# The Promoting Healthy Development Survey-PLUS

**Implementation Guidelines** 





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#### Introduction

The purpose of this manual is to provide detailed guidelines for implementing the Promoting Healthy Development Survey-PLUS (PHDS-PLUS) in Medicaid and other programs and settings. The PHDS-PLUS is a parent survey that assesses whether young children (3–48 months old) receive nationally recommended preventive and developmental services. It is a telephone-administered version of the original PHDS, containing additional items about the child's health, health care utilization, parent's health, and other socio-demographic characteristics

There are six steps necessary to implement the PHDS-PLUS:

- Step 1: Learn about the PHDS-PLUS
- **Step 2: Specify your PHDS-PLUS implementation strategy**
- **Step 3: Prepare for and conduct survey administration**
- **Step 4: Monitor survey administration and prepare for data analysis**
- **Step 5: Construct quality measures and analytic variables**
- **Step 6: Report your PHDS-PLUS findings**

This manual is organized according to the above-listed steps and their respective sub components. Each step is vital to successfully implement a PHDS-PLUS project in your program or setting.

#### Step 1: Learn about the PHDS-PLUS

This section contains an introduction to the development and implementation of the PHDS-PLUS.

- 1.1 What is the PHDS-PLUS?
- 1.2 What is measured by the PHDS-PLUS?
- 1.3 How has the PHDS-PLUS been used in Medicaid?
- 1.4 What is the added value of the PHDS-PLUS to Medicaid?
- 1.5 Development of the PHDS-PLUS
- 1.6 Requirements to implement the PHDS-PLUS
- 1.7 PHDS-PLUS resources



#### 1.1 What is the PHDS-PLUS?

The Promoting Healthy Development Survey-PLUS (PHDS-PLUS) is a parent survey that assesses whether young children age 0–3 (under 48 months of age) receive nationally recommended preventive and developmental services. This tool captures information about the provision of preventive and developmental services recommended by the American Academy of Pediatrics provided in the context of discussions and information exchanges between parents and their children's pediatric clinicians. A listing of the items in the PHDS-PLUS can be found in Appendix 1. The PHDS-PLUS is summarized in the *Fast Facts* illustration on the following page.

#### **PHDS-PLUS Fast Facts**

# Overview of the Survey

The Promoting Healthy Development Survey-PLUS (PHDS-PLUS) is a parent survey that assesses whether young children age 0–3 (under 48 months of age) receive nationally recommended preventive and developmental services. The PHDS-PLUS is designed for telephone administration and takes approximately 15–18 minutes to complete. The PHDS-PLUS is an enhanced, telephone version of the Promoting Healthy Development (PHDS) and includes additional items related to the child's health and health care use and information about parent health. There is also a reduced-item version of the PHDS that can be administered in pediatric provider offices. To date, PHDS-PLUS data have been collected for approximately 14,000 young children enrolled in Medicaid. Results have been analyzed and reported to various audiences, such as health plans, pediatric providers, families, and state policymakers.

#### Quality of Care Topics Assessed in the PHDS-PLUS

**The PHDS-PLUS collects data on 10 health care quality topics** related to clinical and patient-centered care preventive and developmental services for young children:

#### Appropriate Clinical Care

- 1. Anticipatory guidance and parental education (AGPE)
- 2. Family psychosocial assessment (FA)
- 3. Assessment of smoking, alcohol, and drug use in the home (SDA)
- 4. Assessment of parent concerns about child learning, development, and behavior and provision of specific information for parents with concerns (ASKINFO)
- 5. Follow-up for children at risk for developmental, behavioral, or social delays (FURISK)
- 6. Coordination of care for children requiring multiple types of health care services or seeing more than one health care provider (CC)

#### Patient-Centered Care

- 7. Provision of family-centered care that respects, listens to, and partners with parents (FCC)
- 8. Helpfulness of care provided to parents (HELP)

#### Health Information and Community Resources

- 9. Education and information on community resources and issues in the community that may affect child health and well-being (CR)
- 10. Provision of health information on caring for their child, preventing injuries, and ensuring optimal development (INFO)

#### Minimum Comprehensive-Care Composite

11. Provision of comprehensive care, meaning they were provided a minimum threshold of care for four measures listed above (AGPE, FA, FURISK, FCC)

# Additional Information Collected by the PHDS-PLUS

### The PHDS-PLUS also gathers information useful for quality improvement and community assessment:

- 1. Child health (risk for developmental, behavioral, or social delays, special health care need, overall health status, premature birth)
- 2. Parent health (risk for depression, overall health, physical and mental health)
- 3. Parenting behaviors (reading, actions parents take to protect their child from injury)
- 4. Child's health care utilization (number of regular or routine care visits, ER visits)
- 5. Access issues (problems getting the child necessary care)



#### 1.2 What is measured by the PHDS-PLUS?

Eleven health care quality topics assess clinical and patient-centered care as well as other important aspects of preventive and developmental services for young children:

#### Appropriate Clinical Care

- 1. Anticipatory guidance and parental education (AGPE)
- 2. Family psychosocial assessment (FA)
- 3. Assessment of smoking, alcohol, and drug use in the home (SDA)
- 4. Assessment of parent concerns about child's learning, development, and behavior and provision of specific information for parents with concerns (ASKINFO)
- Follow-up for children at risk for developmental, behavioral, or social delays (FURISK)
- 6. Coordination of care for children requiring multiple types of health care services or seeing more than one health care provider (CC)

#### Patient-Centered Care

- 7. Provision of family-centered care that respects, listens to, and partners with parents (FCC)
- 8. Helpfulness of care provided to parents (HELP)

#### Health Information and Community Resources

- 9. Education and information on community resources and issues in the community that may affect child health and well-being (CR)
- 10. Provision of health information on caring for their child, preventing injuries, and ensuring optimal development (INFO)

#### Minimum Comprehensive-Care Composite

11. Provision of comprehensive care, meaning they were provided a minimum threshold of care for four measures listed above (AGPE, FA, FURISK, FCC).

The PHDS-PLUS also provides information on a wide range of critical health care utilization and child and parent health and socio-demographic characteristics, including:

- Child <u>access to and use</u> of health services and financial burden of health care expenses on the family
- <u>Parent/family activities and behaviors</u> to prevent injuries and promote the healthy development of children
- Child and adult/parent respondent socio-demographic information
- Child and adult/parent respondent <u>health status and risks</u>, such as whether a child is at-risk for a developmental or behavioral problem, whether a child has a

special health care need, or whether the child's mother experiences symptoms of depression



#### 1.3 How has the PHDS-PLUS been used in Medicaid?

Medicaid programs have used the PHDS-PLUS for three overarching purposes:

- 1. Quality Measurement and Improvement
  - <u>Demonstrate performance</u> across a broad range of important services
  - <u>Compare performance</u> across different health plans, pediatric providers, or service areas
  - <u>Learn about differences</u> in quality within and across many groups of children
- 2. Program and Policy Planning and Evaluation
  - <u>Identify unmet needs</u> of parents across aspects of care and <u>specific care topics</u>
  - Target and track strategies to improve quality of care
  - <u>Stimulate partnerships</u> and coordinate efforts to improve care across sectors and agencies
  - <u>Determine health risks</u> and health care service needs of children and their families
  - Compare policies for organizing and paying for health care services for children
- 3. Educate and Empower Families, Providers, and Other Partners
  - Inform and activate providers, families, health care leaders, and others as partners

See Table 1.1 on the following page for specific examples of how the PHDS-PLUS has been used in the field.

**Table 1.1: Examples of PHDS-PLUS Applications in the Field** 

Federal and	Washington State used the PHDS-PLUS to complement the Early and Periodic Screening,
State Reporting	Diagnostic and Treatment (EPSDT) measures. It compared differences in the prevalence of parents of young children being counseled on various topics by type of well-visit (EPSDT well-visit rates, chart review, or any type of well-visit). The results were disseminated to individual health care providers.
Contracting and Purchasing	Maine used the PHDS-PLUS to evaluate the quality of care provided by health care providers enrolled in the Primary Care Case Management (PCCM) program. Findings were inserted into the PCCM newsletter and were used to inform quality improvement priorities for PCCM providers.
Monitoring	• Vermont used the PHDS-PLUS findings to inform efforts to improve the Healthy Babies, Kids and Families program (HBKF). They analyzed the findings by whether the parent received a home visit and examined where variations and improvements could be achieved. Furthermore, Vermont is using the PHDS-PLUS items in their HBKF client satisfaction survey to trend their efforts over time.
	The <i>Institute for Health Care Policy</i> has used the PHDS-PLUS as its measurement and evaluation tool for children enrolled in the Florida Healthy Kids program.
	The Commonwealth Fund established the <i>Assuring Better Child Health and Development</i> (ABCD) program to help state Medicaid agencies build capacity to provide health promotion and developmental services to young children and their families. CAHMI was funded to implement the PHDS-PLUS in three out of four of these states to provide baseline information to inform their efforts.
	• <i>Vermont</i> analyzed their PHDS-PLUS findings at practice-level for providers enrolled in the PCCM program. Provider-level reports were then disseminated to inform health care providers about quality of care issues and hopefully to inform their improvement efforts.
Quality Improvement	Three health plans used the PHDS-PLUS as part of their quality improvement programs. They collected health plan–level information, which was then disseminated to quality improvement directors and key provider committees focused on quality improvement implementation initiatives.
	Washington State implemented the PHDS-PLUS at a practice level to inform practice-level improvement efforts via their EPSDT focus area projects.
	The <i>Maine Department of Human Service</i> used the PHDS-PLUS to inform preventive services and quality improvement activities for young children and to enhance their implementation of chart-based encounter forms to guide health care providers.
	<ul> <li>Pediatric health care providers in Vermont implemented the reduced-item PHDS in their pediatric practices to inform their quality improvement efforts. Analyses were conducted at the medical group, office, and provider level.</li> </ul>
Consumer Reporting and Education	A pilot study was conducted in <i>pediatric practices in Vermont</i> to develop and test feedback templates to parents displaying the findings from the PHDS tools. Overall, the templates were very well received and parents expressed high interest in receiving this type of information.
Public Health Monitoring	• As part of its Medicaid external quality review, <i>Washington State</i> used the PHDS-PLUS to collect information at both the health plan and county levels. Public health initiatives related to preventive care were focused on county-level implementation efforts.
	The Vermont Department of Children with Special Health Care Needs analyzed the PHDS-PLUS by special health care need status to evaluate the need for targeted outreach efforts.

**Table 1.2: PHDS-PLUS Measure Scores Across Seven Medicaid Programs** 

	Quality Measure Scores Overall and Across Seven State Medicaid Programs		s Seven
PHDS-PLUS Quality Measure	Overall	Lowest State Score	Highest State Score
Anticipatory Guidance & Parental Education (AGPE) (% reporting discussion OR that it was okay to not have discussed certain topics on all items)	49.6% <sup>s</sup>	36.9%	58.8%
Family-Centered Care (FCC) (% of parents reporting care was "usually or always" provided across the three FCC survey items asked in the 01 and 04 PHDS-PLUS)	71.2% <sup>S</sup>	61.3%	76.5%
Family Psychosocial Assessment (FA) (Proportion reporting that at least 2 of 3 topics were discussed)	47.8% <sup>s</sup>	37.2%	58.0%
<b>Assessment of Concerns About Child Development (ASKINFO)</b> (% of parents asked about their concerns and, if concerned, got information specific to their concerns)	50.1% <sup>S</sup>	34.2%	61.0%
Follow-up for children at-risk for behavioral, social, or developmental delays (FURISK) (% of children at risk for delays for whom some type of follow-up was provided)	59.5% <sup>NS</sup>	54.2%	66.7%
Smoking, Drug, Alcohol Assessment (SDA) (% asked about smoking and drug or alcohol use in the family)	69.0% <sup>S</sup>	62.6%	75.0%
Help with Care Coordination (CC) (% of children requiring more than one type of health care service who received needed help coordinating care)	59.6% <sup>NS</sup>	56.5%	68.1%
Helpfulness of Information and Education Provided (HELP) (% reporting that care was helpful or very helpful to all items answered)	64.6% <sup>S</sup>	59.3%	69.3%
Health Information (HI) (% reporting receipt of written or other type of information about caring for their child, injury prevention, and child development)	77.4% <sup>s</sup>	67.4%	81.9%
Minimum comprehensive care composite (% meeting threshold scores for each of the AGPE,FCC, FA, SDA, and FURISK measures)	25.3% <sup>S</sup>	17.8%	29.8%

Source: 2001–04 CAHMI PHDS-PLUS Data from Seven State Medicaid Programs <sup>S</sup> Denotes variables for which statistically significant variation exists among states for the PHDS measures score. <sup>NS</sup> No significant variation exists among states for the PHDS measures score.



#### 1.4 What is the added value of the PHDS-PLUS to Medicaid?

Medicaid agencies play a pivotal role in ensuring the quality of the preventive and developmental health care services that they provide to nearly two of five children under age 4 in America. Not only does Medicaid have significant leverage to influence the quality goals and improvement efforts of health plans and providers, federal regulations also require state Medicaid programs to demonstrate whether children receive needed services and quality care. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) health care services regulations set forth in the federal Omnibus Budget Reconciliation Act of 1989 (OBRA 89) and the 2003 Balanced Budget Act regulations both require Medicaid programs to demonstrate results and implement a health care quality strategy to assess and improve services to children enrolled in Medicaid.

Prevailing quality measurement strategies in the area of preventive and developmental services for young children primarily rely on counting how many children in certain age groups have had a well-child visit and received recommended childhood immunizations. Common strategies also include medical chart abstractions to assess provision of physical screens such as provider measurement of height, weight, and head circumference.

While important first steps, these methods fail to provide a comprehensive, valid picture of performance across each of the distinct aspects of services recommended. For example, a recent national study found that while children who have at least one well-child visit are much more likely to receive some level of preventive and development services compared with children who do not have such a visit, the majority of children who have visits are still unlikely to receive all recommended services.

Critical aspects of care commonly left out or inadequately addressed in current quality measurement efforts include the many aspects of preventive and developmental services that occur in the context of the relationship and conversations between health care providers and parents and children. These aspects are best assessed by collecting data directly from parents. These include:

- Provision of parental anticipatory guidance and education in the areas of child physical health and injury prevention and child cognitive, social, and emotional development;
- 2. Provider assessment of a *child's developmental status and follow-up* for children at risk for developmental delays;
- 3. Provider assessment of *family well-being and psychosocial risks* that affect a child's health and development such as smoking, drug and alcohol use, parental mental health, and family stress; and

4. **Accessibility of care and family experience** of care that is family-centered, coordinated, and culturally sensitive.

These aspects of care cannot be reliably or validly measured using billing/encounter data or medical chart reviews.

Medicaid programs can enhance the value and maximize the use of quality measurement resources if a comprehensive set of consumer-centered survey data and utilization and program data is collected and integrated at the child level as outlined in this manual. Doing so allows for more robust and actionable evaluations that can inform efforts to improve care across a range of EPSDT services, including areas often not measured such as anticipatory guidance, developmental screening, and follow-up and family psychosocial assessment.

#### **Summary of Medicaid Applications of the PHDS-PLUS**

To date, **nine Medicaid programs** have used the PHDS-PLUS (or the shorter PHDS) to assess and shape efforts to improve preventive and developmental services for young children. The programs are in Florida, Louisiana, Maine, Minnesota, Mississippi, North Carolina, Ohio, Vermont and Washington. In addition, at least three **External Quality Review Organizations (EQROs)** with whom Medicaid programs contract for purposes of fulfilling federal requirements have used or currently use the PHDS-PLUS to advance state Medicaid program quality improvement efforts in the area of preventive and developmental services for young children. Other **national and local efforts** have used all or part of the PHDS-PLUS to assess and inform strategies to improve policies and health care services, including the federal Maternal and Child Health Bureau's National Survey on Early Childhood Health (NSECH), the Vermont Child Health Improvement Program (VCHIP), the National Initiative for Children's Healthcare Quality (NICHQ), and the North Carolina Child Health Improvement's (NC-CHI) Healthy Collaborative project.



#### 1.5 Development of the PHDS-PLUS

The PHDS-PLUS was designed and tested by The Child and Adolescent Health Measurement Initiative (CAHMI) using an explicit peer-reviewed measurement development process. It was designed to fill important gaps in available methods to evaluate quality in the many areas of recommended preventive and developmental services that require parent-reported information in addition to program-wide assessments. Versions of the PHDS-PLUS have been developed for use by Medicaid to assess care provided by health plans and pediatric practices.

The following selection criteria were used to select topics assessed in the PHDS-PLUS survey:

- Appropriateness for all children in the specific age group
- Strength of scientific evidence
- Professional consensus
- There was a not a more reliable, valid, or efficient way to measure the topic
- The topic was important to parents (as derived from cognitive interviews and focus groups)
- The topic can be validly and reliably reported by parents
- Parsimony (e.g., topic is not already largely represented by another, related topic in the PHDS-PLUS)

The six stage development process included:

- **Stage 1**: Develop conceptual framework and investigate relevance of measure
- **Stage 2**: Develop starting point measurement proposal including initial feasibility studies
- **Stage 3**: Develop draft instrument and implementation methodology
- **Stage 4**: Conduct field-testing
- **Stage 5**: Revise and refine as necessary
- **Stage 6**: Develop scientific and technical documentation to support larger-scale implementation and dissemination

#### **Special Note About Cognitive Testing and Reading Grade Level:**

An important component of the development of the PHDS-PLUS was to ensure that it had a low reading grade and cognitive-ease level. Computer programs were used to determine reading grade level estimates based on algorithms that take into account the length of the words used, etc. Therefore, a very common word that in a cognitive interviews may be found to be easy to interpret and read may have a high reading grade level simply because of the length of the word. The cognitive ease of a survey can be assessed by conducting formal cognitive interviews with subjects on the survey items.

Reading grade level experts such as Mark Hochauser, PhD, recommend that you conduct a formal reading grade level assessment with standard computer programs coupled with cognitive interviews.

In accordance with these recommendations, the CAHMI team conducted the following steps to ensure that the PHDS-PLUS is at a sufficient reading grade and cognitive level for parents of Medicaid clients:

- 1998 Formal readability assessments were conducted indicating that the PHDS is written at the 8th–9th grade reading level using various reading grade level computer programs.
- 1998 In-depth cognitive testing was conducted with 15 families representing a range of racial, income, and education groups as well as different types of health insurance coverage, age of child, age and sex of parent, and number of children in family. Parents were uniformly able to complete the self-administered survey in 10–15 minutes and the readability of the survey was confirmed.
- 2001 A second round of cognitive testing was conducted to ensure that the PHDS-PLUS survey—when administered over the telephone—was feasible to administer to parents of children enrolled in Medicaid. The CAHMI team conducted cognitive interviews with 20 parents of children 3–48 months old who were enrolled in Medicaid. Five of these interviews were conducted in person, while the remaining 15 were conducted over the telephone in order to assess the response burden and cognitive ease of the PHDS-PLUS when using a telephone administration. For each item, instances where the respondent required clarification or did not appropriately answer an item were noted. Also, items for which the interviewer had difficulty asking the question without edits to the wording were noted. Survey modifications were made based on these findings in order to improve the reliability, validity, and cognitive ease of the PHDS-PLUS items.



#### 1.6 Requirements to implement the PHDS-PLUS

This manual provides detailed technical guidelines for implementing the PHDS-PLUS in Medicaid. Below is a summary of the strategic and technical requirements for the successful use of the PHDS-PLUS in Medicaid, which are discussed in more detail throughout this manual.

# Summary of Strategic and Technical PHDS-PLUS Requirements for Medicaid

- 1. Determine **priority uses** of PHDS-PLUS Quality Data
- 2. Identify and Engage key partners
- Construct and supply sampling data set to experienced survey vendor
- 4. Contract with and provide ongoing guidance to **survey vendor** 
  - Average time required to administer the PHDS-PLUS: 12–15 minutes
  - Range of costs to administer the PHDS-PLUS: \$18–\$25 per completed survey
  - Range of observed **response rates** for Medicaid: 78%–94% of parents successfully contacted and 35–50% families included in the starting sample.

**Strategic Requirements:** The PHDS-PLUS requires Medicaid programs to (1) clearly define how this tool fits into their overall quality measurement and improvement strategy and (2) to identify key partners.

- Priority Application(s): Medicaid agencies need to determine the priority application or applications for the PHDS-PLUS data. For example, will results be used to (a) assess and compare performance of health care plans; (b) compare quality of care across specific subgroups of children; and/or (c) determine health risks and unmet needs of children living in different parts of the state.
- 2. **Key Partners:** Medicaid agencies need to consider who to involve up front in order to ensure that information derived from the PHDS-PLUS is best used to inform, shape, and stimulate improvements in care. For example, (a) other state health agencies who also track and seek to improve preventive and developmental services for young children; (b) pediatric provider associations

and practices who will need to take action in order to improve care; and/or (c) parents of young children who can be key allies in stimulating improvements in care.

**Technical Requirements:** Medicaid programs will need to (1) supply Medicaid client/parent contact, sampling, and analytic information and (2) ensure survey vendors conduct sampling, administration, and scoring in a high-quality manner.

