <u>ask you</u> to tell them what choices <u>you prefer</u>?</p> <p> <input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always </p>	<p>CC4. In the last 6 months, when there was more than one choice for your child's treatment or health care, did your child's doctor or other health provider ask you which choice was best for your child?</p> <p> <input type="checkbox"/> ¹ Yes <input type="checkbox"/> ² No </p>	<p>Replaced items 44-48 with "child" versions of HEDIS supplemental items on shared decision-making. The new item set (CC5-CC7) represents a refinement of the terms used to describe shared decision making.</p>
<p>48. When <u>decisions</u> were made in the last 6 months, how <u>often</u> did your child's doctors or other health providers <u>involve you</u> as much as you wanted?</p> <p> <input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always </p>		<p>Replaced items 44-48 with "child" versions of HEDIS supplemental items on shared decision-making. The new item set (CC5-CC7) represents a refinement of the terms used to describe shared decision making.</p>
<p>50. Is your child now enrolled in any kind of school or daycare?</p> <p> <input type="checkbox"/> ¹ Yes <input type="checkbox"/> ² No </p>	<p>CC5. Is your child now enrolled in any kind of school or daycare?</p> <p> <input type="checkbox"/> ¹ Yes <input type="checkbox"/> ² No </p>	<p>No change</p>
<p>51. In the last 6 months, did you need your child's doctors or other health providers to <u>contact</u> a school or daycare center about your child's health or health care?</p> <p> <input type="checkbox"/> ¹ Yes <input type="checkbox"/> ² No </p>	<p>CC6. In the last 6 months, did you need your child's doctors or other health providers to contact a school or daycare center about your child's health or health care?</p> <p> <input type="checkbox"/> ¹ Yes <input type="checkbox"/> ² No </p>	<p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
52. In the last 6 months, did you get the <u>help you needed</u> from your child's doctors or other health providers in contacting your child's school or daycare? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC7. In the last 6 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or daycare? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
Specialized Services		
61. In the last 6 months, did you get or try to get any <u>special medical equipment or devices</u> for your child, such as a walker, wheelchair, nebulizer, feeding tubes, or oxygen equipment? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC8. Special medical equipment or devices include a walker, wheelchair, nebulizer, feeding tubes, or oxygen equipment. In the last 6 months, did you get or try to get any special medical equipment or devices for your child? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	Reworded item so that definition of special medical equipment is provided prior to actual question. Removed underlining in order to comply with CAHPS rules for visual emphasis.
62. In the last 6 months, how much of a <u>problem</u> , if any, was it to get special medical equipment for your child? ¹ <input type="checkbox"/> A big problem ² <input type="checkbox"/> A small problem ³ <input type="checkbox"/> Not a problem	CC9. In the last 6 months, how often was it easy to get special medical equipment or devices for your child? ¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always	Reworded item to conform to "Never/Sometimes/ Usually Always" scale used in Health Plan Survey 4.0. Removed underlining in order to comply with CAHPS rules for visual emphasis.
63. Did anyone from your child's health plan, doctor's office or clinic <u>help you</u> with this problem? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC10. Did anyone from your child's health plan, doctor's office, or clinic help you get special medical equipment or devices for your child? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	Reworded item because "problem" is no longer referenced in previous question. Removed underlining in order to comply with CAHPS rules for visual emphasis.
64. In the last 6 months, did you get or try to get <u>special therapy</u> for your child, such as physical, occupational, or speech therapy? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC11. In the last 6 months, did you get or try to get special therapy such as physical, occupational, or speech therapy for your child? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	Reworded item slightly. Removed underlining in order to comply with CAHPS rules for visual emphasis.