- 1. Contact and Eligibility Information: Medicaid agencies will need to construct a sampling data set that includes contact and eligibility information for all Medicaid clients who meet criteria to be included in the PHDS-PLUS sample. This will include providing (a) telephone and mailing information; (b) length of continuous enrollment; (c) whether the child received a well-visit in the past year; (d) number of visits in the past year; (e) child's age; and (f) other variables, such as health plan enrollment, that may be required to identify children for whom Medicaid agencies want to ensure are adequately represented in order to examine PHDS-PLUS quality scores.
- 2. Survey Vendor Supervision and Guidance: To get the most out of the PHDS-PLUS survey, most Medicaid programs will need to ensure that the survey vendor they contract with to sample, administer, and score the PHDS-PLUS has adequate guidance and supervision regarding (a) sampling to ensure sufficient completed sample sizes for different subgroups of children; (b) administering the survey to ensure the highest response rate possible; (c) coding and constructing quality scores and analytic variables based on survey data; and (d) scoring and presenting the data in different ways in order to inform the range of applications defined by Medicaid. (Average costs for survey vendors to administer the PHDS-PLUS have ranged from \$18–\$25 dollars per completed survey.)

**Requirements of Medicaid Clients:** Parents of young children (1) need to be able to be contacted and (2) respond to the PHDS-PLUS.

- 1. **Keeping Contact Information Up-to-Date:** Medicaid clients should be encouraged to keep their contact information up-to-date.
- 2. Responding When Contacted: Medicaid clients should be encouraged to respond to surveys about the health care their child receives as a way to ensure that Medicaid programs have information from parents to assess and ensure the highest quality of care possible. The PHDS-PLUS takes about 12–15 minutes of time to administer by phone. Across Medicaid programs to date, PHDS-PLUS response rates have ranged from 78%–94% of parents who were able to be contacted.

# Checklist for Planning, Implementing and Reporting PHDS-PLUS Results















Prepare for Survey Administration



Conduct Survey & Prepare for Data Analysis



Measures & Plan to Construct Quality Report Findings



Report your PHDS-PLUS Findings

Plan for communicating

findings to each key

Calculate core PHDS PLUS quality variables

audience

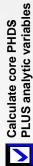
Organize your implementation team

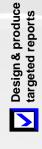
Clarify where you want to end up!

Identify & engage key partners











enrollment & utilization

Create sampling frame & analytic variable datasets

information

Obtain updated



V Plan sampling strategy

Confirm feasibility of sampling strategy

supplemental survey items Develop & test any >

Finalize survey design& CATI program setup

administration process & management plans

Finalize survey administration

Weight survey data to population

> information to collect at time of sampling Identify analytic <u>></u>

#### 1.7 PHDS-PLUS Resources

More information on implementing the PHDS-PLUS is available at **www.cahmi.org** or by contacting The Child and Adolescent Health Measurement Initiative at **cahmi@ohsu.edu**.

For more information on the development of the PHDS-PLUS, contact CAHMI or refer to the following publications:

- Bethell C, Peck C, Schor E. Assessing health system provision of well-child care: The Promoting Healthy Development Survey. *Pediatrics*. 2001 May; 107(5):1084–94.
- Bethell C et al. *Partnering with Parents to Promote the Healthy Development of Young Children Enrolled in Medicaid.* The Commonwealth Fund, September 2002. Available at:
  - http://www.cmwf.org/publications/publications show.htm?doc id=221310
- Bethell, C et al. Measuring the quality of preventive and developmental services for young children: National estimates and patterns of clinicians' performance. *Pediatrics*. 2004 June; 113 (6): 1973–1983.

For more information on national guidelines:

#### **MCHB's Bright Futures**

- http://www.brightfutures.org
- Green M, ed. Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents. Arlington, VA: National Center for Education in Maternal and Child Health, 1994.

#### **AAP Health Supervision Guidelines**

- http://www.aap.org
- American Academy of Pediatrics. Guidelines for health supervision III. Chicago, IL: American Academy of Pediatrics; 1997.

#### **Healthy People 2010**

- http://odphp.osophs.dhhs.gov/pubs/HP2000/2010.htm
- U.S. Department of Health and Human Services. *Healthy People 2010*. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

#### **US Preventive Services Task Force**

- http://www.ahrq.gov/clinic/uspstfix.htm
- U.S. Preventive Services Task Force. Guide to Clinical Preventive Services, 2nd ed. Washington, DC: Office of Disease Prevention and Health Promotion, U.S. Government Printing Office, 1996.

For more information on the other childhood preventive care measures described in this section:

**Health Care Financing Administration (HCFA)** Form 416 (Centers for Medicare and Medicaid Services)

• <a href="http://www.cms.hhs.gov/medicaid/epsdt/416form.pdf">http://www.cms.hhs.gov/medicaid/epsdt/416form.pdf</a>

#### **National Survey on Early Childhood Health (NSECH)**

http://www.cdc.gov/nchs/about/major/slaits/nsech.htm

#### **Step 2: Specify Your PHDS-PLUS Implementation Strategy**

Several steps are needed to design your PHDS-PLUS implementation strategy. You will need to:

- 2.1 Clarify where you want to end up
- 2.2 Identify and engage implementation partners
- 2.3 Plan and confirm the feasibility of your PHDS-PLUS sampling strategy
- 2.4 Develop and test any supplemental PHDS-PLUS survey items
- 2.5 Identify analytic information not based on the survey to be collected at the time of survey sampling

Each of these steps is further discussed in the pages that follow.

#### **STEP 2.1:** Clarify where you want to end up

## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to maximize the value of your PHDS-PLUS project by making sure that you design your project to meet specific goals and reporting requirements. It is easy to miss opportunities for collaboration, data collection, and dissemination of your PHDS-PLUS findings if time is not spent up front clarifying where you want to end up at the completion of the project.

#### In this step you will:

- ✓ Clarify the <u>purpose(s) for collecting PHDS-PLUS</u> data
- ✓ Set **overall goals** for what you want to accomplish by using the PHDS-PLUS
- ✓ Identify <u>overall measures</u> you will use to determine if you have achieved your goals
- ✓ Clarify internal or external **audiences that will evaluate** your project's success
- ✓ Specify <u>evaluation measures</u> for each "evaluation" audience
- ☑ Confirm <u>audiences for reporting</u> PHDS-PLUS results (e.g., providers, families)
- ✓ Specify **key messages** for each "reporting" audience
- ✓ Identify project design and data collection <u>requirements to meet reporting goals</u>



#### **GUIDELINES AND ISSUES TO CONSIDER**

#### Be as specific as possible.

As with any project, you need to set the goal(s) you wish to accomplish. Additionally, these goals need to be specific. For example, administering the PHDS-PLUS because you want to implement a quality measurement project is not specific enough.

Think about the precise priority topics for assessment (e.g., follow-up for children at risk for developmental delays) and unit of analysis (e.g., health plans, pediatric practices), why you want to use PHDS-PLUS, other ways to interpret/use the PHDS-PLUS findings (e.g., receipt of mental health or Title V services), who you want to provide that information to, and how you expect to use the results. When specifying your purpose and goals consider the following:

#### Purpose #1: Quality Measurement and Improvement

- <u>Demonstrate performance</u> of your state program and identify priority areas for improvement.
- <u>Compare performance</u> across different health plans, pediatric providers, or service areas and target and track improvement.
- <u>Learn about differences</u> in quality within and across many groups of children,
   such as those from different racial/ethnic or health status groups.

#### Purpose #2: Program and Policy Planning and Evaluation

- <u>Identify unmet needs</u> of parents and children.
- Educate and stimulate partnerships to improve across sectors and agencies.
- <u>Determine health risks</u> and health care service needs of children and their families.
- <u>Compare policies</u> for organizing and paying for health care services for children.

#### Purpose #3: Educate and Empower Families and Other Partners

- <u>Inform</u> providers, families, health care leaders, and other partners about their roles in ensuring high-quality care and empower them to play active roles in the project.
- ✓ <u>Involve each evaluation and reporting audience</u> in specifying goals, measures of success, and key messages. You can do this through in-person meetings, e-mail requests for input, or phone calls.
- ✓ <u>Decide whether you want to be able to compare PHDS-PLUS findings</u> across groups such as health plans, state programs, geographic areas, and so on. If so, this will have many implications for your PHDS-PLUS project sampling, administration, and scoring steps.

✓ Confirm whether you intend to repeat the PHDS-PLUS in the future or it this is a "one-time" effort. If you will repeat it, when? Repetition will allow trending of PHDS-PLUS measures and could impact the initial design of your project.

#### STEP 2.2: Identify and engage key partners



#### WHAT IS THE PURPOSE OF THIS STEP?

A key component of implementing the PHDS-PLUS in state programs is to identify and involve many partners up front. Doing so can lead to small but important changes to the design of your project that will enhance its relevance and value as well as "buy-in" by essential stakeholders. Like you, many stakeholders need and use information to guide their efforts and may have unique and valuable information about the health and health care of children.

Past users of the PHDS-PLUS have found that because it captures information beyond health care quality information (e.g., child health and health care characteristics, parental health and behaviors) they have been able to partner with multiple organizations with whom they do not normally collaborate on quality measurement projects.

#### In this step you will:

✓ Identify other state agencies and private sector groups that share responsibility for ensuring high-quality preventive and developmental services for young children (e.g., Department of Health, Title V Agency, Department of Children with Special Health Care Needs).

✓ Investigate **valuable data that may be available** through other state agencies and private sector partners. For example, you could indicate which children represented in the PHDS-PLUS survey sample are enrolled in other state programs or who have received certain types of medical, mental, or developmental services.

✓ Search for ways to **share costs and other resources** needed to implement your PHDS-PLUS project. For example, some other state programs may also have responsibility to demonstrate performance in the area of child preventive care services. Combining resources could lead to reduced costs for both agencies. By collaborating with Medicaid, other agencies may benefit from Medicaid's ability to secure federal

matching funds for quality of care related projects and offer other resources in exchange for this benefit.



Broadening the scope of participants in your PHDS-PLUS project can help you:

- ☑ Standardize the performance measures being used in your area
- ☑ Share measurement costs
- ☑ Gain leverage to secure support from the health care sector
- ☑ Streamline communications with patients, consumers, and providers
- ✓ Craft a successful information dissemination strategy
- ☑ Establish a community-wide understanding about the use of quality information
- ☑ Achieve efficiencies in implementing measurement work
- ☑ Reduce the burden on the plans/providers being measured or the consumers/patients being surveyed
- ☑ Ensure the credibility of the initiative by including all prominent organizations in the community

There are many benefits to forming a collaboration to conduct your PHDS-PLUS project. However, there are some challenges as well. By increasing the number of participants, you also increase the likelihood of divergent perspectives about which health care organizations/providers should be held accountable. This also may create a forum for airing other unrelated differences among the organizations. Additionally, there is an inertia created that is inherent in the process with a larger set of participants. Finally, you may need to resolve certain requirements or constraints of individual organizations in specific areas such as data privacy or vendor procurement.

Therefore, before deciding on partnering with an organization, ask yourself the following:

- 1. Do potential co-sponsors share the same goals? If not, can you accommodate their goals?
- 2. Do potential co-sponsors have specific requirements or constraints that would make partnering unfeasible?
- 3. Are there any implementation partners that would make the data collection and analysis and/or the dissemination of the results easier?
- 4. When is the best time to include these partners?
- 5. How will these partnerships affect the timeline, staffing, and budget of the project?

The answers to these questions will help you to decide whether project partners will help or hinder your project. Additional tips for engaging partners are noted below.

#### Be sure to:

#### ✓ Consider a broad range of strategic partners

There are various departments in state and local governments as well as many nonpublic organizations that are focused on providing, measuring, and improving preventive and developmental health services for young children. Obvious examples include:

- 1. State Medicaid and State Children's Health Insurance Program (SCHIP)
- 2. Departments of public health, mental health, social services, and education
- 3. Health plans, pediatric practices, and community-based clinics
- 4. Family organizations and individual families, children, and youth
- 5. Child care organizations
- 6. Parks and recreation
- 7. Professional associations and schools (e.g., American Academy of Pediatrics, American Association of Family Physicians, medical and nursing schools)
- 8. Legislators and other public leaders who shape and influence policy

**Table 2.1 Organizations and Groups to Consider As Partners** 

Category of Persons in Your State	Those responsible for federal and state reporting requirements, health policy decisions	Those involved in purchasing and contracting health care for children enrolled in Medicaid, SCHIP, and Title V	Those focused on quality improvement activities	Those focused on consumer education/information
Examples	Federal reporting requirements (Medicaid, SCHIP, Title V)     State reporting requirements     State legislature     Healthy People 2010     Medicaid Managed Care Quality Assessment (EQRO)     CMS Form 416     Title V MCHB Reports     1115 Walver Requirements	<ul> <li>Health Plans</li> <li>Front-line providers and provider groups (AAP, AAFP)</li> <li>Employer purchasing groups</li> </ul>	<ul> <li>External quality review organizations (EQROs).</li> <li>AAP, AAFP</li> <li>Educational institutions, continuing medical education organizations</li> </ul>	<ul> <li>Persons focused on giving consumers information to inform their choice of health care providers for their child/adolescent</li> <li>Persons focused on giving consumers information about the health and health care for child/adolescent</li> <li>Department of health</li> <li>Consumer advocacy groups</li> </ul>

☑ Clarify the **specific role for each potential partner** before initiating contact

There are several ways to consider partnering with other organizations or group for your PHDS-PLUS project. Partners can be **co-sponsors** or **implementation partners**.

**Co-sponsors** may be similar to your organization and have comparable goals for the project. They may share in the planning, decision-making, and/or the financing of the project. These organizations may have worked with you previously on a similar project or, perhaps, simply share your interest in quality information. For example, state Medicaid agencies may want to consider other agencies within the state, such as a Maternal and Child Health agency. Other examples of organizations that may be interested in co-sponsoring your project are:

- 1. State regulatory agencies
- 2. Other health care purchasers, such as private employers or business coalition
- 3. Consumer advocacy groups
- 4. Community-based quality advocacy groups
- 5. Provider groups and/or professional societies
- 6. Research/academic organizations

In the state of Vermont, PHDS data collected at the provider level was used to inform the efforts of multiple state agencies, parent advocacy groups, consumers, and providers. **Implementation partners** are stakeholders who you want to make aware of your project, as these partners can aid in the implementation of the project. You may not necessarily want these partners to make content decisions about your project, and you may want to wait until after initial planning before you involve them. However, these partners may be critical to a successful project. One strategy for involving implementation partners is to form an advisory group, where members make suggestions and inform their representative groups about the project. For instance, if you are planning a provider-level quality measurement project, implementation partners may include:

- 1. Health plans that contract with the providers
- 2. Other health care purchasers
- Professional organizations, such as the American Medical Association (AMA),
   American Academy of Pediatrics (AAP) or the American Board for Internal
   Medicine (ABIM)
- 4. Individual health care providers who will be receiving the information and asked to improve care
- Consumer advocacy groups focused on children's health care, such as Family Voices

☑ Identify specific <u>benefits potential partners can receive</u> from the PHDS-PLUS project.

For each potential partner, consider what information you will have <u>available in the PHDS-PLUS</u> that they would find valuable. Examine each component of the PHDS-PLUS and think about topic areas of interest to potential partners. Consider issues or populations for which each group has responsibility or on which they can have an impact. Use the worksheet below to stimulate your brainstorming.

# **Example Worksheet 2.1: Information you have to share with key stakeholders**

Stakeholder	Relevant Information from PHDS-PLUS	Rationale: Why is this information useful?
Stakeholder #1:		
Stakeholder #2:		
Stakeholder #3:		

☑ Specify **information and resources partners can bring** to the collaboration.

Partnerships work best when everyone feels they have something important to contribute. Consider information that each stakeholder has or might have that you would find valuable. Use the worksheet below to stimulate your brainstorming.

# **Example Worksheet 2.2: Information key stakeholders have to share with you**

Stakeholder	Relevant Information For You	Rationale: Why might this information useful to you?
Stakeholder #1:		
Stakeholder #2:		
Stakeholder #3:		

## STEP 2.3: Plan and confirm the feasibility of your sampling strategy



The purpose of this step is to ensure you will end up with the completed PHDS-PLUS data you need to meet your project goals.

#### In this step you will:

- ☑ Clarify all <u>units of analysis</u> for which you would like to construct PHDS-PLUS measures
- ☑ Specify <u>sampling eligibility criteria and the</u> <u>minimum completed and</u> <u>starting sample sizes</u> required to allow you to compare performance on PHDS-PLUS measures across groups
- ☑ Outline and verify the **technical soundness** of your sampling strategy



#### Be sure to:

✓ Verify your unit(s) of analysis

This may seem like an obvious step, and you may have already done this while conceptualizing your project. However, it is critical that you are clear about your unit(s) of analysis. In other words, what entities, areas, or groups of children are you measuring? The PHDS-PLUS can be used to measure performance of health plans, provider groups or offices, individual health care providers, and even the population, regardless of the unit of health care delivery. Each of these units of analysis has different specifications for sampling, so you need to decide this first.

Second, you need to ensure that there are valid data to allow you to analyze at the desired unit(s) of analysis. For example, although you may want to analyze the data at the health care provider level, you may not have valid information at that level that can be linked to the child level PHDS-PLUS data. The CAHMI team has found that, while many states have a variable noting the provider with whom the child is enrolled, this variable is not valid for indicating the provider the parent is likely to have in mind when responding to the survey. This could be due to a variety of reasons:

- 1. The provider variable is based on the claims/bills database (this allows for one centralized billing code for a medical group) or
- 2. The child may receive well-child care from providers with whom they are not enrolled (e.g., they see a provider in the same office, therefore the claim is still paid).

Since this is the case, CAHMI recommends that you ask parents/survey respondents to indicate their child's personal doctor or nurse and use that information for provider-level reporting.

The bottom line here is to think about what unit of analysis is most salient and relevant to your priority audiences for the PHDS-PLUS findings. Health care systems vary across markets, so the answers as to who is accountable and who will use the information will differ depending on your health care system.

☑ Determine <u>sampling</u> <u>eligibility</u> for the PHDS-PLUS

# **Example 2.3: Sampling Eligibility Criterion and Sample Strategy for a Health Plan Unit of Analysis**

- 1. **Age criterion**: Select group of children 3–45 months of age (allows for time lag in sampling administration)
- 2. **Enrollment criterion**: Select children continuously enrolled for 12 months or since birth
- 3. **Age-stratification criterion:** Stratify sample by age to ensure sufficient sample sizes within each age group (usually ¼ 3–9.99 months, ¼ 10–18.99 months, ½ 19–45.99 months)
- 4. **Target child:** Randomly select only one eligible child per family
- 5. **Language:** English only

Sampling is the process used to identify children whose parents will be asked to complete the PHDS-PLUS. For illustration, the sampling strategy described above is designed to measure the quality of care provided in a *health plan*. If you are planning to use the PHDS-PLUS to assess a different group, such as a medical group, office, or individual health care provider, modifications will need to be made. Keep in mind that if you are planning to administer the survey in the pediatric office, a different survey and sampling methodology will need to be used (see guide for *In-Office Administration of the PHDS, Reduced Item Version*, listed in resources section).

The sampling algorithm illustrated in the text box above identifies children who will be 3 to 45 months old at the **beginning** of the survey and who were current health plan members continuously enrolled 12 months (commercial) or six months (Medicaid) or since child was born. Continuous enrollment allows for no more than one gap of up to 45 days (commercial) or one month (Medicaid). It also specifies that the sample should be stratified to ensure that sufficient numbers of children are represented in each age subgroup. Only one child per family will be selected and those families who do not speak English as their primary language will not be included in the sample.

#### Important Tip!

If you plan to supplement your survey responses with data other than what is necessary for sampling, make sure to link the data NOW! You will not be able to go back and do this once the survey has been administered. (See Step 2.5 for more information)

#### ☑ Determine the **minimum completed sample** required

The sampling strategy that you implement is dependent on how you will be using the results. If you plan on using the results to compare health care providers, for example, then you will need more completed surveys than if you were using the results to examine the quality of preventive care at the population level. Table 2.2 represents recommended sampling strategies based on different uses for the results. If you are planning multiple uses for your results, choose the sampling strategy with the largest minimum sample required.

Table 2.2: Examples of Children Targeted in State-Specific Samples Developed by Past Users of the PHDS-PLUS

Type of Characteristics you want to sample for	Targeted Samples for These Groups
Child Characteristics	<ul> <li>Race, ethnic groups (e.g., targeted samples for Hispanic children)</li> <li>Special health care needs (based on billing code data)</li> </ul>
Child health care characteristics	<ul> <li>Children who had one or more office visit in the last 12 months</li> <li>Children who had one or more well-child visit in the last 12 months</li> <li>Type of provider who serves as child's primary care provider (e.g., pediatrician, family practice)</li> </ul>
Geographic location where child resides	<ul><li>Rural, Suburban, Urban</li><li>County</li></ul>
Program in which child is enrolled	<ul> <li>Part C</li> <li>SCHIP</li> <li>Health Plan</li> <li>Fee-for-Service, Managed Care Organization, Primary Care Case Management</li> </ul>

The minimum sample required to administer the PHDS-PLUS can be calculated from the information in Table 2.3 below using the following formula. Use the values in the table or substitute your own better estimates to determine the minimum sample required.

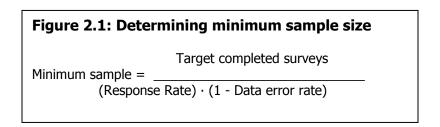


Table 2.3. Determining the minimum sample required to administer PHDS-PLUS

	Comparison of providers <sup>a</sup>	Comparison of health plans <sup>a</sup>	State-level reporting
Target completed	50 per health	250 per health	100 <sup>c</sup>
surveys	care provider	plan	
Estimated data error	1%	1%	1%
rate			
Estimated response rate	40%	40%	40%
Minimum sample <sup>b</sup>	126 per health	632 per health	253
	care provider	plan	

<sup>&</sup>lt;sup>a</sup> Although a smaller sample could be drawn if you are not planning on using the results to compare, we recommend that you assume comparisons will be made if you are reporting results at the provider or health plan levels. Stakeholders will want to make comparisons and false conclusions could be drawn.

Terms used in the determination of your minimum starting sample size are listed below along with an example.

**Minimum Sample**: The minimum number of children that should be sampled for the administration of the survey given the intended use of the results.

**Targeted Number of Completed Surveys**: The minimum number of completed surveys necessary for analysis. A completed survey has to have at least 80% of the items answered and will be discussed in greater detail later in this section.

**Estimated Response Rate**: This is the percentage of parents who respond to the survey. You can never know for sure what the response rate for your survey will be, however, you can estimate this rate based on your own previous survey experience. If you do not have previous experience to base this estimate, we recommend using 40%. This represents a conservative estimate for a response rate based on field-testing and the implementation of similar surveys and should ensure that you have enough completed surveys for analysis. Field testing and previous implementation results of the PHDS have yielded response rates from 20% to 70%. Any response rate estimate that you have from previous survey experience in your area should be substituted for the estimated response rate when determining the minimum sample size. There are a myriad of factors that can influence the response rate of your survey. Suggestions will be provided throughout this section to help you to maximize your response rate.

<sup>&</sup>lt;sup>b</sup> We recommend that each sample contain members enrolled in the same type of health insurance coverage. Therefore, *different* samples should be drawn if you wish to assess quality of care for Medicaid beneficiaries and commercial enrollees.

<sup>&</sup>lt;sup>c</sup> This is the minimum number of surveys. However, to date, all of the Medicaid agencies that have implemented the PHDS-PLUS have set their completed survey goal at N=2,000. This sample size has allowed the state to do a number of analyses that met their strategic and political goals.

**Estimated Data Error Rate**: This is the rate of data errors that you expect within your sample or sampling frame. Data errors are incorrect or bad contact information, enrollment information, eligibility information, or any other information that is necessary for the administration of the survey. You may not know what the data error rate is for your sampling frame, but you are likely to find some data errors. We recommend using a rate of 1% to 2% if you do not know. If you do know the data error rate, this number can be substituted in the chart above and will increase or decrease your minimum sample size.

## **EXAMPLE 2.4: Determining Minimum Sample Size**

State A chose to administer the PHDS-PLUS for its Medicaid program. The state primarily contracts directly with health plans and would like to use the PHDS-PLUS results mainly for quality improvement. However, they also will be publishing the results in a consumer guide. Because they contract with several health plans and want the plans to have enough time to implement a quality improvement plan, the state has decided to administer the PHDS-PLUS on a rotating basis. Parents of young children affiliated with plans in the northern counties will receive the survey this year with the southern counties following the next year. The survey will then be administered every other year on a rotating basis to measure improvement. Two years ago, the state administered the PHDS-PLUS at the state level and had a 52% response rate. They also conducted an audit of their provider records just last year and expect their data error rate to be less than 0.05%. Their minimum sample size for health plans for each of the three age groups in the PHDS-PLUS is 50. See Figure 2.2 below.

Minimum sample size = 
$$\frac{50}{(.52) [1-(.05)]}$$
 = **102**

## ✓ Specify and verify the **soundness of your sampling strategy**

Figure 2.2 provides an illustration of a sampling strategy for the PHDS-PLUS. You will need to specify and confirm the soundness of your strategy, and we recommend confirming the feasibility of obtaining all needed data before finalizing your plan. For example, it is not uncommon for data elements or contact information needed to administer the PHDS-PLUS to be lacking for key subgroups of children you would like to include in your sampling.

✓ <u>Utilize Tele-match</u>, a telephone number verification service or similar kind of service to verify the telephone numbers of each case in your identified sample.

# EXAMPLE OF A SAMPLING STRATEGY FOR THE PHDS-PLUS INCORPORATING A CORE AND STATE-SPECIFIC SAMPLING STRATEGY AND BASED ON A COMPLETED SURVEY GOAL OF N=2000. FIGURE 2.3:

# Part 1: Identify Children Eligible for Sampling

Step 1: Identify children who will be 3 months to 45 months old at the time of survey administration.

Step 2: Identify children who have a valid phone number

CHILDREN ELIGIBLE TO BE SAMPLED

Step 3: Identify children who meet the continuous enrollment requirement. (Remember – Age-specific continuous enrollment requirement)

Step 4: Deduplicate for families – Assure that only one family or household address is eligible for sampling.

# Goals and Objectives for the CORE SAMPLE

Part 2: Select Children for the Core Sample

across the state and will allow for comparative analysis to other states who To identify a random, representative sample of continuously enrolled children in Medicaid who will be 3-45 months old <u>at the time of survey</u> administration. This sample will allow for assessment of quality of care have used the PHDS-PLUS.

To stratify the Core SAMPLE by the child's age at the time of survey administration to assure that sufficient samples of children in three age groups are identified. To identify a sufficient starting core sample that will be able to yield n=625 completed surveys from the Core SAMPLE via telephone administration.

Goals and Objectives for the STATE-SPECIFIC SAMPLE To target specific groups of children in the state. This sample will allow for assessment of quality of care for specific groups of particular interest to the state.

Part 3: Select Children for the State-Specific Sample

Within each of these groups, to identify a random, representative STATE-SPECIFIC SAMPLE of continuously enrolled children in Medicaid who will

be 3-45 months old <u>at the time of survey administration</u>

Within each of these groups, to stratify the STATE-SPECIFIC SAMPLE

by the child's age at the time of survey administration to assure that

sufficient samples of children in three age groups are identified.

To identify a sufficient starting STATE-SPECIFIC SAMPLE that will be able to yield n=1375 completed surveys via telephone administration.

## Sample 1A:

(1/4 of Core Sample)

Core Sample- Children 3-9.99 mos. old, Cont. Enrolled Since Birth

Completed Survey Goal: 156

**SELECT 542 CHILDREN** 

## (1/4 of Core Sample) Sample 1B:

Core Sample- Children 10-18.99 mos. old, Cont. Enrolled Since Birth and/or for 12 mos.

Core Sample- Children 19-45 mos. old, Cont. Enrolled for 12

Completed Survey Goal: 156

## (1/2 of Core Sample) Sample 1C

Completed Survey Goal: 1087

SELECT 542 CHILDREN

## SELECT 542 CHILDREN

# State Specific Sample:

Fargeted Sample for Groups of Children in the State.

% of sample is children 3-9.99 months old, % of sample is children 10-18.99 months old, % of sample is children 19-45 months old.

Completed Survey Goal: 1375

## **SELECT 4775 CHILDREN**

## - 33

## •

## STEP 2.4: Develop and test any supplemental survey items



The purpose of this step is to consider whether there are a small number of items (3–5) you can add that will enrich your PHDS-PLUS data for you or your strategic partners.

## In this step you will:

- ☑ Identify any important topics to add to the PHDS-PLUS that would enrich the PHDS-PLUS data
- ☑ Identify <u>existing and tested survey items</u> for topics of interest or develop and test new items
- ☑ Double check the <u>impact of new items included in your sampling strategy</u> to be sure you will have a sufficient completed sample to meaningfully evaluate responses to your new items



## Be sure to:

- ✓ Make sure the items you add are <u>age-appropriate</u> for children uner age 4.
- ☑ Only include new survey items that cannot be found **more reliably using another data source**, such as the medical record or administrative data.
- Do not develop new survey items if there are <u>already reliable and valid items</u> about the topic of interest. In many instances, existing survey items have already been tested and implemented.

You may wish to examine the following surveys for supplemental items:

- National Survey of Early Childhood Health (NSECH). Visit http://www.cdc.gov/nchs/about/major/slaits/nsech.htm for more information.
- National Health Interview Survey (NHIS). Visit http://www.cdc.gov/nchs/nhis.htm for more information.
- National Survey of Children with Special Health Care Needs (NS-CSCHN).
   Visit http://www.cshcndata.org for more information.
- 4. National Survey of Children's Health (NSCH). Visit http://www.nschdata.org for more information.
- 5. Behavioral Risk Factor Surveillance Survey (BRFSS). Visit http://www.cdc.gov/brfss/ for more information.

✓ Test any new items you design yourself to make sure the wording is interpreted in the way you intended. Do this "cognitive testing" even if only with a small group of parents of young children.

☑ Think about the **placement of any new survey items**. The survey should flow from topic to topic with similar items grouped together rather than jumping between different topics. Discontinuity complicates the cognitive task of completing the survey and can frustrate the respondent. All items that collect demographic information should be in the last section of the survey. Also, adding an item in a certain place in the survey can lead to unintended "order effects." This occurs when the answer to a previous question can "prime" or influence how a person responds to a following question in an undesireable way.

Minimize the number of different <u>time frames and response options</u> included in a survey. Wherever possible, ensure that added items have similar framing and response option language to that used throughout the rest of the survey. For example, if you are asking about discussions with their child's doctor use the anchoring text: "In the last 12 months did your child's doctor or other health provider talk with you about..." as well as the response options included in the PHDS-PLUS for similar items.

## **Examples of PHDS-PLUS Supplemental Survey Items**

Tailoring the PHDS-PLUS by adding 3–5 questions has been an important and valuable component for states. Below are examples of items that the states who partipated in the Promoting Healthy Development State Learning Network (PHDSLN) added to the PHDS-PLUS.

## Topic: Parent Perception About Well-Child Care (items derived from the NSECH)

Well-child care visits are visits that are made to a doctor or health care provider who takes care of (CHILD) when (he/she) is not sick, but needs a check-up or a shot. (In the last 12 months/Since CHILD'S birth), how many times has (he/she) had a well-child visit for a check-up or shot?

Let's talk about the well-child care (CHILD) has received (in the last 12 months/since [his/her] birth). Think about the last time you took (CHILD) for a check-up. How long was the doctor or health care provider who examined (CHILD) in the room with you?

How would you rate (CHILD)'s check-ups (during the last 12 months/since [his/her] birth)? Please include all the doctors, nurses, and other health providers that (CHILD) may have seen (Scale of 0–10).

## Topic: Home Visiting Nurse

A public health nurse is a nurse or visiting nurse that comes to your home for a visit about (CHILD). In the last 12 months, how many times did a public health nurse visit your home?

## Topic: Care Coordination (items derived from the NSCH)

In the last 12 months (or since child's birth), did your child need any special services, equipment, or other care for his/her health?

1a. How much a problem, if any, was getting the special services, equipment, or other care that he/she needed? Would you say you had a big problem, moderate problem, small problem, or no problem at all?

## Topic: Day Care (items derived from the NSECH)

In a typical week, how many hours does your child spend in the care of someone other than a parent or guardian?

- 1a. Is the person who usually cares for child a relative or non-relative?
- 1b. Is your child mostly cared for in your home, in someone else's home, or in a day care center?

## Topic: Obesity

How much does your child currently weigh? \* What is your child's current height? \*

\*Items used to calculate the child's Body Mass Index. Only applicable to children 2 years or older.

## **STEP 2.5: Identify analytic information to be collected at the time** of sampling



## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to identify data that can be linked to PHDS-PLUS results in order to enhance the value of the data collection. Supplemental data, in this case, refer to any data that are not directly needed for the administration of the survey but can be used for analytic purposes. For example, you may want to add an indication of whether the child had a HEDIS-defined well-care visit, or you may even want to have the child's claims history for more detailed analyses. Due to new federal regulations on data privacy (from the Health Insurance Portability and Accountability Act, or HIPPA), it is best to collect any child-level information prior to administering the survey, since obtaining information retroactive to receipt of completed surveys is often not acceptable. The confidential survey administration process recommended in this manual does not allow for any person-identifying information, such as the enrollee ID, to be linked with completed survey data.

## In this step you will:

✓ Identify **data elements to collect** at the same time as survey sampling such as those outlined in Figure 2.4 below (e.g., child enrollment and utilization). These data file elements will be used for analytic purposes.

Obtain and link data elements to the sampling data file before pulling the starting sample.

Figure 2.4: Examples of Data Elements to Collect at the Time of Sampling

## Child Characteristics

- Race-ethnicity
- Date of birth
- Gender
- County
- Geographic region (e.g., urban, suburban, rural)
- Public health district

## Child Enrollment Characteristics

- Months of continuous enrollment
- Program child is enrolled (Medicaid, SCHIP)
- Medicaid Program child is enrolled (fee-for-service, managed care organization, primary care case management)
- Where applicable, child's health plan
- Where applicable, child's primary care provider (including specialty, e.g., pediatrician, family medicine)
- Enrollment in Part C program

## Child Health Care Utilization Characteristics

- Number of office visits (non-emergency room, urgent care)
- Number of well-child visits
- Number of urgent care visits

(For each of the above, the provider who delivered the care and the setting in which the care was provided e.g., private practice, federally qualified health center, rural health center)

## Whether Child Utilized Services in Other Departments

- Dept. of Health services (e.g., whether the child received a visit from a public health nurse)
- Dept. of Children with Special Health Care Needs services (e.g., whether the child received care coordination services)
- Dept. of Mental Health Services services (e.g., whether the child received care from a Dept. of Mental Health provider)



## **GUIDELINES AND ISSUES TO CONSIDER**

## Be sure to:

✓ <u>Align dates</u> for utilization and enrollment data elements to survey timeframe (e.g., past 12 months from start of survey administration).

☑ Include utilization data if possible. In the PHDS-PLUS data that has been collected to date with Medicaid clients, more than 95% of families who complete the survey respond that their child has seen a doctor or other health care provider in the last 12 months or since the child's birth. As such, details on utilization will be available for most children and can be valuable when analyzing PHDS-PLUS results. For example, it can be very useful to examine findings for children according to the number of visits they have had in the past year or by whether utilization indicates the presence of certain types of health problems.

**Example 2.5: State-Specific Analyses Conducted Using Analytic Variables** 

State	Example Research Questions	Example of Analytic Variables Constructed
Louisiana	Examine quality of care findings by whether the child is enrolled in the Community Care Program, and to examine if there are variations in the findings by the length of time the child has been enrolled in the CCP program	Binomial variable of whether the child is enrolled in the Community Care program  Categorical variable related to the length of enrollment (e.g., more than 12 mos., less than 12 mos., not currently enrolled)
	For children enrolled in the CCP program, to examine quality of care findings by the type of provider who serves as the child's primary care provider	Categorical variable of the type of pediatric clinician who provided a majority of the well-child care
	Examine quality of care findings for children enrolled in the Part C program	Binomial variable of whether the child is enrolled in the Part C program
	Examine quality of care findings by place where the child receives care (private practice, federally qualified health center, rural health center)	Categorical variable of the place where child received well-child care
Minnesota	Examine quality of care findings by health plan	Categorical variable of the health plan child is enrolled
	Examine quality of care findings by child's race-ethnicity	Categorical variable of the child's race/ethnicity
	Examine quality of care findings by whether child received visits from a public health nurse	Categorical variable of the number of public health visits the child had
	Examine quality of care findings by the number of and kinds of health care services the child utilized	Categorical variable of the number of well- child visits the child had in the last 12 months
	Examine quality of care findings by where the child has received care	Categorical variable related to the place where child received well-child care

## Examples of State Specific Analyses Conducted Using Analytic Variables (continued)

State	Example Research Questions	Example of Analytic Variables Constructed
Mississippi	Examine quality of care findings ONLY for children who had one or more office visit	Binomial variable of whether the child had an office visit in the last 12 months
		Binomial variable of whether the child had a well-child visit in the last 12 months
		Categorical variable of the number of well- child visits the child had in the last 12 months
	Examine quality of care findings for children enrolled SCHIP	Binomial variable of the program to which the child is enrolled (Medicaid, SCHIP)
	Examine quality of care findings by the number of and kinds of health care services the child used	Categorical variable of type of pediatric clinician who provided a majority of the well-child care
	Examine quality of care findings by where the child has received care	Categorical variable of the place where child received well-child care
	Examine quality of care findings by WHO delivered the care	Categorical variable of type of pediatric clinician who provided a majority of the well-child care
Ohio	Examine quality of care findings by geographic region where the child resides	Categorical variable of the region the child resides (e.g., urban, suburban, rural/Appalachian, rural/non-Appalachian
		Binomial variable of whether the child lives in a zip code that is at high risk for lead poisoning
	Examine quality of care findings by child's race/ethnicity	Categorical variable of the child's race/ethnicity
	Examine quality of care findings for children enrolled in the Title V program	Binomial variable of whether the child is enrolled in the Title V program

## **Step 3: Prepare for and Conduct Survey Administration**

Preparing for survey administration requires four major steps:

- 3.1 Organize your implementation team
- 3.2 Create the sampling frame and analytic variable data sets
- 3.3 Specify your survey administration process and timeline
- 3.4 Finalize survey design and CATI set-up

Guidelines for each of these steps are provided below.



## STEP 3.1: Organize your implementation team



## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to develop a specific working team, work plan, and timeline for your PHDS-PLUS project and to assemble the data needed for a survey vendor to begin to assist you with PHDS-PLUS sampling and administration.

## In this step you will:

- ☑ Build an internal and external team to implement the PHDS-PLUS project
- ✓ Assign **specific roles** to each team member
- ✓ Hire a survey vendor



## Be sure to:

✓ Specify which tasks are to be completed <u>internally and which require external</u> partners or vendor.

When building your internal and external PHDS-PLUS team, consider the following:

- Which parts of the process can you handle with internal staff? Which parts require hiring an external vendor?
- Do internal staff members have the skills/expertise as well as the availability necessary to complete the tasks that will be assigned to them?
- Do you have the resources to compensate for areas where you do not have adequate internal staff? How will you do so?
- What is the status of your data systems that will be used for sampling and for gathering information for utilization? Will you need to contract with an external organization to gather population files that will to be used for these purposes?

☑ Immediately involve all <u>leaders whose approval is needed</u> to implement your PHDS-PLUS project activities or dissminate PHDS-PLUS findings.

Obtaining the full support of senior leadership is essential to the success of your PHDS-PLUS project. While it is possible to conduct the PHDS-PLUS without the early involvement and support of senior leadership, they may be the key to community-wide distribution of the results—justifying the value of the project to others, such as state legislators, or approving any contracts you enter into with external vendors. As such, we recommend engaging all individuals whose approval is needed for implementation or dissemination of PHDS-PLUS at the beginning of your project.

✓ Carefully craft a survey vendor Request for Proposal (RFP)

Now that you have determined which parts of the project will be contracted out to external entities, you will likely need to find a suitable survey vendor. Your organization most likely has specific rules and requirements for hiring a vendor. Depending on these requirements, this can be a lengthy process.

The process begins by writing a Request for Proposals (RFP). However, it may be called something different in your state or organization. This is the document that informs potential bidders of exactly what work needs to be done, how it should be done, and when it needs to be finished. This document should be as detailed and specific as possible. Make sure bidders understand exactly which costs they are responsible for, such as survey printing and mailing costs or report development and testing. Be sure to review the technical specifications sections before you write the RFP to make sure all necessary details are included. Also include management tasks such as regular progress meetings and/or interim reports, decision-making processes, and conflict resolution procedures.

All deliverables that you expect from the vendor also should be specified in the RFP. This includes interim deliverables, such as progress reports and interim completed PHDS-PLUS survey data sets, as well as final deliverables, such as the data set and all documentation about the project. The contract is based on the tasks listed in the RFP, so make sure it includes all of the items you need. If you make changes later on, it will most likely cost you more than if they were included in the original RFP.

The RFP should provide potential bidders with information on the processes for bidding as well as evaluating and selecting a vendor. Normally, the RFP issued by a state agency is required to be posted on a Web site so that all interested parties have an equal opportunity to learn about the project. It is important to include the following information in your RFP:

- Include the deadlines and format for which proposals should be submitted
- Include information about how bidders can ask questions or get clarification when preparing the proposals
- Include detailed specifications about the criteria used to score the proposals and select the vendor
- Include provisions for data security and confidentiality. Person-identifiable data
  are necessary only for the administration of the survey. Include provisions for
  the return or destruction of data files with identifying information that were
  needed for the sampling and administration of the survey

## ✓ Carefully **evaluate candidate survey vendors** who respond to your RFP

When evaluating survey vendors who respond to your RFP, the minimum scoring criteria should evaluate applicants on their ability to demonstrate their capability to implement the following components of a PHDS-PLUS project:

## General characteristics

- An understanding of the <u>overall project</u> and the goal of the PHDS-PLUS
- Responded comprehensively to <u>all tasks</u> described in the RFP
- Sufficient and qualified staff to do the work
- <u>Sufficient facilities and resources</u> (especially if the survey is being administered through the telephone and requires a CATI)

## PHDS-PLUS specific characteristics

- Experience and <u>expertise in sampling</u> based on utilization and/or administrative data characteristics, specifically:
  - Experience in obtaining <u>population files from state agencies</u> and pulling samples for survey administration based on enrollment and program markers such as where a client resides, the program in which the client is enrolled (Medicaid, SCHIP, specific health plans and/or providers), and by eligibility criteria (Foster Care, Part C, Supplemental Security Income, etc.).
  - <sup>o</sup> Experience in <u>creating weighted</u>, <u>stratified sampling files</u> based on information about the child's enrollment in Medicaid and child's age.
  - Experience pulling survey <u>samples at the level or unit of analysis</u> <u>desired</u>, such as health care provider or office or where the child resides (e.g., zip code, counties and/or parishes) to compare "rural" versus "urban" samples.
- Experience in conducting <u>parent-based surveys</u> about the quality of care received, specifically:
- Experiences conducting a <u>telephone survey administration including building CATI</u> systems that have skip patterns based on respondent answers to certain questions within the survey or based on data derived from Medicaid administrative and/or utilization data.
- Experience conducting telephone surveys with parents of young children.
- Demonstrated ability to <u>maximize response rates</u> and producing acceptable telephone response rates. The telephone response rate is calculated as the total

number of completed phone interviews divided by all possible phone respondents. An acceptable response rate is 40% or higher.