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
<p>65. In the last 6 months, how much of a <u>problem</u>, if any, was it to get special therapy for your child?</p> <p>¹<input type="checkbox"/> A big problem ²<input type="checkbox"/> A small problem ³<input type="checkbox"/> Not a problem</p>	<p>CC12. In the last 6 months, how often was it easy to get this therapy for your child?</p> <p>¹<input type="checkbox"/> Never ²<input type="checkbox"/> Sometimes ³<input type="checkbox"/> Usually ⁴<input type="checkbox"/> Always</p>	<p>Reworded item to conform to “Never/Sometimes/ Usually Always” scale used in Health Plan Survey 4.0.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>66. Did anyone from your child’s health plan, doctor’s office, or clinic <u>help you</u> with this problem?</p> <p>¹<input type="checkbox"/> Yes ²<input type="checkbox"/> No</p>	<p>CC13. Did anyone from your child’s health plan, doctor’s office, or clinic help you get this therapy for your child?</p> <p>¹<input type="checkbox"/> Yes ²<input type="checkbox"/> No</p>	<p>Reworded item because “problem” is no longer referenced in previous question.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>67. In the last 6 months, did you get or try to get treatment or counseling for your child for <u>an emotional, developmental, or behavioral problem</u>?</p> <p>¹<input type="checkbox"/> Yes ²<input type="checkbox"/> No</p>	<p>CC14. In the last 6 months, did you get or try to get treatment or counseling for your child for an emotional, developmental, or behavioral problem?</p> <p>¹<input type="checkbox"/> Yes ²<input type="checkbox"/> No</p>	<p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>68. In the last 6 months, how much of a <u>problem</u>, if any, was it to get this treatment or counseling for your child?</p> <p>¹<input type="checkbox"/> A big problem ²<input type="checkbox"/> A small problem ³<input type="checkbox"/> Not a problem</p>	<p>CC15. In the last 6 months, how often was it easy to get this treatment or counseling for your child?</p> <p>¹<input type="checkbox"/> Never ²<input type="checkbox"/> Sometimes ³<input type="checkbox"/> Usually ⁴<input type="checkbox"/> Always</p>	<p>Reworded item to conform to “Never/Sometimes/ Usually/Always” scale used in Health Plan Survey 4.0.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>69. Did anyone from your child’s health plan, doctor’s office, or clinic <u>help you</u> with this problem?</p> <p>¹<input type="checkbox"/> Yes ²<input type="checkbox"/> No</p>	<p>CC16. Did anyone from your child’s health plan, doctor’s office, or clinic help you get this treatment or counseling for your child?</p> <p>¹<input type="checkbox"/> Yes ²<input type="checkbox"/> No</p>	<p>Reworded item because “problem” is no longer referenced in previous question.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>

**Crosswalk of Children with Chronic Conditions Item Set:
Version 3.0 Compared to Version 4.0**

<p align="center">3.0 version (Child Medicaid Managed Care)</p>	<p align="center">4.0 Version (Child Medicaid)</p>	<p align="center">Change/Rationale</p>
<p>70. In the last 6 months, did your child get care from <u>more than one kind</u> of health care <u>provider</u> or use <u>more than one kind</u> of health care service?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC17. In the last 6 months, did your child get care from more than one kind of health care provider or use more than one kind of health care service?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>71. In the last 6 months, did anyone from your child’s health plan, doctor’s office, or clinic <u>help coordinate</u> your child’s care among these different providers or services?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC18. In the last 6 months, did anyone from your child’s health plan, doctor’s office, or clinic help coordinate your child’s care among these different providers or services?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p align="center">Prescription Medicines</p>		
<p>83. In the last 6 months, did your child <u>get a prescription</u> for medicine or did you refill a prescription for your child?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC22. In the last 6 months, did you get or refill any prescription medicines for your child?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Reworded item slightly to improve flow and syntax.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>84. In the last 6 months, how much of a <u>problem</u>, if any, was it to get your child’s prescription medicine?</p> <p>¹ <input type="checkbox"/> A big problem ² <input type="checkbox"/> A small problem ³ <input type="checkbox"/> Not a problem</p>	<p>CC23. In the last 6 months, how often was it easy to get prescription medicines for your child through his or her health plan?</p> <p>¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always</p>	<p>Reworded item to reference health plan and to conform to “Never/Sometimes/ Usually/Always” scale used in Health Plan Survey 4.0.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>
<p>85. Did anyone from your child’s health plan, doctor’s office, or clinic <u>help you</u> with this problem?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>CC24. Did anyone from your child’s health plan, doctor’s office, or clinic help you get your child’s prescription medicines?</p> <p>¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No</p>	<p>Reworded item because “problem” is no longer referenced in previous question.</p> <p>Removed underlining in order to comply with CAHPS rules for visual emphasis.</p>