The contract will be based on the project detailed in the RFP. The contracting process will be easier if your RFP contains specific details on the scope of the work, deliverables, and timelines. Consult your legal department to make sure all of the necessary <u>legal language and requirements</u> are included. This is most likely standardized for all contracts with external yendors.

In addition, ensure that the data collection and sharing are compliant with the Health Insurance Portability and Accountability Act (HIPPA) in that any sharing of personal health information between organizations is strictly protected. Include provisions for the return or destruction of personal health information (PHI) once the project is completed. Create a <u>HIPAA Business Associate agreement</u> between all parties who will have access to the data.

## STEP 3.2: Create the sampling frame and analytic variable data sets



## WHAT IS THE PURPOSE OF THIS STEP?

## In this step you will:

- ✓ Create the child-level sampling frame data set (as specified in Step 2)
- ✓ Create the child-level analytic variable data set (as specified in Step 2)
- Deliver the data sets to selected survey vendor
- ✓ Have the survey vendor pull your PHDS-PLUS sample



## **GUIDELINES AND ISSUES TO CONSIDER**

## Be sure to:

## ✓ Align with <u>federal protocols</u>

The federal Centers for Medicare and Medicaid Services (CMS) has protocols for state Medicaid agencies to use when conducting surveys. We recommended conducting your PHDS-PLUS sampling in a way that is consistent with these protocols. A five-step approach that ensures valid and reliable data is outlined below, including:

- 1. Identifying the study population (see Step 2 of this manual)
- 2. Defining the sample frame (see Step 2 of this manual)
- 3. Determining the type of sampling to be used (stratified random sampling)
- 4. Determining the needed sample size (see Step 2 of this manual)
- 5. Specifying the sample selection strategy (ensure vendor documents this clearly)

Several other aspects of the CMS protocols should also be adhered to in regards to sampling. For example, stratified random sampling is recommended to achieve population goals (e.g., sufficient numbers of children across age groups, etc.). This technique calls for dividing the population into specific pre-identified strata or sub-groups that are homogenous with respect to certain characteristics of the population. Random sampling techniques are then applied to obtain eligible samples from each stratum or subgroup.

Provide survey vendor with a sampling and analytic data set <u>data dictionary</u>

Be sure to outline the specific variables you want to include in the child-level sampling and analytic (utilization, enrollment, etc.) data sets and obtain a data dictionary from your survey vendor before the PHDS-PLUS sample is pulled. This is to ensure that all variables that need to be linked to the survey data set will be available to you. Once the sample is pulled you may not be able to go back to get additional variables. In particular, be sure your vendor creates variables making clear to which each of the stratified sampling groups each child belongs (e.g., age, continuous enrollment, age group, any state-specific sampling strategies).

## -

## STEP 3.3: Layout and implement your survey administration process



## WHAT IS THE PURPOSE OF THIS STEP?

Establishing a specific work plan and realistic timeline is essential to the success of your PHDS-PLUS project. In the current political environment, many expect instant results with a quality measurement initiative. However, those who are familiar with the process for measuring quality know that it takes time to collect, analyze, and report the data and have those data utilized in a way that can begin to inform and affect improvements in care. Make sure you set a reasonable timeline for the overall project. It is very important to allow enough time for the administration of the survey, analysis of the results, and report development, testing, and production.

This section provides detailed information about the technical requirements for implementing the PHDS-PLUS. The timelines listed in the technical specifications below have been researched and tested in the field to ensure the best response rates and highest quality of data. Compressing the necessary time can compromise data quality and reliability.

## In this step you will:

- ✓ Understand the **key steps and timeline** for administering the PHDS-PLUS
- ✓ Verify your work <u>plan and delegation of tasks</u> within your implementation team
- ✓ Prepare to **specify in a contract** with an internal or external vendor/department how you would like the PHDS-PLUS to be administered



The PHDS-PLUS was developed specifically for telephone administration. Telephone administration requires fewer steps than mail administration, but can be more labor-intensive as many callbacks may be required. In addition, a telephone survey only can be administered to those for whom telephone information is available.

As outlined in Step 3.2, an important preliminary step to survey administration is the utilization of the Tele-match telephone number verification service or similar kind of service to verify the telephone numbers of each case that was sampled.

## **SURVEY ADMINISTRATION PROCESS:**

## **Step 1: Pre-notification letter**

For each selected case that has a viable address, a pre-notification letter should be mailed. This letter should be made available in all the languages for which the survey is to be administered. Pre-notification letters should be customized at the respondent level (e.g., "To the parent/guardian of [Child Name]") and also should include the logo of the specific state program and the signature of the appropriate agency's executive.

The pre-notification letter informs the parent about the following:

- The target child for whom the survey should be completed.
- That they were randomly chosen to assist the state in providing information that would be useful in improving the health care of children in their state.
- That the parent or guardian who takes the child to the doctor most often should complete the survey.
- That the survey will take approximately 15–20 minutes to complete.
- Provides a toll-free, 1-800 number for parents to use to call the vendor and provide a new phone number at which they should be contacted, ask questions regarding the study, verify the study's legitimacy, or request no further contact pertaining to the study.

**Appendix 2** provides an example of a pre-notification letter.

Similar to the protocols developed for External Quality Review, the pre-notification letter is a strategy utilized to maximize response rates, ensure confidentiality, and describe how the results will benefit the respondent and how the survey is to be completed.

Make sure that the United States Postal Service's "Address Correction Service" is utilized. This will ensure that you get accurate and complete information about the number of pre-notification letters that were not received by parents due to a bad address.

## <u>Step 2: Toll-free number available for parents to call with questions or to schedule an interview</u>

Throughout the field phase, a live toll-free 1-800 number should be maintained from 10:00 am to 11:30 pm (local time) Monday through Saturday and 3:00 pm to 11:30 pm (local time) on Sunday for respondents. Calls outside these hours should be referred to voicemail.

## **Step 3: CATI Administration**

One week after the pre-notification letter is sent, interviewers should begin making phone calls. The entire survey takes approximately **15 minutes** to administer. Up to 20 attempts should be made to contact a parent or guardian by telephone. Telephone calls should be made at different times and different days to increase the chances of reaching a parent or guardian.

During survey administration, the interviewer should refer to the child by his or her first name so that it is clear that the respondent should answer the survey questions relative only to the target child. The parent or guardian in the household who knows the child's health and health care history best should be the survey respondent.

Interviewers should be prepared to answer questions the parents might have about the project and the survey, particularly if parents have concerns about confidentiality that would prevent them from completing the survey.

Interviews should be conducted with parents of <u>eligible children only</u>. Do not let the parent complete the survey for any other child except for the target child identified at the time of sampling. When a household is contacted by telephone, the respondent (most often a parent) who is most knowledgeable about experiences with the care provided should be chosen to complete the interview.

During the CATI administration phase every effort should be made to interview difficult-to-reach respondents. For example, after determining that the telephone number in the

sample database is incorrect, steps should be taken to find the correct number, up to and including accepting new telephone numbers for the respondent taken from another member of the household. Also, if a respondent is away from the household, firm appointments should be made to attempt re-contact when the respondent returns. In addition, if a respondent is too ill at the time of the call, a firm appointment should be set to attempt re-contact at a later date within the survey administration time period.

CATI calls should be made from 10:00 am to 8:00 pm local time, Monday through Friday, and from 11:00 am through 8:00 pm local time on Saturdays. No calls should be on Sundays. Protocols for the number of call attempts and preferred times for calls should be in compliance with state-specific telemarketing laws. A minimum of 20 callbacks distributed across daytimes, evenings, and Saturdays should be attempted for each sampled case in the database during the field period.

If a respondent answers **80% or more of the core items in the survey** (does not include items for which a parent may be appropriately skipped out of answering), a survey is considered complete.

**Example 3.1: Survey administration timeline** 

Task	Date
Mail pre-notification letter	Day 1
Toll-free line for parents to call	Day 1
<ul> <li>Live toll-free, 1-800 number maintained from 10:00 am to 11:30 pm (local time), Monday—Friday, and 11:00 am to 11:30 pm on Saturday.</li> </ul>	
Calls outside these hours referred to voicemail.	D 0
<ul> <li>CATI Administration</li> <li>If the respondent says that they are busy, be sure to offer them the option of scheduling a time for the interview. Remember, these are parents of young children with chaotic schedules. Scheduling callbacks for interviews has been successful in the past.</li> <li>Avoid CATI administration on Sunday.</li> <li>Make sure that CATI administration is in compliance with state telemarketing laws.</li> <li>CATI administration should NOT be conducted past 8 pm or made prior to 10 am Monday–Friday and not prior to 11 am nor past 8 pm on Saturday.</li> <li>Each survey takes approximately 15 minutes to complete.</li> </ul>	Day 8
Completion of CATI interviews	Until Survey
<ul> <li>Time period will vary depending on the number completed surveys, number of interviewers, and whether the survey vendor is conducting surveys for multiple clients at once.</li> </ul>	Quota is Reached OR Each Number in the Starting Sample Called 20 Times.



## **ISSUES TO CONSIDER**

## Be sure to:

☑ Print the pre-notification letter on letterhead that parents recognize and find credible: Make sure that the envelope and pre-notification letter are on letterhead that parents will recognize and trust so that they do not throw it away as junk mail.

☑ Check whether there are other surveys targeted to parents of similar children: Make sure that there is not another survey going on at the same time that could lower your response rate. If there is, considering administering the survey at a different time.

✓ **Take into account holidays:** Make sure that survey administration does not occur on holidays. If it does occur during holidays, make sure your timeline accounts for a break in survey administration.

☑ **Build off of positive experiences in your state:** Each state and the parents in each state are different. Research whether your department or other departments have administered a survey to parents of young children before. What times worked best in that survey's implementation? What days worked best?

☑ Consider issues related to the season: Summer can be a difficult time for survey administration as families are often on vacation. Higher response rates are often observed in late fall or late winter. Avoid survey administration during the first week of school or during school holidays.

## **Lessons from the field:**

**From whom should the letter come?** If your PHDS-PLUS project is a collaboration with other partners, think about whether the cover letter should come from one or all of the organizations participating. Think about who parents trust and would be most likely to be influenced by to complete the survey.

**Real World Example:** The CAHMI implemented the PHDS in Vermont in collaboration with Medicaid and two pediatric medical groups. We randomized the pre-notification letters so that half were from Medicaid and half were from the pediatric medical groups. There were no differences in response rates between those who had received letters from the state or from pediatric medical groups.



## **Additional Tips**

## **☑** Estimating the Time of Survey Administration

Factors that affect the time of survey administration include:

- An interviewer can interview only a single respondent at a time
- Interviews can be conducted only during certain hours

 Unlisted phone numbers, the high incidence of phone lines used for purposes other than voice, and "Do not call" Web sites make it harder to find appropriate and willing respondents.

## ☑ Data Privacy and Confidentiality

Data privacy and confidentiality were critical during the research and the development of the PHDS-PLUS and its implementation protocol. The recommended protocol for implementing the PHDS ensures the privacy and confidentiality of the data. If you contract the administration of the survey to an external vendor, make sure to include data privacy and confidentiality provisions in the RFP and the contract.

Be sure that the organization conducting the survey administration signs a HIPAA Business Associate agreement. Check with your legal department about HIPAA compliance. The HIPAA privacy provisions establish how covered entities must safeguard the confidentiality of patients' protected health information. Your legal department can help you determine whether you are a covered entity under HIPAA and whether your project adequately safeguards the confidentiality of patients' protected health information as specified in the HIPAA regulations.



## **Additional Resources**

As mentioned earlier, there are additional versions of the PHDS that can be administered via mail and/or in doctors' offices. For more information about how items from the PHDS have been administered by varying modes of administration, go to the CAHMI Web site at <a href="https://www.cahmi.org">www.cahmi.org</a>.

To learn about a reduced-item version of the PHDS that is designed for administration in offices serving pediatric patients, download the "Manual for In-Office Administration of the Promoting Healthy Development Survey, Reduced-Item Version" on the CAHMI Web site at <a href="https://www.cahmi.org">www.cahmi.org</a>.

For more information about CMS standards for administering and validating surveys see <a href="http://www.cms.hhs.gov/medicaid/managedcare/protosrvy.pdf">http://www.cms.hhs.gov/medicaid/managedcare/protosrvy.pdf</a>.



## STEP 3.4: Finalize survey design and CATI set-up



## WHAT IS THE PURPOSE OF THIS STEP?

## In this step you will:

- ☑ Finalize the PHDS-PLUS you will administer
- Develop the final script for the CATI



## **GUIDELINES**

**Appendix 1** provides an overview of the survey items in the PHDS-PLUS. This overview does not include important framing text and wording that is used to transition from one component of the survey to the next. The purpose of this high-level overview document is to give you an "at a glance" view of the PHDS-PLUS to review the PHDS-PLUS items and to consider what items you may want to add.

**Appendix 3** provides the detailed script for the CATI. This script includes important text that the interviewer will use at the beginning of survey administration that is not necessarily a core component of the survey nor considered a survey item, but rather ensures that the correct person is identified to complete the survey and allows the respondent to actively consent to survey administration.

As discussed in Section 2, you can add three to five supplemental items to the PHDS-PLUS. However, it is imperative that the questions asked fit the overall theme of the survey and are placed in an appropriate section of the survey. Look at the sections of the survey and place the items in a similar section and next to items with similar framing text and tone. See Section 2.4 for additional guidelines on adding additional items to the PHDS-PLUS.



## Be sure to:

☑ Double **check the skip patterns** in the CATI survey

There are a number of skip patterns in the survey that are based on the child's age or on the survey responses. Be sure to check that the skip patterns in the CATI are correct.

The most essential skip patterns to check are:

- The skip pattern based on questions **U1-U3** asking respondents how many health care visits the child has had in the last 12 months. Respondents who report that their child has had no visits in the last 12 months are skipped out of a majority of the survey.
- The skip patterns related to the age-specific sections of the anticipatory guidance and parental education component of the PHDS-PLUS. The CATI variable used to determine which section of the survey the respondent should be read is Q59.
   For each of the three age groups, make sure that that the CATI goes to the correct age-specific section of the anticipatory guidance and parental education component of the survey.

✓ Make sure that the CATI uses the **child's correct age** for the age-specific skip patterns

Question **Q59** in the CATI clarifies which age group the child falls into. Prior to CATI administration, the child's age is calculated using the date of birth provided by Medicaid. As specified in the CATI, at the beginning of the survey, the interviewer should confirm the age of the child. On average, between 5%–10% of the time the child's age (as calculated based on the date of birth) is <u>NOT</u> correct and the respondent will provide the correct age of the child. Make sure that this corrected information is incorporated into variable **Q59**.

**<u>Train interviewers</u>** about the purpose of the survey and walk through each section of the survey

It is imperative that each person who administers the CATI understands the purpose of the survey and why we are asking the respondent questions about the child's health and health care use.

- Emphasize the importance of the framing language included in the CATI prior to each section of the survey. This language sets the stage for the questions that will be asked and addresses questions and comments that the CAHMI team received during the cognitive interviews with families.
- Educate interviewers that the "Assessment of the Family" section (CATI Items
   AF1-AF5) includes questions that ask the parent whether their child's doctor or
   other health provider asked about specific issues in the family such as smoking,
   alcohol, substance abuse, and depression. These questions are NOT asking the
   respondent whether he/she participates in the behavior or has those emotions.
   Make sure that the interviewer deliberately emphasizes the words "did your
   child's doctors or other health provider ASK you if you..." in questions AF1-AF5.

☑ Be cautious about adding <u>questions that ask the respondents about their</u> <u>health</u> or parenting behaviors.

The central purpose of the PHDS-PLUS is to gather information about the preventive and developmental health care provided during office visits. At the beginning of survey administration respondents are informed that this is the primary purpose of the survey. If the respondents are asked too many questions about themselves or their parenting behaviors then they begin to wonder why so many questions are focused on them rather than their child's health care. This could cause them to stop the survey administration.

Ask your <u>partners about what kinds of information they would like</u> to have and add previously tested questions that address those topics.

This is a great way to get "buy-in" and support for your PHDS-PLUS project. By asking what kinds of information your partners would like to have and by adding questions that address their interest(s), you will give your partners a sense of ownership in the survey project and interest them in the findings.

## **ADDITIONAL TIPS**

## **Removing items** from the core survey

The CAHMI **strongly** recommends using the PHDS-PLUS in its entirety, but recognizes that you may need to remove items in some cases to accommodate your needs. Before you remove any items from the core survey, consider the following:

- Start with the items that do not touch on quality of care, such as general information on parenting behaviors, parent health, child's health, and child's use of health care. Do any of these items fail to provide you with information that you can use for this project? Can you get valid information about this same topic from enrollment or member/claims databases?
- The only quality measure that CAHMI would suggest omitting, as a last resort, would be the "Helpfulness of Care" measure. The other quality measures all measure whether specific aspects of recommended care were received, whereas "Helpfulness of Care" asks respondents whether the care that was received helped them with their parenting.

## ✓ Testing and preparation of questionnaires and invitations

Thorough testing of the CATI should be conducted on "dummy" respondents. This includes ensuring that questionnaire logic works correctly (there are many scenarios to test) and that the respondent database populates correctly across all the questions.

## ☑ Institutional Review Board (IRB) Approval

You may be wondering if you need approval from an Institutional Review Board (IRB), especially if you do not have an IRB within your organization. You may even think that IRB reviews are only for research projects. However, you should obtain IRB approval to conduct the PHDS or any other survey. Patients' rights should be first and foremost. IRBs ensure that consumer/patient rights are protected. The technical specifications in this manual are meant to address legal issues that will allow for IRB approval. These specifications are based on past pilots of the PHDS and have endured IRB reviews and approvals. They were developed to ensure the highest data privacy and confidentiality standards.

If your organization does not have an IRB, you can still have a review. Independent IRBs often will review projects on a contractual basis. Also, almost every educational

institution has an IRB. If you partner with your local university, they may be able to have their IRB review the project at no cost to you.

## ✓ Translating the survey into other languages

The PHDS-PLUS is currently available in English. The shorter PHDS for mail-based administration has been translated and implemented in Spanish and is available to assist with the Spanish translation of the PHDS-PLUS by contacting CAHMI at <a href="mailto:cahmi@ohsu.edu">cahmi@ohsu.edu</a>. If you require the survey in a language other than English, you should:

- Translate the survey into the other language
- Translate the newly translated survey back into English
- Compare the translated English survey with the original English survey

This translation and back-translation process may identify wording that is not culturally comparable. In addition to any translation issues that are identified, you should also verify the cultural comparability of the survey with the population being surveyed. Cultural comparability refers to the meanings of words and phrases among different populations. For example, some cultures do not understand the meaning of "health plan." Therefore, simply translating the words health plan could change the meaning of the survey item since it would no longer be interpreted in the same way as in the English version. In some cases, you may need to change item wording to retain the meaning of the survey item rather than using literal translation.



## **ADDITIONAL RESOURCES**

For the Spanish version of the PHDS visit the CAHMI Web site at www.cahmi.org.

For more information about the Promoting Healthy Development State Learning Network, go to the CAHMI Web site at <a href="https://www.cahmi.org">www.cahmi.org</a>.

For more information about CMS standards for administering and validating surveys see <a href="https://www.cms.hhs.gov/medicaid/managedcare/protosrvy.pdf">www.cms.hhs.gov/medicaid/managedcare/protosrvy.pdf</a>.

For more information on HIPAA privacy provisions or a copy of the final rule go the Department of Health and Human Service's Web site at <a href="https://www.hhs.gov/ocr/hipaa/">www.hhs.gov/ocr/hipaa/</a>.

For more information about the National Survey of Early Childhood Health go to <a href="https://www.cdc.gov/nchs/about/major/slaits/nsech.htm">www.cdc.gov/nchs/about/major/slaits/nsech.htm</a>.

For more information about the National Health Interview Survey, The National Survey of Children with Special Health Care Needs, and the Behavioral Risk Surveillance Survey go the Centers for Disease Control and Prevention Web site at <a href="https://www.cdc.gov.">www.cdc.gov.</a>

## **Step 4: Monitor Survey Administration and Prepare for Data Analysis**

Four steps are involved in ensuring the proper administration of the PHDS-PLUS and preparing your data files for analysis:

- 4.1 Monitor survey administration
- 4.2 Clean and code your PHDS-PLUS data set
- 4.3 Integrate updated child enrollment and utilization information
- 4.4 Weight your data set to represent your target population

Guidelines for each of these steps are provided below.

## •

## **STEP 4.1: Monitor Survey Administration**



## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to closely track the quality of your survey administration process and to monitor and troubleshoot any problems with securing an optimal response rate and accurate data entry.

## In this step you will:

- ☑ Receive and review weekly tracking reports from your survey vendor
- ✓ Assess and troubleshoot problems with response rates



## **GUIDELINES AND ISSUES TO CONSIDER**

## ☑ Weekly survey tracking report

Survey responses should be tracked throughout the administration process. At a minimum, a variable indicating the survey disposition should be maintained by your survey vendor and reported on a weekly basis throughout the administration process. Values for this variable can include:

- Interview conducted Parent was able to be contacted and the survey was administered
- Complete At least 80% of the survey items for which all parents should answer were completed

- *Incomplete* Less than 80% of the survey items were completed
- *Data error/bad contact info* Bad addresses, disconnected phone, fax/computer line, etc.
- *Ineligible* One or more of the eligibility criteria were not met (e.g., age >48 months or parent reports that child is not enrolled in the health plan)
- *Deceased* Child has passed away
- Language barrier Respondent speaks a language different from the survey administrator
- *Refused* Parent refused to complete survey
- No answer No answer/answering machine/screened by caller-ID

## <u>Calculate interim response rates and troubleshoot response problems</u>

Your *raw response rate* is simply the number of questionnaires returned divided by the number of children in your starting sample. However, this rate is often misleading and not representative of the true response rate. Therefore, an *adjusted response rate* should be calculated on an interim basis throughout survey administration to track whether you are meeting response rate targets.

For the adjusted response rate, both the numerator (number of respondents) and the denominator (number sampled) are adjusted based on certain factors:

- First, the numerator (number of respondents) is adjusted from the total number
  of questionnaires returned to the number of <u>complete</u> questionnaires returned.
  This means that only surveys with at least 80% of the items for which all parents
  should have answered should be counted in the numerator of the response rate.
  Therefore, you should not include items that should have been appropriately
  skipped in your count of the number of items the parent answered. You can
  adjust this algorithm if you want to allow responses to be considered if less than
  80% of items are completed.
- Second, the denominator (number sampled) is adjusted to include only those children who are eligible for the survey and for whom the telephone number you have is valid and therefore the parent could have been contacted to complete the survey. Thus, the denominator is adjusted by those who are ineligible, deceased, or have an unusable phone number in the data file. The formula to adjust your response rate is:

Response Rate= Number of 80% or more completed surveys

Number of children sampled – (deceased + ineligible + unusable phone number)

If your response rate falls short of projections you may need to troubleshoot with your survey vendor and consider adding and/or altering administration steps. For instance, you may decide to add an additional phone call, send a postcard, alter your introductory message left on voicemail systems, or introduce a small incentive for participation in the survey.



## STEP 4.2: Clean and code your PHDS-PLUS data set



## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to obtain an accurate data set from your survey vendor, and this includes consistent and accurate cleaning and coding of the data set in preparation for constructing PHDS-PLUS quality measures and the analytic variables needed to report your PHDS-PLUS project findings.

## In this step you will:

- ✓ Obtain and check interim data sets for accurate data labeling and entry
- ☑ Prepare data files for analysis



## GUIDELINES AND ISSUES TO CONSIDER

Obtain and check interim data sets for accuracy of data entry and survey administration

Your survey vendor should provide you with a test and interim data sets according to a predetermined schedule. For example, you should receive a data set once the first 100 survey responses have been received and entered into a database by your survey vendor.

You should ask your vendor to send a test data set that is based on a handful of "mock interviews" that they conduct. This test data set will test the CATI and the help you to check the data variables created by

## **Quick Data Quality Tips:**

- Always be sure data variables are labeled
- Make sure your data dictionary is updated for any changes made to data labels or response codes. Good documentation is essential!
- Create a backup of your data set in case of emergency. Also, create temporary and permanent data sets wisely. Think about what you would need to do if you lost the data.
- Always keep a copy of your original data set.

the CATI. When you receive the test data set you should make sure that your vendor is using the data variable labels agreed upon and that responses to survey items are also assigned the agreed upon values (e.g., 1 = ``no''; 2 = ``yes''). If errors are found, request that they be corrected immediately. In addition, you should examine whether any survey items appear to include an unusual number of missing values (more than 2% of respondents) or if survey skip patterns are not being followed (e.g., responses are recorded for individuals who should <u>not</u> have been asked a question because they did not qualify for that item).

Missing values and erroneous skip pattern data entries indicate problems with CATI and should be noted and addressed <u>before</u> the administration process begins. Corrections may involve conducting follow-up spot training with survey interviewers or adjusting the CATI set-up.

## Preparing the data files for analysis

Valid PHDS-PLUS findings require careful preparation of your data prior to starting your analysis. The following are necessary steps to prepare the data for analysis. They do not necessarily need to be conducted in the order presented.

## **Data Prep Step #1:** Verify survey completeness

You should receive the data from the vendor for all of the interviews that they have conducted. However, for your analysis you should limit the data to include only surveys with at least 80% of the items completed.

## Data Prep Step #2: Check for ineligible cases

Make sure parents who responded have children who meet the sampling criteria for age and continuous enrollment. (a) Run a frequency on the age variable from the survey responses. Compare responses of cases where parent-report indicates their child is outside the parameters of 48 months against the administrative data used to generate the sampling frame. Use the parent report as the "gold standard" and exclude cases in which the child was erroneously included in the sampling frame. (b) Remove records where the child was found not to be in the health plan, provider, or unit from which you are sampling.

## **Data Prep Step #3:** Check for duplicate data records

Make sure every record has a unique identifier.

## **Data Prep Step #4:** Check for out-of-range values

Run frequencies on all of your variables to check for out-of-range values or odd-looking distributions. For example, one item asks respondents to rate their health care on a scale from 0–10. In most cases, the distribution should cluster around seven, eight, or nine. If a large number of responses were "1" then you may have a data entry error where some of those responses should have been coded as 10. At this point, you may not be able to go back and correct the data error. If the error is random and affects only a few cases then you may want to exclude those cases. However, if the error seems to be systematic and impacts a large number of responses, it may be worth it to find the source of the error and correct it.

## **Data Step #5:** Identify problems with skip patterns

Run frequencies and cross-tabulations to verify that skip patterns were followed correctly. If errors seem to be random and affect only a small number of records (less than 2%), assume the item stem (question instructing the respondent to go to a different question) is accurate and then correct the response for the incorrect skip. Systematic errors or problems with a significant number of cases should be verified.

If you want to be absolutely certain that skip patterns were followed, you can make it a requisite that only the children of parents who responded appropriately to the filter question are included when you create the new variables.

## **Data Prep Step #6:** Assign missing values

Missing values should be recoded in some way so that you know not to include them in the analyses. If you recode missing responses to "0" be very careful not to include them in your analyses as this will affect your results. Designate missing values in the data set to ensure that they are omitted when calculating measures. Also, recode the response options of "refused" (primarily for telephone administration) to be a missing value. Examine the number of "I don't know" responses that you get. If this total percentage is less than 2%, then you should recode them to be missing values.

## **STEP 4.3: Integrate updated child enrollment and utilization information**

## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step to make sure that data for each child are as current as possible at the time that you calculate your PHDS-PLUS quality indicators and create reports of your findings to key audiences.

### In this step you will:

- ☑ Identify <u>variables</u> that may need to be <u>updated</u> for each sampled child
- ☑ Obtain and merge updated data variables into your analytic variable data set

### GUIDELINES AND ISSUES TO CONSIDER

As discussed in Steps 2.5 and 3.2, many variables that are derived from enrollment and utilization data sets are valuable for purposes of analyzing and reporting PHDS-PLUS findings. Examples of these variables are listed in Figure 4.2 below and include information on utilization of services, program enrollment, geographic location, and so on. Some of these variables are expected to change over time. For each person in the starting sample, it is important to update these variables to incorporate new data entries or changes that may have occurred between the time that the initial PHDS-PLUS sample was pulled and the time that the survey was actually completed by parents of children included in your sample.

Figure 4.1: Examples of Data Elements to Collect at the Time of Sampling

### Child Characteristics

- Race-ethnicity
- Date of birth
- Gender
- County
- Geographic region (e.g., urban, suburban, rural)
- Public health district

### Child Enrollment Characteristics

- Months of continuous enrollment
- Program child is enrolled (Medicaid, SCHIP)
- Medicaid Program child is enrolled (fee-for-service, managed care organization, primary care case management)
- Where applicable, child's health plan
- Where applicable, child's primary care provider (including specialty, e.g., pediatrician, family medicine).
- Enrollment in Part C program

### Child Health Care Utilization Characteristics

- Number of office visits (non-emergency room, urgent care)
- Number of well-child visits
- Number of urgent care visits

(For each of the above, the provider who delivered the care and the setting in which the care was provided e.g., private practice, federally qualified health center, rural health center)

## Whether Child Utilized Services in Other Departments

- Dept. of Health services (e.g., whether the child received a visit from a public health nurse)
- Dept. of Children with Special Health Care Needs services (e.g., whether the child received care coordination services)
- Dept. of Mental Health Services services (e.g., whether the child received care from a Dept. of Mental Health provider)

# STEP 4.4: Weight your data set to represent your target population



### WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to to be sure that your final data set is representative of the desired sample of children you would like to report at the end of your project. Weighting is a standard component of most survey projects, especially if you oversampled for certain population subgroups (e.g., racial/ethnic groups) or there are response biases (e.g., some populations subgroups are systematically less likely to respond to your survey).

### In this step you will:

✓ Clarify your <u>desired population</u> of children to be sure your findings are representative and decide whether weighting your data is required
 ✓ <u>Develop a weighting methodology</u> and <u>construct sampling weights</u> to use during your data analysis



### **GUIDELINES AND ISSUES TO CONSIDER**

### Determining whether weighting is required

The sampling and survey administration strategy specified throughout this manual is designed in the following manner: (1) To obtain sufficient samples of completed surveys for the three age groups that correspond to the age-specific sections of the PHDS-PLUS survey (3–9 months, 10–18 months, 19–48 months old) and (2) to target groups of particular interest in your state.

You will need to weight your data if:

- 1. You collect both a core and state-specific sample as suggested AND
- 2. You want to be able to combine the data from your core and state-specific samples in order to create reports that describe PHDS-PLUS findings across your state.

### Developing a weighting methodology

Your survey vendor should be able to construct valid weights once you clarify the population of children about which you would like to report PHDS-PLUS findings (e.g., all children enrolled in Medicaid). Below are issues and tips to consider as your weighting method is developed.

### 1. Clarify the Baseline Population to be Used in Calculating the Weights

Since the children eligible to be sampled for the PHDS-PLUS were ONLY those who had a phone number in the data file and who met the continuous enrollment requirement, data will ONLY be able to be weighted to represent this group of children. Therefore, the baseline populations to which you may refer for purposes of sampling is the population of continuously enrolled children in Medicaid who are 3–48 months old and who were eligible to be sampled for the PHDS-PLUS survey.

### 2. Specify the Core Factors to be Used in Calculating Weights

At a minimum, you will need to weight your data according to the child's age. This is because your PHDS-PLUS samples were initially stratified by age to ensure sufficient samples of children in the following age groups were obtained: 3–9 months (25% of starting/completed sample), 10–18 months 25% of starting/completed sample, 19–48 months (50% of the starting/completed sample). To make your PHDS-PLUS findings representative, you will need to determine the actual age distribution of the population of continuously enrolled children in Medicaid who are 3–48 months old and who were eligible to be sampled for the PHDS-PLUS survey according to these groups and weight the data accordingly. Other variables you may need to include in your weighting methodology are race, geographic location, type of health care provider or health plan, or any other variables for which you oversampled or are under- or over-represented in your completed sample due to a known response bias. An example weighting method is provided below in example 4.1.

### **Example 4.1: Weighting from the Field**

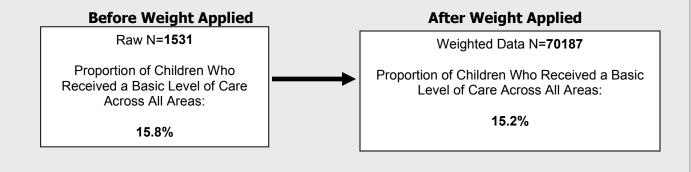
State X used the core and state-specific sampling strategy recommended by the CAHMI. For their state-specific sample, they decided to ONLY include children who had one or more well-child visits in the last 12 months.

Factors the state used in weighting their sample:

- ✓ Proportion of children in the three age groups who had a well-child visit in the last 12 months.
  - Group 1. Proportion of children 3–9 months old who had a well-child visit
  - Group 2. Proportion of children 10–18 months old who had a well-child visit
  - Group 3. Proportion of children 19–48 months old who had a well-child visit
- ✓ Proportion of children in the three age groups who did NOT have a well-child visit in the last 12 months.
  - Group 4. Proportion of children 3–9 months old who DID NOT have a well-child visit
  - Group 5. Proportion of children 10–18 months old who DID NOT have a well-child visit
  - Group 6. Proportion of children 19–48 months old who DID NOT have a well-child visit

### Weighting Process Utilized

- ✓ The population of continuously enrolled children in Medicaid who were 3–48 months old and who were eligible to be sampled for the PHDS-PLUS survey was analyzed.
- ✓ The proportion of children in each of the six groups noted above was determined.
- ✓ A weight was created based on the figures obtained.
- ✓ Each child whose parents responded to the survey was categorized in one of these six age groups and a weight was assigned to each.





### TIPS FOR INCREASING YOUR RESPONSE RATE

- **Use letterhead for all correspondence**. This establishes trust with the respondent and adds credibility to the project.
- **Personalize the letters**. People are more likely to notice a letter addressed to them rather than a general greeting.
- **Use an express shipping service**, such as FedEx or UPS, for the prenotification letter. Research has shown that people are more likely to respond to express mail than regular mail.
- **Provide an explanation** for how the survey will be used to improve health care for children.
- **Call at family-friendly times**. It is important to realize that the families you are calling have young children. Therefore, the call times should be respectful of the schedules of young children.
- Utilize a survey vendor that has experience surveying parents of young children. Whenever possible, contract with a survey vendor who has experience conducting surveys with parents of young children.
- **Provide a means to receive findings**. Let parents know how to get a copy of the findings of the study after it is complete.

### TIPS FOR PREPARING YOUR DATA FILES FOR ANALYSIS

While data preparation is often considered part of the analysis, this task is included in the data collection section because it is often completed by the vendor while administering the survey. Additional data preparations and cleaning are also included in the next section.

If you are using a vendor to administer the survey, the vendor should submit to you a data file that contains the following:

- 1. Coded responses for all items, including blank, do not know, refused to answer, and item skipped
- 2. Survey disposition, such as if the survey was completed, the reasons for incomplete surveys (see list above in *Step 4.1: Monitor Survey Administration*)
- 3. Other variables linked when the sampling frame was generated
- 4. Administrative data used for generating the sampling frame
- 5. Age of child in months
- 6. Months of continuous enrollment in the last 12 months
- 7. Any supplemental data linked prior to the removal of identifying information used for survey administration

### 8. A data dictionary for the file

Data entry or the coding process should be verified. You may also choose to audit the process by comparing the coded values against the original survey.

You also may choose to have your vendor conduct some initial data preparations, such as:

- 1. Verifying ineligible cases
- 2. Checking for duplicate data records
- 3. Running frequencies on all variables to check for values that are out of range
- 4. Identifying problems with skip patterns

You may want to have the vendor verify these with the original surveys to ensure that errors stem from the respondent and not from the administration process. Once these are identified, you will need to make decisions on how they will be handled for the analysis. Refer to the next section for more detail on analyzing the results.

### **Step 5: Construct Quality Measures and Analytic Variables**

Four steps are involved in constructing the PHDS-PLUS quality measures and evaluating these measures for various subgroups of children using your PHDS-PLUS survey and administrative data based analytic variables:

- 5.1 Calculate core PHDS-PLUS quality measures
- **5.2 Calculate core PHDS-PLUS analytic variables**
- **5.3** Calculate any alternative versions of the quality measures
- 5.4 Evaluate quality measurement results for subgroups of children

Guidelines for each of these steps are provided below.

### STEP 5.1: Calculate Core PHDS-PLUS Quality Measures

## WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to develop both child-level and group-level scores for each of the core PHDS-PLUS quality measures that were outlined in Step 1 of this manual and summarized in greater detail in Table 5.1.

### In this step you will:

- Learn about the core PHDS-PLUS quality measures
- Recode child level PHDS-PLUS survey responses
- ✓ Calculate child and group level quality measure scores
- ☑ Specify and assign "good care" cut-points to each measure

## **GUIDELINES AND ISSUES TO CONSIDER**

### **Learn about the PHDS-PLUS Quality Measures**

Table 5.1 describes each of the nine core PHDS-PLUS quality measures. Each measure is derived using anywhere from two to 18 PHDS-PLUS survey responses. The nine core measures are:

- 1. Anticipatory guidance and parental education provided by doctors or other health care providers
- 2. Provision of written or other types of health information to parents on caring for their child, preventing injuries, and ensuring optimal development
- 3. Assessment of parent concerns about child learning, development, and behavior and provision of specific information for parents with concerns
- 4. Follow-up for children at risk for developmental, behavioral, or social delays
- 5. Assessment of the well-being of parents and safety within the family
- 6. Assessment of smoking, alcohol, and drug use in the home
- 7. Coordination of care for children requiring multiple types of health care services or seeing more than one health care provider
- 8. Provision of family-centered care that respects, listens to, and partners with parents
- 9. Helpfulness of care provided to parents

Table 5.1: PHDS-PLUS items included in each quality measurement topic

Quality Measure		Topics Included in Quality Measure	PHDS-PLUS Survey Items <sup>1</sup>	# of Items
1.	Anticipatory Guidance and Parental Education from Doctor or Other Health Care Providers	All respondents (Items 3a-h): Assesses whether a core subset of AAP-recommended anticipatory guidance topics are discussed, including child's growth and development, behaviors to expect, physically caring for the child, reading and playing with child and helping child grow and learn, making house and car safe and preventing child from injury, issues related to child care and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).		
		Age Specific Items:  3–9 Months: Assesses whether age-specific anticipatory guidance topics are discussed, including breastfeeding, issues related to food and feeding, sleeping positions and sleep area, night waking and fussing, child's responses and communication, how to avoid burns.	Section 6: 3– 9 Month Old Section- 1-15 (Ga1-Ga15ai)	15
		<u>10–18 Months</u> : Assesses whether age-specific anticipatory guidance topics are discussed, including nutrition, bedtime routines, preventing bottle mouth, child's communication, child's independence, guidance and discipline techniques, what to do if child swallows poisons, and parent education about toilet training.	Section 6: 10–18 Month Old Section- 15 (Gb1- Ga18ai)	18
		<b>19–48 Months:</b> Assesses whether age-specific anticipatory guidance topics are discussed, including nutrition and eating habits, bedtime routines, child's social interactions and communication skills, child's independence, guidance and limit setting, what to do if child swallows poisons and other safety issues, and toilet training.	Section 6: 19–48 Month Old Section (Gc1-Gc15ai)	15
2.	Health Information	Assesses whether information provided outside/inside the doctor or other health provider's office (mail, in clinic pamphlets, videos, etc.) on the following: safety tips, health care utilization tips, developmental information.	Section 11: 1-3 (H1-H3)	3
3.	Ask About and Address Parental Concerns	Assesses whether providers routinely ask parents about their concerns about their child's learning, development, and behavior and if parents who have concerns received specific information addressing their concerns ( <u>Items in Section</u> 7: <u>Questions #5 and #7</u> ) used to determine whether parents have concerns.	Section 6: 6, 7a (D16, D17A)	2
4.	Follow-Up for Children at Risk for Developmental Delays	For children who are determined to be at risk for developmental, social, or behavioral delays ( <u>Items Section 7:Question #5</u> )*, whether some type of appropriate follow-up health care occurred. Follow-up items include testing of child's learning development and behavior, referral to specialist, whether a doctor or other health	Section 8: 1 (D18A-D18D)	4

<sup>&</sup>lt;sup>1</sup> Items listed are based on Appendix 1. Items in parentheses are based on the Appendix 3.

		provider noted a concern that should be watched carefully.		
5.	Assessment of Well-Being of Parent(s) and Safety Within the Family	Assesses whether health care providers talk with parent about their own well-being and safety within the family, including depression, emotional support, and whether there are firearms in the home.	Section 10: 3-5 ( <i>AF1-AF5</i> )	3
6.	Assessment of Smoking and Substance Use in the Family	Assesses whether health care providers talk with parent about smoking, alcohol, and drug use in the family.	Section 10: 1-2 ( <i>AF1-</i> <i>AF2</i> )	2
7.	Care Coordination	Assesses whether children requiring more than one type of health care service received needed help coordinating care.	Section 2: 4a (A7)	1
8.	Family-Centered Care	Parent reports that child's health care provider delivers care in a family-centered manner, including respect, understanding specific needs of child and concerns of parent, building confidence in the parent, explaining things in way the parent can understand, and showing respect for a family's values, customs, and how they prefer to raise their child.	Section 9 (FC1-FC6)	6
9.	Helpfulness of Care Provided	Parent report of how helpful all information from child's health care providers was in specific areas of parenting.	Section 12 (E1-E4)	4

<sup>\*</sup>See Table 5.4 for information on determining if a child is at high or moderate risk for developmental, behavioral, or social delays.

### **Recode child level PHDS-PLUS survey responses**

### Recoding Step 1: Map Items to Quality Measures

Map the items to each of the corresponding quality measures, as shown in Table 5.2. The question numbers correspond to the core survey, which is included in Appendix 1. If you added questions and renumbered the survey, the question numbers in your survey may differ.

## <u>Recoding Step 2</u>: Create New Items: Recode Response Options Used to Score Quality Measures

Prior to creating scores for the quality measures, create new items in order to assign a quantitative value to survey item response options (e.g., "yes" vs. "no"). Recode the response options for each survey item used in a quality measure so that the values fall between **0 and 100**, where zero indicates quality health care was not received and 100 indicates quality health care was received. Be sure not to recode the original items in the data set. Rather, you should create new items in case you make a mistake. Use the following Table 5.2 as a guide to rescore

each of the items. Missing responses are NOT given a valid score and are NOT included in the calculation of the quality measure.

**Important Note:** There are two versions shown for how to score the anticipatory guidance and parental education (AGPE) quality measure presented in Table 5.2.