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
Screener Items		
87. Does your child currently need or use <u>medicine prescribed by a doctor</u> (other than vitamins)? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC25. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
88. Is this because of any medical, behavioral or other health condition? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC26. Is this because of any medical, behavioral, or other health condition? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	No change
89. Is this a condition that has lasted or is expected to last for <u>at least 12 months</u> ? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC27. Is this a condition that has lasted or is expected to last for at least 12 months? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	No change Removed underlining in order to comply with CAHPS rules for visual emphasis.
90. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC28. Does your child need or use more medical care, more mental health services, or more educational services than is usual for most children of the same age? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	Reworded item slightly to improve clarity.
91. Is this because of any medical, behavioral or other health condition? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	CC29. Is this because of any medical, behavioral, or other health condition? ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No	No change

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
92. Is this a condition that has lasted or is expected to last for <u>at least 12 months</u> ? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC30. Is this a condition that has lasted or is expected to last for at least 12 months? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
93. Is your child <u>limited or prevented</u> in any way in his or her ability to do the things most children of the same age can do? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC31. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
94. Is this because of any medical, behavioral, or other health condition? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC32. Is this because of any medical, behavioral, or other health condition? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	No change
95. Is this a condition that has lasted or is expected to last for <u>at least 12 months</u> ? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC33. Is this a condition that has lasted or is expected to last for at least 12 months? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
96. Does your child need or get <u>special therapy</u> , such as physical, occupational, or speech therapy? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC34. Does your child need or get special therapy such as physical, occupational, or speech therapy? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
97. Is this because of any medical, behavioral, or other health condition? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC35. Is this because of any medical, behavioral, or other health condition? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	No change

Crosswalk of Children with Chronic Conditions Item Set: Version 3.0 Compared to Version 4.0		
3.0 version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Change/Rationale
98. Is this a condition that has lasted or is expected to last for <u>at least 12 months</u> ? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC36. Is this a condition that has lasted or is expected to last for at least 12 months? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
99. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets <u>treatment or counseling</u> ? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC37. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.
100. Has this problem lasted or is it expected to last for <u>at least 12 months</u> ? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	CC38. Has this problem lasted or is it expected to last for at least 12 months? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Removed underlining in order to comply with CAHPS rules for visual emphasis.

Appendix B. Reporting Composites Based on Core Items Only

The **3.0 version** of the Health Plan Survey generates **five** reporting composites for children:

- Getting needed care for a child
- Getting care quickly for a child
- How well the child’s doctors communicate
- Courtesy, respect, and helpfulness of office staff
- Health plan customer service, information, and paperwork

The **4.0 version** of the Health Plan Survey produces **four** reporting composites, which differ somewhat from the 3.0 measures:

- Getting needed care for a child
- Getting care quickly for a child
- How well the child’s doctors communicate
- Health plan information and customer service

This table shows the core items in each composite in both versions of the Health Plan Survey.

Getting Needed Care for a Child			
3.0 Version (Child Medicaid Managed Care)	Response Format	4.0 Version (Child Medicaid)	Response Format
Q7 Since you joined your health plan, how much of a problem, if any, was it to get a personal doctor or nurse you are happy with?	<ul style="list-style-type: none"> • A big problem • A small problem • Not a problem 		<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always
Q13. In the last 6 months, how much of a problem, if any, was it to see to a specialist that your child needed to see?		Q20. In the last 6 months, how often was it easy to get appointments for your child with specialists?	
Q26. In the last 6 months, how much of a problem, if any, was it to get the care for your child that you or a doctor believed necessary?		Q24. In the last 6 months, how often was it easy to get the care, tests, or treatment you thought your child needed through his or her health plan?	
Q28. In the last 6 months, how much of a problem, if any, were delays in health care while you waited for approval from your child's health plan?			

Getting Care Quickly for a Child

3.0 Version (Child Medicaid Managed Care)	Response Format	4.0 Version (Child Medicaid)	Response Format
Q18. In the last 6 months, when you called during regular office hours, how often did you get the help or advice you needed for your child?	<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always 		<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always
Q20. In the last 6 months, when your child needed care right away for an illness, injury, or condition, how often did your child get care as soon as you wanted?		Q4. In the last 6 months, when your child needed care right away for an illness, injury or condition how often did your child get care as soon as you thought he or she needed?	
Q22. In the last 6 months, not counting times you needed health care right away, how often did your child get an appointment for health care as soon as you wanted?		Q6. In the last 6 months, not counting times your child needed health care right away, how often did you get an appointment for health care at a doctor's office or clinic as soon as you thought your child needed?	
Q29. In the last 6 months, how often was your child taken to the exam room within 15 minutes of his or her appointment?			

How Well the Child's Doctors Communicate

3.0 Version (Child Medicaid Managed Care)	Response Format	4.0 Version (Child Medicaid)	Response Format
Q32. In the last 6 months, how often did your child's doctors or other health providers listen carefully to you?	<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always 	Q12. In the last 6 months, how often did your child's personal doctor listen carefully to you?	<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always
Q34. In the last 6 months, how often did your child's doctors or other health providers explain things in a way you could understand?		Q11. In the last 6 months, how often did your child's personal doctor explain things in a way that was easy to understand?	
Q35. In the last 6 months, how often did your child's doctors or other health providers show respect for what you had to say?		Q13. In the last 6 months, how often did your child's personal doctor show respect for what you had to say?	
Q38. In the last 6 months, how often did doctors or other health providers explain things in a way your child could understand?		Q15. In the last 6 months, how often did your child's personal doctor explain things in a way that was easy for your child to understand?	

How Well the Child’s Doctors Communicate

3.0 Version (Child Medicaid Managed Care)	Response Format	4.0 Version (Child Medicaid)	Response Format
		Q16. In the last 6 months, how often did your child’s personal doctor spend enough time with your child?	

Courtesy, Respect, and Helpfulness of Office Staff

3.0 Version (Child Medicaid Managed Care)	Response Format	4.0 Version (Child Medicaid)	Response Format
Q30. In the last 6 months, how often did office staff at your child’s doctor’s office or clinic treat you and your child with courtesy and respect?	<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always 		
Q31. In the last 6 months, how often were office staff at your child’s doctor’s office or clinic as helpful as you thought they should be?			

Health Plan Information and Customer Service

3.0 Version (Child Medicaid Managed Care)	Response Format	4.0 Version (Child Medicaid)	Response Format
Q76. In the last 6 months, how much of a problem, if any, was it to find or understand information (about how the child’s health plan works)?	<ul style="list-style-type: none"> • A big problem • A small problem • Not a problem 		<ul style="list-style-type: none"> • Never • Sometimes • Usually • Always
Q79. In the last 6 months, how much of a problem, if any, was it to get the help you needed when you called your child’s health plan’s customer service?		Q26. In the last 6 months, how often did customer service at your child’s health plan give you the information or help you needed?	
Q81. In the last 6 months, how much of a problem, if any, did you have with paperwork for your child’s health plan?			
		Q27. In the last 6 months, how often did customer service staff at your child’s health plan treat you with courtesy and respect?	

Appendix C. Reporting Measures Based on Children with Chronic Conditions Items Only

Sponsors can report four measures for children with chronic conditions:

- Access to prescription medicines
- Access to specialized services
- Family-centered care
 - Having a personal doctor or nurse who knows the child.
 - Shared decisionmaking.
 - Getting needed information.
- Coordination of care and services

This table shows the items as they appear in the 3.0 and 4.0 versions of the questionnaires. It also explains how the measure has changed, if at all.