- Version A is the average proportion of topics that parents reported was discussed. This measure answers the question of how many recommended AGPE topics, on average, are discussed, regardless of whether parent questions were answered.
- Version B uses a scoring algorithm that weights each response option
  according to whether the parents' informational needs about that topic were
  met. The item only receives full credit if a topic was discussed <u>and</u> the
  parent's questions were answered. This version measures the degree to
  which parents' informational needs were met on the anticipatory guidance
  items.

The version you decide to use should be based on your research questions and goals for the study. You might even want to create both versions and compare the results.

**Table 5.2: Recoding of Response Options for Quality Measures Survey Items** 

	Dune nine of					
	Quality Measure	PHDS-PLUS Survey Items	Original Response Options	Recoding of Response Options		
1.	Anticipatory Guidance and Parental Education from Doctor or Other Health Care Providers Version A: Average proportion of topics parents report were discussed	Section 6: 3– 9 Month Old Section- 1-15 (Ga1-Ga15ai) Section 6: 10–18 Month	1=Yes, the topic was discussed 2=No, the topic was not discussed	100		
	ascussed	Old Section- 15 (Gb1- Ga18ai) Section 6: 19–48 Month Old Section (Gc1-Gc15ai)	, , ,	0		
	Version B: Average proportion of topics parents report were (a) discussed or (b) not discussed nor did the parent wish to	Same as above	1=Yes, the topic was discussed 2=No, the topic was not discussed Follow-up question asked of those			
	discuss with their child's health care provider		topic was not discussed:  1=Yes, I wish the topic had be discussed	en <b>0</b>		
			2=No, I did not wish the topic had been discussed	100		
2.	Health Information	Section 11: 1-3 (H1-H3) Section 8: 1	1 = Yes	100		
		(D18A-D18D)	2 = No	0		
3.	Ask About and Address Parental Concerns	Section 6: 6, 7a (D16, D17A)	For those parents who respond "r items in question #5, Section 7 (L to question #7, Section 7 (D17)			
			Score Question #6, Section 7 (D1	6)		
			1 = Yes	100		
			2 = No  For those parents who respond "a one or more items in question #5			
			D15) AND/OR "ves" to auestion #			
			Score Question #7a, Section 7 (D 1 = Yes	100		
			2 = No	0		
4.	Follow-Up for Children at Risk	Section 8: 1	1 = Yes	100		
	for Developmental Delays	(D18A-D18D)	2 = No	0		
5.	Assessment of Well-Being of Parent(s) and Safety Within the	Section 10: 3-5 ( <i>AF1</i> -	1 = Yes	100		
	Family	AF5)	2 = No	0		

6.	5. Assessment of Smoking and Substance Use in the Family	Section 10: 1-2 ( <i>AF1-</i>	1 = Yes	100
			2 = No	0
7.	Care Coordination	Section 2: 4a	1 = Yes	100
		(A7)	2 = No	0
8.	Family-Centered Care	Section 9	1 = Never	0
		(FC1-FC6)	2 = Sometimes	0
			3 = Usually	100
			4 = Always	100
9.	9. Helpfulness of Care Provided	Section 12 ( <i>E1-E4</i> )	1 = Very helpful	100
			2 = Helpful	75
			3 = Somewhat helpful	25
			4 = Not at all helpful	0
			5 = We did not discuss	Missing

**Recoding Step 3:** Parents Who Answered Minimum Number of Items for Each Quality Measure

Parents must have answered at least **half** of the items that are included in the quality measure to have a score calculated for that measure. If a parent answered less than half of the items in that measure, their score is considered to be missing.

For Quality Measure 7: Helpfulness of Care Provided, parents are instructed to rate how helpful the counseling or discussion for a specific topic was only if the parent and doctor talked about the topic. If a doctor or health care provider did not talk with the parents about learning to protect the child from injury, the parent could not validly report how helpful the counseling was. Thus, a parent had to report having talked with the doctor about at least two of the four counseling topics included in the "Helpfulness" Quality Measure to receive a valid score.

The last column in Table 5.2 lists the total number of items to be answered per quality measure. For this purpose, sub-items (lettered items within the same item number) are counted as an individual item. If a measure has an odd number of items, round up.

### **Create Scores for Each Quality Measure**

Once you have finished recoding steps 1–3, you are ready to calculate a score for each quality measure for <u>each child</u> included in the study. A total of three different scoring methods is used to calculate the quality measures. The scoring methods used for each of the quality measures are described in Table 5.3 below, followed by examples so you can see exactly how the measure is calculated.

**Table 5.3: Algorithms for Creating Quality Measure Scores** 

Quality Measure    Minimum # of Items Parents Must Answer				
Parental Education from Doctor or Other Health Care Providers  Version A: Average proportion of topics parents report were discussed  19—48 mos: 7  Version B: Average proportion of "yes, item was discussed" responses.  Version B: Average proportion of "yes, item was discussed" responses.  Version B: Average proportion of "yes, item was discussed" responses.  Version B: Average proportion of "yes, item was discussed" or "no, item was not discussed and parent noted they did not wish it had been discussed.  2. Health Information  2. Average proportion of "yes" responses.  2. Proportion of parents who are asked about their concerns and/or who receive specific information to address their concerns.  4. Follow-Up for Children at Risk for Developmental Delays  4. Follow-Up for Children at Risk for Developmental Delays  5. Assessment of Well-Being of Parent(s) and Safety Within the Family  6. Assessment of Smoking and Substance Use in the Family  7. Care Coordination  3 Average proportion of "yes, item was discussed" responses.  Average proportion of "yes" responses.		· ,	of Items Parents Must	How Quality Measure Is Calculated
Document   Document	1.	Parental Education from Doctor or Other Health Care		
discussed" or "no, item was not discussed and parent noted they did not wish it had been discussed or (b) they already had information on topics that were not discussed.  2. Health Information 2. Average proportion of "yes" responses.  3. Ask About and Address Parental Concerns Follow-Up for Children at Risk for Developmental Delays  4. Follow-Up for Children at Risk for Developmental Delays  Awerage proportion of parents who are asked about their concerns and/or who receive specific information to address their concerns.  A. Follow-Up for Children at Risk for Developmental Delays  Awerage proportion of parents whose children received follow-up care addressing child's risk for developmental, behavioral delays.  Moderate Risk: Parent said yes at least once to any of follow-up questions (24a-e). High Risk: Parent said yes to both 24c and 24e OR said yes to any of the following: 24a, 24b, or 24d  5. Assessment of Well-Being of Parent(s) and Safety Within the Family  6. Assessment of Smoking and Substance Use in the Family  7. Care Coordination  1. Proportion of parents who report help in		proportion of topics parents report were	10–18 mos: 8 19–48	
3. Ask About and Address Parental Concerns  2 Proportion of parents who are asked about their concerns and/or who receive specific information to address their concerns.  4. Follow-Up for Children at Risk for Developmental Delays  2 Risk-specific scoring. Proportion of parents whose children received follow-up care addressing child's risk for developmental, behavioral delays.  Moderate Risk: Parent said yes at least once to any of follow-up questions (24a-e). High Risk: Parent said yes to both 24c and 24e OR said yes to any of the following: 24a, 24b, or 24d  5. Assessment of Well-Being of Parent(s) and Safety Within the Family  6. Assessment of Smoking and Substance Use in the Family  7. Care Coordination  1 Proportion of parents who are asked about their concerns and/or who receive specific information to address their concerns.  2 Average proportion of "yes" responses.		proportion of parents indicating that all topics were (a) discussed or (b) they already had information on topics that	above	discussed" or "no, item was not discussed and parent noted they did not wish it had been
3. Ask About and Address Parental Concerns       2       Proportion of parents who are asked about their concerns and/or who receive specific information to address their concerns.         4. Follow-Up for Children at Risk for Developmental Delays       2       Risk-specific scoring. Proportion of parents whose children received follow-up care addressing child's risk for developmental, behavioral delays.         Moderate Risk: Parent said yes at least once to any of follow-up questions (24a-e). High Risk: Parent said yes to both 24c and 24e OR said yes to any of the following: 24a, 24b, or 24d         5. Assessment of Well-Being of Parent(s) and Safety Within the Family       2       Average proportion of "yes" responses.         6. Assessment of Smoking and Substance Use in the Family       2       Average proportion of "yes" responses.         7. Care Coordination       1       Proportion of parents who report help in	2.	Health Information	2	Average proportion of "yes" responses.
whose children received follow-up care addressing child's risk for developmental, behavioral delays.  Moderate Risk: Parent said yes at least once to any of follow-up questions (24a-e). High Risk: Parent said yes to both 24c and 24e OR said yes to any of the following: 24a, 24b, or 24d  5. Assessment of Well-Being of Parent(s) and Safety Within the Family  6. Assessment of Smoking and Substance Use in the Family  7. Care Coordination  1 Proportion of parents who report help in	3.		2	Proportion of parents who are asked about their concerns and/or who receive specific
Parent(s) and Safety Within the Family  6. Assessment of Smoking and Substance Use in the Family  7. Care Coordination  2 Average proportion of "yes" responses.  1 Proportion of parents who report help in	4.	-	2	whose children received follow-up care addressing child's risk for developmental, behavioral delays.  Moderate Risk: Parent said yes at least once to any of follow-up questions (24a-e).  High Risk: Parent said yes to both 24c and 24e OR said yes to any of
6. Assessment of Smoking and Substance Use in the Family 7. Care Coordination 2 Average proportion of "yes" responses. 1 Proportion of parents who report help in	5.	Parent(s) and Safety Within	2	Average proportion of "yes" responses.
	6.	Assessment of Smoking and	2	Average proportion of "yes" responses.
providers or services.	7.	Care Coordination	1	coordinating care among these different
8. Family-Centered Care  3 Average proportion of "always" or "usually" responses across all of the items in the measure.	8.	Family-Centered Care	3	Average proportion of "always" or "usually" responses across all of the items in the
9. Helpfulness of Care Provided 2 Mean score across all recoded items for a score between 0–100.  *See below for algorithm to determine if child is at high moderate low or no risk for developmental.				Mean score across all recoded items for a score between 0–100.

<sup>\*</sup>See below for algorithm to determine if child is at high, moderate, low, or no risk for developmental, behavioral, or social delays.

## Scoring algorithm for child's risk of developmental, behavioral, or social delays

Identifying children at risk: Questions 15–17 are derived from the Parents Evaluation of Developmental Status (PEDS) tool. Specific concerns that parents have about their children at specific ages can be an indication of a child's risk for developmental/behavioral delays. Children whose parents have one or more "indicator" concerns (parent said "yes" or "a little") are identified as being at risk. Overall, the PEDS has an age- and concern-specific scoring algorithm. The following table describes the scoring algorithm used to identify children as high, moderate, low, and no risk of developmental/behavioral delays. The scoring algorithm is specific to three age-groups: 3–17.99 months, 18–35.99 months, and 36–48 months.

Children whose parents have noted concerns for only one indicator item are at moderate risk for delays. Children whose parents note two or more concerns to indicators items are at high risk for delays.

Table 5.4: Risk Category

Age of Child	High Risk	Moderate Risk	Low Risk	No Risk
<b>3–17.99</b> mos.	Parent noted "a lot" or "a little" concern to <b>two or more</b> of the following items:  > 15a > 15b > 17a	Parent noted "a lot" or "a little" concern to <b>one</b> of the following:  > 15a-b > 17a with any other concerns to any PEDS item	Parent noted "a lot" or "a little" concern to <b>one</b> or more of the following:  > 15c > 16a-c > 17b-c > If parent only noted a concern to 17a	Parent noted "not at all concerned" to all PEDS items
<b>18– 35.99</b> mos.	Parent noted "a lot" or "a little" concern to <b>two or more</b> of the following items:  > 15a-c	Parent noted "a lot" or "a little" concern to <b>one</b> of the following:  > 15a-c	Parent noted "a lot" or "a little" concern to <b>one</b> or more of the following:  > 16a-c > 17a-c	Parent noted "not at all concerned" to all PEDS items
<b>36–48</b> mos.	Parent noted "a lot" or "a little" concern to <b>two or more</b> of the following:  > 15a-c > 16b	Parent noted "a lot" or "a little" concern to <b>one</b> of the following:  > 15a-c > 16b	Parent noted "a lot" or "a little" concern to <b>one</b> or more of the following:  > 16a > 16c > 17a-c	Parent noted "not at all concerned" to all PEDS items

### **EXAMPLE 5.1: HEALTH INFORMATION QUALITY MEASURE**

Here is the scoring for Joel, Anne, and Steve for *Quality Measure #2: Health Information*. This quality measure includes items 14a-d.

Their responses were as follows:

Joel: 14a. Yes 14b. No 14c. Yes 14d. No Anne: 14a. Yes 14b. Yes 14c. Yes 14d. Missing Steve: 14a. Yes 14b. Missing 14c. Missing 14d. Missing

Their responses are given the following values:

Joel: 14a. 100 14b. 0 14c. 100 14d. 0

Anne: 14a. 100 14b. 100 14c. 100 14d. No value Steve: 14a. 100 14b. No value 14c. No value 14d. No value

Therefore, their scores on the Quality Measure are:

Joel:  $\underline{Numerator}$   $\underline{100 + 0 + 100 + 0} = \underline{200} = \underline{50}$   $\underline{Denominator}$  4

Steve: No score since he did not answer at least two of the four items included in the quality measure

Notice that Item 14d. was not included in Anne's score (numerator or denominator) since her response was missing. Also, a score was not given to Steve since he did not answer the minimum number of items required.

#### **EXAMPLE 5.2: HELPFULNESS OF CARE PROVIDED**

Here is the scoring for Ted's answers to the items for *Quality Measure #7: Helpfulness of Care Provided*. This measure includes items 13a-d.

Responses and corresponding values:

13a. Somewhat helpful2513b. Very helpful10013c. Not at all helpful013d. Helpful75

Ted's score for the Quality Measure is:

 $\underline{Numerator} (25 + 100 + 0 + 75) = 50$   $\underline{Denominator} \qquad 4$ 

#### **EXAMPLE 5.3: FOR FOLLOW-UP CHILDREN AT RISK OF DEVELOPMENTAL DELAY**

Here is the scoring for Jack, Janet, and Chris for *Quality Measure* #3: Follow-up for Children at Risk of Developmental Delay. This measure is comprised of items 24a-e and is scored only for those children who have been identified as being at risk for a developmental delay.

Jack and Janet are both at <u>high</u> risk for developmental delay. Chris and Larry are both at <u>moderate</u> risk for developmental delay.

### Their responses were as follows:

Jack (high risk):	24a. Yes	24b. No	24c. Yes	24d. No	24e. No
Janet (high risk):	24a. No	24b. No	24c. Yes	24d. No	24e. Yes
Chris (mod. risk):	24a. No	24b. No	24c. No	24d. No	24e. Missing
Larry (mod. risk):	24a. Yes	24b. Missing	24c. Missing	24d. Missing	24e. Missing

Therefore, their scores on the quality measure are:

Jack: **100** (answered "yes" to at least one of the necessary items)

Janet: **100** (answered "'yes" to both 24c and 24e) Chris: **0** (did not answer "yes" to any of the items)

Larry: **100** (answered "yes" to at least one item, even though the remaining were missing)

## <u>Create a Group-Level Score for each Quality Measure for the Unit Being Measured</u>

Once scores are calculated for each individual child on each quality measure, these individual-level scores need to be combined into a score for the entire unit you are interested in measuring, such as a health plan, provider, or total population sampled. This is done by averaging all of the individual scores on a quality measure.

Group-level score =  $\Sigma$  each individual respondents' quality measure scores # of individuals with a quality measure score

In other words, the group-level score is an average score for all respondents for whom a score could be calculated on that measure. Therefore, the denominator for the group-level score for the quality measure is NOT the total number of respondents; rather, it is the number of children whose parent answered at least half of the items for that quality measure.

### **EXAMPLE 5.4: Group-Level Score**

Let's say that you are scoring Quality Measure #2: Health Information for the Happy Health Plan, and Charlie, Lynn, Polly, and Sam are the children in the health plan whose parents have responded to the survey. (Forget about small numbers for the moment.)

The individual quality measure scores for each of the respondents are as follows:

Charlie = 75

Lynn = 100

Polly = 0

Sam = no score (only answered 1 of the 4 items included in the quality measure)

The group-level score for Quality Measure #2 is:

Score = 
$$\frac{75 + 100 + 0}{3} = \frac{175}{3} = \frac{58.33}{3}$$

Notice that Sam was not included in the calculation (numerator and denominator) since he did not have an individual score for the quality measure.

All of the group-level scores for each quality measure are calculated in this manner. Note that most statistical packages can calculate these scores for you automatically.

### **Example 5.5: Overall Quality Scores:**

Here are examples of scores on each of the eight quality measures for three different children. Notice how each of the versions of the overall quality scores tells a slightly different story.

Quality Measure	Jill	Jose	Jack
#1 (Version A)	93.3	87.5	68.7
#2	100.0	100.0	75.0
#3*	missing	100.0	missing
<u>#4</u>	83.3	100.0	83.3
#5	100.0	100.0	0.0
#6	82.5	92.5	70.0
#7	81.3	62.5	75.0
Overall Quality Score	90.1	91.8	62.0
Meets the "Average Across All" Threshold (mean score of 75+ across all quality measures)	yes	yes	no
Meets the "On Every" Threshold (score of 75+ on every quality measure)	yes	no	no

<sup>\*</sup>Only scored for children who are at risk for a developmental, behavioral, or social delay

Even though the overall mean score for Jose is greater than Jill's score, Jill met the 75-point threshold on ALL of the quality measures, whereas Jose only scored 62.5 on the "Helpfulness of Care" measure, falling below the 75-point threshold.



### STEP 5.2: Calculate core PHDS-PLUS analytic variables



### WHAT IS THE PURPOSE OF THIS STEP?

### In this step you will:

✓ Calculate the analytic variables you have decided to use in reports of your PHDS-PLUS findings based on Step 2.4, 2.5, and 3.2.

Your analytic variables are constructed using three sources of data:

- 1. <u>Survey responses</u> from items included in the core survey that are not used in the quality measures. These items are included to provide additional information about children and families included in the PHDS-PLUS sample and include topics on:
  - Utilization of the health care system (e.g., emergency room, doctor's office, and hospital visits)
  - Doctors asking about and addressing parents' concerns
  - Whether the child has had one person whom parents consider a personal doctor or nurse
  - Socio-demographic characteristics of child and parent
- 2. <u>Administrative Data</u>: These are the data collected when pulling the sampling frame for the entire sample.

For example:

- Whether the child has had a Health Plan Employer Data and Information Set (HEDIS)—defined well-visit
- Type of program in which child is enrolled (FFS, managed care)
- Continuous enrollment
- 3. <u>Supplemental Items</u>: These are additional survey items you may have decided to include in the PHDS-PLUS during Step 2.4. As with the analytic items from the care survey, these items provide additional information about the children in the sample and their parent(s).

For example:

- Children with Special Health Care Needs Screener
- Screener for maternal depression
- Impact of care on parental confidence as parent
- Financial barriers to care

These data can be used to provide descriptive information about the sample on their own, and they also can be used to stratify the results of quality measures using cross-tabulations. Cross-tabulations often can present the results in a way that is easier to understand and can make the results more actionable for quality improvement because they highlight the quality of care findings for specific groups.

## STEP 5.3: Calculate any alternative versions of the quality measures



### WHAT IS THE PURPOSE OF THIS STEP?

### In this step you will:

- Consider other options for scoring PHDS Quality Measures
- ☑ Calculate alternative measures

## GUIDELINES AND ISSUES TO CONSIDER

It is often helpful to look at information from different angles and perspectives to gain a more complete, multidimensional picture. The 0–100 quality measure scores discussed in this section are only one way to assess your PHDS-PLUS results. There are a variety of options for scoring and combining the quality measures on the PHDS-PLUS. Think about your research questions and which of the scoring methods outlined here best answer those questions and will make a compelling story. Be creative when approaching your scoring. While we have provided recommendations here, there is no "one-size-fits-all" method when it comes to scoring data.

Additional ways to consider scoring the PHDS-PLUS measures include:

- 1. **Threshold Measures:** Proportion of children above and below a specific "threshold" score
- "All or Nothing" Measures: Proportion who received all or none of recommended care
- 3. **Negative Indicator Measures:** Proportion of children who did NOT receive recommended care
- 4. **Overall Composite Quality Measures:** Proportion of children who received a threshold level of care across more than one quality measure

**1. Threshold Measures:** Proportion of children above and below a specific "threshold" score

Once you have created the mean scores for each of the quality measures, it may be helpful to identify those who received a threshold level of care. The threshold scoring method creates a binomial measure using the mean-based measure scores and assesses how many people received a certain level of an aspect of care.

Table 5.5 below provides some options for creating threshold measures.