Reporting Measures Based on Children with Chronic Conditions Item Set Only		
3.0 Version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Type of Change
Parents' Experiences with Prescription Medicines		
84. In the last 6 months, how much of a problem, if any, was it to get your child's prescription medicine?	CC23. In the last 6 months, how often was it easy to get prescription medicines for your child through his or her health plan?	Question reworded; response options have changed -- from "problem scale" to "difficulty scale."
Parents' Experiences Getting Specialized Services for Their Child		
62. In the last 6 months, how much of a problem, if any, was it to get special medical equipment for your child?	CC9. In the last 6 months, how often was it easy to get special medical equipment or devices for your child?	Question reworded; response options have changed -- from "problem scale" to "difficulty scale."
65. In the last 6 months, how much of a problem, if any, was it to get special therapy for your child (physical, occupational, or speech)?	CC12. In the last 6 months, how often was it easy to get this therapy for your child?	Question reworded; response options have changed -- from "problem scale" to "difficulty scale."
68. In the last 6 months, how much of a problem, if any, was it to get this treatment or counseling for your child (for an emotional, developmental, or behavioral problem)?	CC15. In the last 6 months, how often was it easy to get this treatment or counseling for your child?	Question reworded; response options have changed -- from problem scale to difficulty scale.

Reporting Measures Based on Children with Chronic Conditions Item Set Only		
3.0 Version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Type of Change
Parents' Experiences with the Child's Personal Doctor or Nurse		
8. In the last 6 months, did your child's personal doctor or nurse talk with you about how your child is feeling, growing, or behaving?	Q17. In the last 6 months, did your child's personal doctor talk with you about how your child is feeling, growing, or behaving?	[Note: This item is not actually a part of the item set, but is included in this composite.]
10. Does your child's personal doctor or nurse understand how these medical, behavioral, or other health conditions affect your child's day-to-day life?	CC20. Does your child's personal doctor understand how these medical, behavioral, or other health conditions affect your child's day-to-day life?	Stayed the same.
11. Does your child's personal doctor or nurse understand how your child's medical, behavioral or other health conditions affect your family's day-to-day life?	CC21. Does your child's personal doctor understand how your child's medical, behavioral, or other health conditions affect your family's day-to-day life?	Stayed the same.
Parents' Experiences with Shared Decision-making		
45. When decisions were made in the last 6 months, how often did your child's doctors or other health providers offer you choices about your child's health care?	CC2. Choices for your child's treatment or health care can include choices about medicine, surgery, or other treatment. In the last 6 months, did your child's doctor or other health provider tell you there was more than one choice for your child's treatment or health care?	Question reworded; response options have changed -- from difficulty scale to yes/no.
46. When decisions were made in the last 6 months, how often did your child's doctors or other health providers discuss with you the good and bad things about each of the different choices you were given?	CC3. In the last 6 months, did your child's doctor or other health provider talk with you about the pros and cons of each choice for your child's treatment or health care?	Question reworded; response options have changed -- from difficulty scale to yes/no.
47. When decisions were made in the last 6 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?	CC4. In the last 6 months, when there was more than one choice for your child's treatment or health care, did your child's doctor or other health provider ask you which choice was best for your child?	Question reworded; response options have changed -- from difficulty scale to yes/no.

Reporting Measures Based on Children with Chronic Conditions Item Set Only		
3.0 Version (Child Medicaid Managed Care)	4.0 Version (Child Medicaid)	Type of Change
48. When decisions were made in the last 6 months, how often did your child's doctors or other health providers involve you as much as you wanted?		[No equivalent]
Parents' Experiences with Getting Needed Information about Their Child's Care		[Note: The 4.0 version of this measure is one item only.]
41. In the last 6 months, how often did your child's doctors or other health providers make it easy for you to discuss your questions or concerns?		Item deleted from this item set and moved into supplemental item set under communication
42. In the last 6 months, how often did you get the specific information you needed from your child's doctors and other health providers?		Item deleted from this item set and moved into supplemental item set under communication
43. In the last 6 months, how often did you have your questions answered by your child's doctors or other health providers?	CC1. In the last 6 months, how often did you have your questions answered by your child's doctors or other health providers?	Stayed the same.
Parents' Experiences with Coordination of Their Child's Care		
52. In the last 6 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or daycare?	CC7. In the last 6 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or daycare?	Stayed the same.
71. In the last 6 months, did anyone from your child's health plan, doctor's office or clinic help coordinate your child's care among these different providers or services?	CC18. In the last 6 months, did anyone from your child's health plan, doctor's office, or clinic help coordinate your child's care among these different providers or services?	Stayed the same.