**Table 5.5: Threshold Scores for Each Quality Measure** 

	Quality Measure	Threshold Score for Quality Measure- Used for Determining that Sufficient Level of Quality of Care was Received
1.	Anticipatory Guidance and Parental Education	
	Version A: Average proportion of topics parents report were discussed	Parent responded yes to discussions of about <b>80%</b> or more of the topics. <i>Quality measure value: 80.0</i>
	Version B: Average proportion of parents indicating that all topics were (a) discussed or (b) they already had information on topics that were not discussed	Parent responded, "Yes, item was discussed" or "No, item was not discussed" and "I did not wish the topic was discussed" to all topics  Quality measure value: 100.0
2.	Health Information	Parent responded "Yes," they had seen or heard information about all of the items.  Quality measure value: 100.0
3.	Ask About and Address Parental Concerns	n/a (This measure is already a proportion measure)
4.	Follow-Up for Children at Risk for Developmental Delays	n/a* (This measure is already a proportion measure)
5.	Assessment of Well-Being of Parent(s) and Safety Within the Family	Parent responded "Yes" to being asked about at least <b>2 of the 3</b> of the family assessment items. <i>Quality measure value: 66.7</i>
6.	Assessment of Smoking and Drug Use in the Family	Parent responded "Yes" to <b>both</b> items about smoking and substance use in the home. <i>Quality measure value: 100.0</i>
7.	Care Coordination	n/a (This measure is already a proportion measure)
8.	Family-Centered Care	Parent responded "Usually" or "Always" across all of the items.  Quality measure value: 100.0
9.	Helpfulness of Care Provided	Parent responded, <i>on average</i> , that the care received from their child's health care provider was "Helpful" or "Very helpful" across all of the items. <i>Quality measure value: 75.0</i>

Though these thresholds are recommended by CAHMI based on their experiences with the measures, you may want to experiment with adjusting the thresholds to various levels depending on how you hope to use the data and your expectation about what care can and should be received. For example, you may want to raise the threshold bar once everyone becomes accustomed to the measurement process and has sufficient

time to implement a quality improvement strategy. Be sure to adjust your interpretation of each threshold score when doing so.

## 2. "All or Nothing" Measures: Proportion who received all or none of recommended care

A second possibility for scoring your quality measures is to see how many children and their parents are receiving <u>all</u> aspects of anticipatory guidance and counseling, reported their care as being <u>usually or always</u> helpful, or that the care was <u>usually or always</u> provided in a family-centered manner. These measures provide information on how consistent and comprehensive the care is that young children receive. Table 5.6 below lists examples for constructing "all or nothing" PHDS-PLUS quality measures.

**Table 5.6: All or Nothing Threshold Scores for Quality Measures** 

	Quality Measure	Threshold Score for Quality Measure- Used for Determining that a Sufficient Level of Quality of
1.	Anticipatory Guidance and Parental Education	Care was Received
	Version A: Average proportion of parents reporting that "yes" the topics were discussed	Parent responded "Yes" to discussing <b>all</b> of the topics for a given age group.
	Version B: The degree to which parents noted that their informational needs were met	Parent responded, "Yes, item was discussed and questions were answered" or "No, item was not discussed but I already had information about this topic" to <b>all</b> topics for a given age group.
2.	Health Information	Parent responded "Yes," they had seen or heard information about all of the items.
3.	Ask About and Address Parental Concerns	n/a
4.	Follow-Up for Children at Risk for Developmental Delays	n/a
5.	Assessment of Well-Being of Parent(s) and Safety Within the Family	Parent responded "Yes" to discussing <b>all</b> of the family assessment items.
6.	Assessment of Smoking and Drug Use in the Family	Parent responded "Yes" to <b>both</b> items about smoking and substance use in the home.
7.	Care Coordination	n/a
8.	Family-Centered Care	Parent responded "Usually" or "Always" to <b>all</b> of the items asking about family-centered care.
9.	Helpfulness of Care Provided	Parent responded that the care received from their child's health care provider was "Helpful" or "Very helpful" on <b>all</b> of the items.

## **3. Negative Indicator Measures:** Proportion of children who did NOT receiving recommended care

The measures described in Step 5.1 tell you whether children receive recommended care. You can also create measures that highlight care that children did <u>not</u> consistently receive. For this scoring method, instead of looking at who <u>did</u> get care, you are looking at who <u>did not</u> get care. This approach provides information for doctors and health care providers on missed opportunities to provide aspects of recommended care.

For example, instead of reporting that 39.2% of parents indicated that their child's doctor or health care provider discussed all topics included in the Anticipatory Guidance and Parental Education quality measure, you could report that 60.8% of parents indicated that their child's doctor or health care provider did <u>not</u> discuss one or more of the anticipatory guidance topics with them. You use the same score, but report it in a different way.

Example 5.5: Positive and Negative Indicators Using the PHDS Quality Measures:					
<u>Measure</u>	<b>Positive Indicator</b>	Negative Indicator			
Anticipatory Guidance and Parental Education	% of parents responding "yes, items were discussed" to <u>all</u> items	% of parents responding "no, item was not discussed" to one or more of the items			
Follow-Up for Children at Risk for Developmental Delays	% of parents responding "yes" to <u>at least one</u> of the items	% of parents responding "no" to <u>all</u> of the items			
Family-Centered Care	% of parents responding "usually or always" to all items	% of parents responding "never" or "sometimes" to <u>at least one</u> item			

**4. Overall Composite Quality Measures:** Proportion of children who received a threshold level of care across more than one quality measure

You may find it useful to combine the information from two or more quality measures into composite quality measures. Such composite measures provide a signal of whether children usually or always received all aspects of recommended care included in the composite measure. As with the individual quality measures, several methods can be used to create composite measures, depending on the message you are trying to convey.

1. <u>Overall Quality Threshold Measure</u>: As with the threshold measures for the individual quality measures, an overall threshold composite measure provides an

easily interpretable outcome of whether the child received the recommended care across each quality measure. There are two primary ways to calculate the Overall Quality Threshold Score:

a. Overall "Average Across All" Threshold Score:

To create this measure, children are categorized into two groups according to whether they have (1) an overall mean score of 75 points or above <u>across all</u> quality measures, or (2) an overall mean score below 75 <u>across all</u> measures. This measure indicates the proportion of children who meet the 75-point threshold and, *on average*, "usually" or "always" received all aspects of recommended care.

### b. Overall "On Each" Threshold Score:

To create this measure, children are categorized into two groups according to whether they have (1) an overall mean score of 75 points or above <u>on each</u> quality measure or (2) an overall mean score below 75 on one or more quality measures. This measure indicates the proportion of children who meet the 75-point threshold *on each* measure. This scoring method indicates whether a child "usually or always" received all aspects of recommended care.

2. Overall Negative Indicator Score: Both of the threshold scores listed above could be presented as the percent of children who received all aspects of recommended care <u>less often</u> than "usually" or "always." Basically, this would be the children who either had a score of less than 75 points for the Overall "Across All" Threshold Score or scored below the threshold on one or more of the Quality Measures for the Overall "Within Each" Threshold Score.

For instance, if 69.0% of children met the 75-point threshold for the Overall "Across All" Threshold Score, then 31.0% of children fell below the threshold, indicating that, on average, they received recommended care less often than "usually" or "always." When making a point about the quality of care experienced it is sometimes helpful to highlight the negative rather than the positive, to emphasize a point.

### Step 5.4: Evaluate quality measurement results for subgroups of children

The core PHDS-PLUS also includes additional topic areas that are extremely useful for analyses. Following is a list of the topic areas and the subtopics included within each. See Appendix 1 and Appendix 3 for specific survey questions relevant to each topic.

### 1. Health Care Utilization

- Emergency room visits
- Doctor office/clinic visits
- Overnight hospital visits
- Whether child has personal doctor or nurse

These items provide useful information about where a child has been for care. At a minimum, basic frequencies should be run for these items as well as stratified by demographic characteristics. In previous research, having a personal doctor or nurse has been linked with a higher quality of care and is one important way to examine the results.

#### 2. Assessment of Child's Health

- Risk of developmental, behavioral, or social delays
- Asking about and addressing parents' concerns
- Developmental assessment by doctor

As discussed previously, the Parent Evaluation of Developmental Status (PEDS), is included in the PHDS-PLUS and assesses a child's risk for developmental problems. While this measure is used to create a valid denominator for the *Quality Measure #3* Follow-Up for Children at Risk, it is also a useful lens through which to examine the various quality measures. Children at high or moderate risk tend to score lower on several of the measures. These data also may be very useful in conducting analyses with other supplemental data.

### **Example 5.6: Recommended Cross-Tabulations**

(items from core survey)

- Percent of concerned parents who were asked about their concerns
- Percent of concerned parents who were given specific information by their child's health care providers to address those concerns
- Quality measures by:
  - Whether child has a personal doctor or nurse
  - O By age group
  - By gender of child
  - O By educational level of parent
  - O Whether child is first-born child in household
- 3. Demographic information about parent and child
  - Information about child
    - o **Gender**
    - Race/ethnicity
    - First-born child
    - Age
  - Information about parent/family
    - o **Gender**
    - Age
    - Number of children in household
    - Relationship to child
    - Education

All results can be stratified by basic demographic information. Demographic information can be important in quality improvement reports. Providers can use the information to evaluate their own behavior and detect differences in care between various demographic groups. However, the level of detail may be overwhelming in consumer reports. You may choose only to highlight striking results in a consumer report.

### Analyses Using Administrative Data

Administrative data are used to determine which children are eligible to be included in the study. If you recall from *Step 3: Prepare for Survey Administration*, age and continuous enrollment status are usually required to be part of the sample. Other data are often included in the original sampling file as well. When developing your

analysis plan, determine which administrative variables you would like to keep and use for analytic purposes.

While utilization of health care, that is, having had a well-visit, is not a requirement for sampling, you may find it helpful to examine differences in scores based on *types* of well-visits children had in the past year. For example, one state Medicaid program examined differences in the prevalence of parents having discussed the anticipatory guidance topics with their child's health care provider by type of well-visit, including Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) well-visits and any other type of well-visit.

Use these variables to stratify the Quality Measure results to gain insight into the process measures of well care that you may be currently calculating. You may also want to examine these variables against some of the other analytic topics measured in PHDS-PLUS.

### Supplemental Items

Thus far, the suggestions for additional analyses have concentrated on areas that are measured using the core PHDS-PLUS survey. However, there are several additional topics included in the supplemental item section of the survey that may be of interest to you or your organization. Two topic areas in particular have generated a great deal of interest: (1) identifying children with special health care needs and (2) a screener to identify parents at risk for depression. Both of these areas can be used to examine the Quality Measures and additional areas in greater depth.

### 1. Identifying Children with Special Health Care Needs

CAHMI has developed a screener to identify children and adults with special health care needs. This screener operationalizes the federal Maternal and Child Health Bureau's definition of special health care needs using a consequences-based approach. This approach is not condition-specific as with other approaches and identifies children across the range and diversity of chronic conditions and special needs. This allows a more comprehensive assessment of health care system performance than is attainable by focusing on a single diagnosis or type of special need. In addition, the relatively low prevalence of chronic conditions and special needs among children often makes it problematic to find adequate numbers of very young children with specific diagnoses or types of special needs. In many cases, an approach that is not specific to a given condition makes it possible to identify enough children to enable statistically robust quality comparisons across the health care system and/or providers. For more information on the screener, please refer to the Children With Special Health Care Needs Screener User's Manual published by CAHMI. (www.cahmi.org)

### 2. Screening for Risk of Parental Depression

Parents at risk for depression are:

- less likely to report receiving care
- more likely to take a child to the emergency room



### Additional Tips and Resources

### **Statistical Analyses**

When comparing performance or scoring among different groups, statistical analyses are required to test and see if the differences are meaningful and real. However, the statistical test that is used will depend on the type of data you are testing. It is beyond the scope of this manual to be a statistical primer, therefore we suggest that when you compile your team you identify someone to be the lead person for these analyses. As an introduction to those analyses, the following table lists three of the most common statistical tests used in the analyses described in this section. Your vendor may also be able to provide these services.

Table 5.7: Typical Statistical Tests Run in Quality Health Care Reporting

Type of Comparison	Statistical Test	Example Research Question
Differences in mean scores between two groups	T-test	Do parents who are at risk for depression have a lower mean score on the Quality Measure of Helpfulness of Care than parents who are not at risk for depression?
Differences in mean scores between three or more groups	Analysis of Variance (ANOVA)	Are there differences in the mean scores for the Quality Measure of Assessment of Well-Being for Parent(s) and Safety Within the Family by racial/ethnic groups (e.g., white, African American, Hispanic, other)
3. Differences in binomial scores for two or more groups (e.g., crosstabulations of threshold scores)	Chi-square (χ²)	Are parents of children with special health care needs more likely to meet the threshold for having discussed the anticipatory guidance topics than parents of children without special health care needs?

## **Step 6: Report Your PHDS-PLUS Findings to Stimulate System Change**

Sharing information from the PHDS-PLUS can help you launch or strengthen partnerships and efforts to improve services, policies, and programs for children, youth, and families. Information from the PHDS-PLUS can be helpful in creating a shared understanding about the health and health care needs of young children and their families and can be used to motivate stakeholders to work together.

There are three steps to begin using your PHDS-PLUS data findings to inform, motivate, and engage partners in improving services, policies, or programs for children, youth, and families:

### **6.1 WHO**

Identify and learn about the audiences that play important roles in achieving your goals for evaluating and/or improving services, policies, or programs.

#### 6.2 WHY and WHAT

Select information from the PHDS-PLUS that will be of interest to each potential partner, person, or organization you want to engage or influence.

### 6.3 WHERE, WHEN, and HOW

Decide the best way to present this information—what format to use and when, where, and how to disseminate your findings.

Exercises, guidelines, and tips you or your team can use for each of these steps are suggested below. Specific examples of reports of PHDS-PLUS findings are included in Appendices 4–7.



### STEP 6.1: WHO: Identify and learn about your key audiences



### WHAT IS THE PURPOSE OF THIS STEP?

### In this step you will:

☑ Learn about each of your key audiences

☑ Get feedback on your plans for communicating PHDS-PLUS findings to each audience



### **GUIDELINES AND ISSUES TO CONSIDER**

Learning more about your audience makes your project more successful by ensuring that the resources invested in the project are utilized most effectively. During the project conceptualization and planning phase, you identified your primary as well as any secondary audiences for reporting your PHDS-PLUS findings and began thinking about the characteristics of these audiences and their health information needs. You may have answered the following questions during this process:

- What format for communicating findings do they prefer?
- What other information do they need to help them understand and find your PHDS-PLUS results credible?
- Do they need support to help them use the information?
- How do they receive other health-related information?
- What are the best ways to reach them?
- When are they most receptive to this type of information?
- Will they trust the information?

If you could not answer these questions, how can you find out more about your audience? You may want to consider conducting some research about your audience to learn more about them. You can use this information to make sure your quality report is relevant and useful. We suggest you do the following:

**Go directly to the source**. One of the best ways to learn more about your audience is to talk with members of it directly. This can be done either by interviews, focus groups, or even a small survey. The benefit of interviews and focus

groups is that you can modify your questions based on their responses. Be sure to document what you learn from your audience and how it impacts the development of your report.

### Contact groups or organizations that may already know your audience.

There may be groups or organizations that function as intermediaries for your audience. They would know a great deal about your audience and could most likely answer any questions you may have. In addition, they may have existing channels that you want to consider for audience research, dissemination, and marketing of the final report. Examples of intermediaries include consumer advocacy groups, employer business coalitions for employers, and professional provider organizations.

### Consider similar information that your audience may already receive.

Perhaps similar information is already being distributed to your audience. For example, parents may already receive information about all children rather than just young children, who are the focus of the PHDS-PLUS. Think about what information is contained in these reports. Who sponsors that report and how was the report disseminated? What is the message that is conveyed by the report? Does the audience trust the information? What does the audience do with the information? You may not have the resources necessary to conduct your own audience research, so options such as this one that require less effort may be very helpful in understanding your audience and their health information environment.



## STEP 6.2: WHY and WHAT: Select your primary purpose and key information to include in your PHDS-PLUS reports



### WHAT IS THE PURPOSE OF THIS STEP?

The purpose of this step is to specify what information is available in the PHDS-PLUS that your key stakeholders would find valuable.

### In this step you will:

- ✓ Specify what information to include in your PHDS-PLUS reports
- ☑ Consider specific issues and guidelines for communicating with different audiences for different purposes



### **GUIDELINES AND ISSUES TO CONSIDER**

Your PHDS-PLUS report will contain both PHDS-PLUS results and background or contextual information that readers will need to understand the report. When deciding what information to include, consider what messages you want your report to convey. In other words, what do you want your audience to <u>learn</u> from this information and what do you want them to <u>do</u> with the information?

Based on some of the reporting principles discussed throughout this manual, audience-specific suggestions and guidelines for content to include in your PHDS-PLUS reports are listed below. These are merely suggestions; your actual content should be tested with each audience. It is important to remember that research in the area of quality reporting is still in its infancy. There is no right answer or one single formula for creating an effective report. These guidelines can give you a good starting point.

## <u>Tips for communicating with government agencies for federal and/or state reporting</u>

Requirements for federal and state reporting are typically set by the agency requesting the information. Usually, they will require a special form (e.g., HCFA Form 416) or a particular format (e.g., record layout for electronic reporting). If a specific format or form is not specified, follow the directions given by the agency and keep the report as simple as possible.

### Use the PHDS-PLUS results to complement federal and state reporting requirements

The PHDS-PLUS contains more detailed information than what is generally required in most governmental reporting. Thus, the PHDS-PLUS results can be used to expand on the information provided by those mandatory reports. In addition, the PHDS-PLUS captures parental preferences about whether informational needs were met about specific topics.

As a case example, one state decided to assess Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) visits by comparing the information gleaned through a chart review with parent-reported information provided by the PHDS-PLUS. Since this state was already reporting EPSDT findings to health care providers, where possible they also included the PHDS-PLUS findings in that report. Focus groups with providers determined that this approach increased the relevancy and usability of the reports.

### Use the PHDS-PLUS quality measures for an overall snapshot of care

In most cases, federal and state reporting requirements stipulate that measures must answer whether recommended and eligible services are received. They should address broad aspects of care and are intended to provide an overall picture of quality and performance. Therefore, for general federal and state reporting the overall mean Quality Scores from the PHDS-PLUS quality measures are most appropriate.

Review the ways you can score the Overall Quality Summary Measures presented in Section 5. You might consider reporting the percent of children who received all aspects of recommended preventive care. In other words, rather than reporting the average score as with the quality measures, you would report the percentage of children who received each one of the recommended aspects of preventive care.

### Spotlight specific items that are hot issues for state legislation

Many of the individual items and/or areas included in the PHDS-PLUS are useful to report if your state has a specific topical focus for which an item-specific measure would be of interest (e.g., car seat use, reading, *Healthy People 2010* goals such as smoking).

# <u>Tips for communicating with purchasers for value-based purchasing and contracting decisions</u>

To date, users of the PHDS-PLUS have used the survey to compare different entities and/or to inform improvements. The PHDS-PLUS measures have been shown to differentiate between quality of care provided at a health plan, medical group, office, and health care provider level.

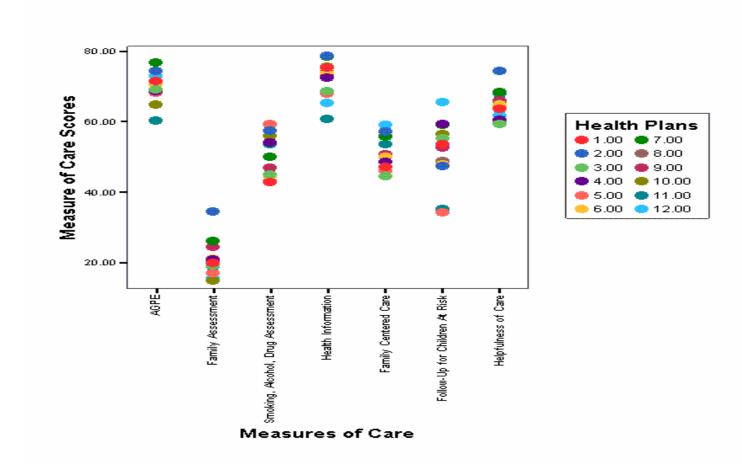
## Compare quality of care

Because this information will be used for comparison, displaying the results side-by-side for easier evaluation is most useful for purchasers. One way to present comparative information on the quality measures across health plans is shown in Figure 6.1. Not only does the picture show which quality measures need the greatest improvement, but it also displays the relative performance of each of the health plans. Notice that no one health plan does the best in every single category, which leaves room for targeted improvement.

# Present results using a layered approach

Purchasers use a multitude of information when making contracting decisions, so a layered approach is often suggested when preparing these types of reports. The first "layer" should provide a summary of aggregated results that can be reviewed quickly. Since purchasers can be more technically savvy in terms of health-related information, a table comparing the quality measures scores by plan might work best. In addition, we recommend stratifying the measures by key groups to demonstrate variations in the level of quality care. For example, it is often useful to stratify the findings by the age of the child. In general, younger children tend to score higher on the quality measures than older children. The subsequent layers can provide more detailed information on specific, targeted topics.

**Figure 6.1. Comparison of Quality Measures Across Health Plans** 



#### Tips for Communicating Findings to Frontline Health Care Providers

- Show comparative data to "pull them in" and give them a sense of overall findings
- Findings can be compared with benchmark data or state-level findings
- Explain how measures of care are scored
- Provide item-level findings, shown by categories
- Provide background information, links to additional resources
- Provide contact information to address questions
- Disseminate during in-person meetings prior to faxing or mailing results
- Findings cover letter should come from someone they recognize and trust

Frontline health care providers will find the PHDS-PLUS results useful for quality improvement purposes. To ensure that the information you provide is most useful and most likely to have the intended effect, use the guidelines below when reporting for quality improvement purposes.

- Show aspects of care correlated with higher quality measure scores
- Report both Quality Measure—level and item-level findings

When reporting the PHDS-PLUS results for quality improvement, you should report the Quality Measure—level findings that "send signals" about the performance in each domain of care (i.e., Quality Measures) as well as the item-level, actionable information that gives health care providers information about specific aspects of care.

Link findings to health behaviors and other quality indicators

To reinforce the validity of your results and emphasize the importance, it is helpful to link your findings to issues surrounding the health of young children, such as child's risk of developmental, social, or behavioral delays as well as correlates of higher quality, such as having a personal doctor or nurse.

- Compare information to national benchmarks, such as the National Survey of Early Childhood Health (NSECH)
- Increase your chances that the quality feedback you provide will be accepted, trusted, and acted upon

Since the PHDS-PLUS results are providing feedback on performance, be prepared for resistance from this audience. No one likes to be told, especially in a public document, that his/her performance is less than adequate. There are several steps you can take to ensure that your data collection efforts will have an impact:

- ✓ Highlight areas where high-quality care was found, as well as areas for improvement.
- ✓ Include a description of your methodology in addition to an explanation of what the PHDS-PLUS results can and cannot tell you.
- ✓ Remind the audience that the PHDS-PLUS Quality Measures simply measure aspects of the most highly respected national guidelines.

## **Tips for Communicating Finding to Parents of Children**

- Use a child-centric format (pictures, graphics)
- Use many text boxes, break out the information into smaller portions
- Explain why the findings presented are important and the role that the parent can have in improving their child's health care
- Provide item-level findings and specific tips for what parents can do to improve their child's health care
- Build parents' expectations by informing them about what they can and should expect
- Provide a chart that shows quality of care findings to a benchmark
- Provide links to additional resources
- Provide contact information for questions

Results from the PHDS-PLUS should be reported to the consumer, or parent, for two primary reasons: 1) to help parents make more informed choices about their child's health care, and 2) to empower and educate the parent on the type of care and service they should expect from the health care system. How the information from the PHDS-PLUS should be presented to parents can be very different depending on the purpose. Use the tips in this section to help create your consumer reports.

# <u>Communicating with parents to help them select health care plans or providers</u>

# Provide comparative information

If the report is intended to provide consumers with information to make more informed health care decisions, then a data display that facilitates comparison is useful. Also, due to different cognitive abilities, consumers may need assistance with interpreting several pieces of information to inform their decision. It is very challenging to process pieces of information, such as results from several measures, and make a decision.

# Layer information to account for all types of consumers and to make the results easier to interpret

Since everyone has different health information needs and experiences with the health care system, there is no "average" consumer. Consequently, creating a report for one subgroup of this audience will likely make the report less effective for another subgroup. Also, different groups of people

# ADDITIONAL TIPS FOR CREATING CONSUMER REPORTS:

- Conserve white space. White space makes the document appear more manageable to consumers at first glance. Too little white space can be overwhelming.
- Be concise—minimize text when possible. While background and context are important, presenting the text in a clear, concise way can significantly affect the overall length of the report.
- Use bullets and lists when possible. Lists are easier to read and process as compared with paragraph text. Moreover, bullets and lists result in more white space.

put more or less value on different aspects of quality care. Thus, layering information is probably your best strategy for creating a report that different consumers will find useful. This allows those who are not interested in a lot of detail the opportunity to glean the necessary information from the report very quickly. Parents can choose to focus on those aspects of care that resonate most with them.

# Provide some background information on quality measurement to help consumers understand the information presented

The general public may have little or no knowledge of health care and how quality is measured. Also, parents may be skeptical of the source of the information. Therefore, significant background information will be necessary to help them understand the information and why it is important to them. Background information includes descriptions and definitions of:

- Why measuring health care quality is important
- Which aspect of health care quality you are addressing in the report (e.g., health plans, providers)

- The PHDS-PLUS and why consumer assessments are important to understanding health care quality
- The source of the PHDS-PLUS information and/or who sponsored the survey
- What the PHDS-PLUS results can tell you and how to use the information

# Consult with your audience to see if the information is easily understood

Testing of your report is critical to ensure the audience understands the information and uses it in the way you intended. Refer to the subsection (at the end of Task Q: Presenting Your Results) on using graphical ways to help readers understand comparative information below for more suggestions and caveats for creating your report.

## Communicating with parents to educate and empower them as partners

PHDS-PLUS results also can be used to inform and strengthen existing relationships, especially parents' relationships with providers. The results can be used to educate parents regarding what they can and should expect during a visit to their child's doctor or other health care provider. Since this information is being used to empower the parent, you should also include reminders that they are partners in their child's health care and should expect family-centered care from their child's providers.

# • Avoid comparative information, but do include a "gold standard" Since parents aren't making a choice about their child's health care, comparative information is generally not useful and can interfere with the message you are trying to convey. Instead, present details on the care that parents should expect from their child's health care providers and demonstrate how close those providers are to the goal.

# Avoid complex tables and charts

The majority of parents aren't versed in reading and interpreting data tables and charts, so they should be avoided. Often a simple bar chart showing how close the doctor is to some standard or goal can be a very effective way to present results.

# Present both positive and negative information

Parents want to see a balance of what their child's doctor is doing right, as well as the areas where he or she could improve. Focusing only on the negative may make the parent feel overwhelmed or helpless. Using a mixture of positive and negative indicators when presenting the results helps them feel good about the

care their child is receiving and also helps the parent to set goals in certain areas.

# • Highlight which aspects of care can be improved

Present results in terms of what action can be taken. Is there a list of questions or checklist the parent can bring to the next visit?



# STEP 6.3: WHERE, WHEN, HOW: Decide the best way to present your PHDS-PLUS information



# WHAT IS THE PURPOSE OF THIS STEP?

# In this step you will:

✓ Design your PHDS-PLUS reports

☑ Develop and implement a plan for disseminating your PHDS-PLUS reports



#### **GUIDELINES AND ISSUES TO CONSIDER**

To ensure that your data from the PHDS-PLUS is relevant and meaningful they must:

- 1) Be communicated and presented in way that is understandable and useful to each stakeholder
- 2) Inform and quide actions that can be taken by each stakeholder to address the issues you present

Now that you have identified key partners or audiences in Step 1 and the PHDS-PLUS data findings you want to share with them in Step 2, you are ready to begin to design your PHDS-PLUS findings reports and plan for dissemination.

An example workshop is provided below to help your team brainstorm the type, format, content, and dissemination of a report to each key audience. Keep in mind that you can also consider integrating other data to which you have access using the worksheet on the following page. This worksheet asks you to consider the following for each communication to each stakeholder:

Example 6.1: Worksheet to design your reports on your PHDS-PLUS data findings

data findings			
Your Audience/Stakeholder:			
Individual topics or measures from the PHDS-PLUS to include	1. 2. 3.		
Relevant subgroup of children and youth and geographic comparison areas for each PHDS-PLUS topic or measure	1. 2. 3.		
Other data to include and source of this data	1. 2.		
Background information and key points to make to establish relevance of your PHDS-PLUS data findings for your audience	1. 2. 3.		
Tone of the communication (e.g., motivate through emphasizing the negative vs. positive; emphasize the gaps/needs vs. what can be done)	1. 2. 3		
Format and length (e.g., one-page summary, PowerPoint presentation)	1. 2. 3		
Explanation of data source and validity of findings required	1. 2. 3		
Actions you want them to take and resources you want them to know about (e.g., come to our meeting, go to our Web site, tell your doctor)	1. 2. 3		
Dissemination and follow-up strategy (e.g., e-mail with phone follow-up)	1. 2. 3		

#### **Decide on a Format**

How you deliver your message can be as important as what you have to say. Two commonly used formats for reports include the following:

- **1. Written reports/materials**. Written reports can be brief, such as a pamphlet or brochure, or lengthier, such as booklet or binder. If a written report is the format you choose, consider any logistical requirements that you may have such as reproduction costs, size (Does it have to fit a certain size envelope for mailing?), weight (Are you limited by weight in terms of postage costs?), number of pages, binding, etc.
- **2. Web-based reports** are becoming more popular. One advantage to Web-based reports is that the reports can be easily tailored to specific users. One disadvantage of Web-based reports is that they will only be available to those with access to the Internet.

## **Determine your Dissemination Strategy**

One of the most important factors in the overall success of your survey effort is your ability to "tell a story" through interpretation and dissemination of the data. If your audience never receives the data, they cannot use them! How, where, and when are all important questions you need to consider when planning the dissemination. Here are some ways in which you may want to think about dissemination of a data report.

<u>In-Person Meetings</u> – In-person meetings are an extremely valuable way to provide information. In-persons meeting allow you to connect eye-to-eye with audiences and provide a larger context about the report findings and how they may be valuable.

<u>Mail</u> – Mail can be an effective way to reach each member of your audience as long as you have reliable mailing addresses. Include an introductory letter from someone they trust.

<u>Listservs and Web site Postings</u> – Increasingly, materials are being disseminated electronically. By distributing information through a listserv or Web site, you may allow many others to disseminate your information. Be sure that it is posted in a secure format.

<u>Fax</u> – Fax can be an effective way to reach each member of your audience as long as you have reliable fax numbers. Some focus groups and interviews have

shown that health care providers are more likely to read information when it is faxed as opposed to when it is mailed to their busy offices.

<u>Intermediaries</u> – Think about intermediaries that could disseminate this information for you. Are there other family or professional groups or organizations through which you could reach your desired audience? Consider the influence that the intermediary may have on your audience in disseminating the report.

<u>Public Availability</u> – Making the report available for the public to request or access through public places, such as a local library, is an option. This is a good way to provide additional copies once the initial distribution has been conducted.

No one method is most effective. The key to successfully disseminating your report is to make sure you are reaching your audience where and when they need it. Regardless of the how you disseminate the report, it is important to indicate where readers can go if they have questions. This could be a phone number, a Web site, or other information source.



# **Quick-Guide Summary of Tips for Effective Presentation of Data**

As noted throughout this section, data from the PHDS-PLUS are not relevant and meaningful unless they are <u>communicated and presented</u> in a way that is understandable and useful to each audience. Presenting technical information about health care quality can be challenging for several reasons. First, this information typically involves statistical methods that may be difficult to describe. Second, how well your audience will understand the results and how the results were calculated may vary tremendously. Finally, you most likely have a lot of information to choose from when deciding which measures and results should be included in your report. Including too little can be a missed opportunity to communicate quality to your audience; however, including too much can be overwhelming to your audience. A summary of general suggestions for how to make the PHDS-PLUS information you present manageable are listed below.

# **Quick-Guide Summary List of Tips**

- Tailor the presentation to the audience and purpose
- Provide background information on the data you use—who is the data about?
- Include pictures, graphics, quotes, or stories that connect the findings to real people
- Break out the information in text boxes to make it more digestible
- Keep it brief

- Give an overall picture, and then target specific findings
- Display the data in the most meaningful ways, e.g., 20% of households or "1 of 5 households"
- Use specific numbers when possible, e.g., 9.8 million children nationally have special health care needs, 12.8% of the population of children
- Balance positive and negative ways of expressing the findings according to the point you are trying to make, e.g., less than a quarter, more than 75%
- Be careful when dealing with very small numbers
- Provide findings in relation to a benchmark, such as state findings compared with national or regional findings
- Explain why the findings presented are important
- Suggest ways that a specific audience might use the data to improve care
- Credit the source of the data and include when, how, and by whom they were collected
- Provide links to additional resources
- Use multiple dissemination strategies to reach as many audiences as possible
- Provide contact information for questions

#### **More Information and Additional Tips**

 Layer information. Members of your audience will have different needs in terms of both the amount of information they want to have and the way the information is presented. An easy way of creating one report that will meet the needs of various members in your audience is to layer the information. This approach is almost like creating multiple sub-reports that are contained in one final report. Each sub-report would have a different level of detail and/or presentation. Think of a tabbed report where each tab was intended for a different subgroup of your audience.

The first layer might include very high-level information—the view from 10,000 feet above. This layer is intended for those who do not have a lot of time or are only minimally interested in reviewing quality information. You may only want to include a few aggregate measures in this layer. Limit the amount of detail you present in this layer and refer readers to subsequent layers if they would like additional or more detailed information.

Subsequent layers could include additional information and/or detail. For example, you might consider adding two additional layers. The first might be the "ground level view," which would include a few more measures with slightly more detail intended for those who are interested in quality information but may not have the cognitive ability to process highly technical information. The second could then be the "microscopic view," which would include a higher level of detail for those who are interested in technical aspects.

• **Comparing against benchmarks.** Comparison with benchmark data can be a useful way of helping readers to understand the results.

#### Beware of relative benchmarks!

CAHMI does not recommend comparison to <u>relative</u> benchmarks since such comparisons can be VERY misleading to readers. Relative benchmarks are benchmarks that change based on the results of the survey sponsors, such as a state average among all health plans.

Here is an example of how such a comparison can be misleading.

A state agency is creating a public report that includes results from all health plans operating in the state. This is the first year that all the plans have administered the PHDS and most are new at monitoring quality. As you might expect, the scores from the plans are fairly low when compared with national recommendations or even other states; however, the state is confident that simply reporting the results will motivate quality improvement among the plans. Instead of comparing the results to national guidelines, they choose a relative benchmark—the state average among health plans. Consequently, several plans have results that are higher than the state average. When the report is released, these plans feel they have results that are "above average" and do prioritize quality improvement initiatives focused on preventive care for young children. In reality, these plans are performing well below the recommended national guidelines.

- **Combining other data sources:** Combining your PHDS-PLUS results with data from other sources can help to make them more valuable to the end reader.
- Organize information into smaller segments: Readers can often have a
  difficult time processing large amounts of information. Breaking the information
  into "bite-size" pieces can help readers to understand the information being
  presented. This can be accomplished by creating a series of smaller text boxes
  rather than larger sections of text or graphs. Readers can then process the
  limited information in the text box before moving on to the next text box. This
  approach is effective not only for consumers but also for providers and
  purchasers who may not have the time or focus to absorb a lot of information at
  one time. Graphics that are meaningful to the target audience can also be
  added.
- Presenting statistical information and methodological issues: Presenting statistical information and methodological issues is one of the most challenging parts of reporting the results. Most consumers do not understand statistical tests,

confidence intervals, or probability. However, statistical comparisons must be used to ensure that true differences are identified. Below are some suggestions based on the audience for your report. Remember that these are general suggestions and your audience may be different; therefore, testing is essential.

- Non-technical audiences (Consumers, some purchasers, policymakers): Most consumers and some purchasers will not understand the statistics behind the analysis. Policymakers often do not have the time to review detailed information and are more interested in a summary of the findings. It is probably enough to indicate that statistical tests have been used to identify true differences in the results and provide a way for readers to get additional information if they are interested. Again, layering information is the best way to meet the needs of different members of your audience. Purchaser and policymaker audiences can be quite diverse. For every purchaser or policymaker that does not want the technical detail, another purchaser or staff member does want to review the technical detail. If you are creating a layered report, the statistical detail can be included in subsequent layers intended for readers who want more technical information. Refer to the next description for more detail.
- Technical audiences (Providers, health plans, some purchasers, regulators, policymakers' staff members): Many readers will be interested in the more detailed statistical aspects of the analyses. Still, these audiences are diverse. While some will have the background and expertise to understand the statistical formula that you used in the analysis, others may be turned off by having that detail included in the body of the report. Reports for these audiences should include a description of the statistical methods used; however, this information is best included as an appendix to the main report. This allows those who are interested in the information access to the detail without overwhelming other readers by including it in the text. Details you may want to consider for the body of the report include indicating the sample size, confidence intervals, and p-values in graphs and charts, for example.
- **Balancing positive and negative measures:** The same information can be used to present results in a positive or negative measure. Positive measures illustrate high or quality performance, whereas negative measures highlight poor performance. Positive and negative approaches each present slightly different pictures of performance. No one measure is right nor can one measure present a comprehensive picture of quality. You may even want to report the results in multiple ways. The key is to balance positive and negative measures.



## **Additional Resources**

- 1) For more information about **creating health care quality reports**, visit the TalkingQuality Web site at <a href="http://www.talkingquality.gov">http://www.talkingquality.gov</a>.
- Visit <a href="http://www.nschdata.org">http://www.nschdata.org</a> for additional tips and resources on communicating data findings to stimulate system change.
- 3) For more information about focus groups and cognitive interviews the Child and Adolescent Health Measurement Initiative has conducted about **reporting quality of care findings**, visit the Web site at <a href="http://www.cahmi.org">http://www.cahmi.org</a>.
- 4) For more information about focus groups and interviews the Foundation for Accountability has conducted about **reporting quality of care findings**, visit the CAHMI Web site at <a href="http://www.cahmi.org">http://www.cahmi.org</a>.
- 5) For an **example of an issue brief** that can be created for audiences such as the state Medicaid director, visit the Kansas Health Foundation Web site at <a href="http://www.kansashealth.org">http://www.kansashealth.org</a>.
- 6) For more information about work the **National Academy for State Health Policy** (NASHP) has done in working with states to use health and health care findings to implement changes in state programs and policies, visit the Web site at <a href="http://www.nashp.org/">http://www.nashp.org/</a>.
- 7) Visit <a href="http://www.familyvoices.org">http://www.familyvoices.org</a> for additional family-friendly information on using data, links to other data sources, and sample reports.
- 8) For more information about strategies the Center for Children with Special Needs has used to **convene various stakeholders**, visit their Web site at <a href="http://www.cshcn.org">http://www.cshcn.org</a>.
- 9) For more information about how to work with families of children and adolescents with mental health conditions, visit the Federation of Families for Children's Mental Health at <a href="http://www.ffcmh.org">http://www.ffcmh.org</a>.



Promoting Healthy
Development Survey - PLUS
(PHDS-PLUS)

The PHDS-PLUS is a 128-item telephone/interviewer-administered survey largely derived from the mail/self-administered Promoting Healthy Development Survey (PHDS) (78% of PHDS-PLUS is in the PHDS). It takes 12–15 minutes to administer. This document provides a high-level summary of the questions asked in the survey.



The PHDS-PLUS survey was developed under the rubric of the Child and Adolescent Health Measurement Initiative.

# CAHMI

The Child and Adolescent Health Measurement Initiative

# Promoting Healthy Development Survey-PLUS (PHDS-PLUS) Core Text of Survey

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#### **Section 1. Child Information**

This section provides descriptive information about the child.

- 1. The questions in this survey ask about the health care that (child) has received in the past year or since he/she was born. May I speak with the person in the household who is most often responsible for taking (child) to the doctor to get health care?
- 2. From the information that I have it looks like (child) is [#] months old. Is this correct?
- 3. How are you related to (child)?
- 4. Is it correct that (child) is [Gender listed in enrollment file]?
- 5. Is it also correct that (child) is currently enrolled in Medicaid or (state specific name for Medicaid or SCHIP)? 1
- 6. So I'll know how to refer to (child) during the interview, is it alright with you that I continue to use (child's first name)? 1

#### Section 2: Health Care Utilization

This section provides information about the nature and frequency of the child's health care use.

- 1. In the last 12 months (not counting times [child] went to an emergency room) how many times did (he/she) go to a doctor's office or clinic?
- 2. In the last 12 months, how many times did (child) go to an emergency room?
- 3. In the last 12 months, how many times was (child) a patient in a hospital overnight or longer? 2
- 4. In the last 12 months, has (child) needed care right away for an illness or injury?
  - a. When (child) needed care right away for an illness or injury, how often did (child) get this care as soon as you wanted?

# **Response Code Legend**

- 1 Yes, No
- 2 Open-ended response.
- A lot concerned, A little concerned, Not at all concerned
- 4 Never, Sometimes, Usually, Always 9 A lot of trouble, Some trouble, No
- 6 Not at all helpful, Somewhat helpful, Helpful, Very helpful
- 6 Excellent, Very Good, Good, Fair, Poor

- Man, Woman
- **8** White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race
- trouble at all
- Mother, Father, Aunt or Uncle, Older brother or sister. Grandmother or Grandfather, Guardian, Other relative

#### **Section 3: Access Issues**

This section provides information about access issues such as whether the child ever needed health care but not receive it or received health care later than the parent would have liked.

- 1. In the last 12 months (For children younger than 12 months, since child's birth) was there any time that (child) needed health care but did not get it?
  - a. Why did (child) need\_health care?

Was it for a......

Regular or routine visit?

A medical problem or concern?

A behavioral problem or concern?

A speech and/or language problem or concern?

For another reason?

b. Why didn't (child) receive care for [insert type of care indicated in 1a]?

Was it because....

You could not afford it or had no health insurance?

You had no doctor to go to for (child)?

(Child's) doctor did not consider it a problem?

(Child's) doctor had no one to refer (child) to?

You had transportation/childcare problems?

Problems related to work?

Insurance did not cover the visit?

Doctor's schedule was full/no free appointments?

c. Did the lack of health care for (child's) medical problem ... 

Create concerns about (child's) future development?

Create problems for (child) attending day care?

Create problems for you and/or your spouse/partner meeting work responsibilities?

- 2. In the last 12 months (For children younger than 12 months, since child's birth) was there any time that (child) received care, but got the care later than you would have liked?
- a. Why did (child) need health care?

Was it for a.....

Regular or routine visit?

A medical problem or concern?

A behavioral problem or concern?

A speech and/or language problem or concern?

For another reason?

b. Why was (child's) care for [Insert response to 2a] delayed?

Was it because....

You could not afford it or had no health insurance?

You had no doctor to go to for (child)?

(Child's) doctor did not consider it a problem?

(Child's) doctor had no one to refer (child) to?

You had transportation/childcare problems?

Problems related to work?

Insurance did not cover the visit?

Doctor's schedule was full/no free appointments?

c. Did the delay in health care for (child's) medical problem ... 1

Create concerns about (child's) future development? Create problems for (child) attending day care?

Create problems for you and/or your spouse/partner

meeting work responsibilities?

#### **Section 4: Care Coordination**

This section provides information about the level of care coordination for children who get care from more than one kind of provider or use more than one kind of health care service.

- 1 In the last 12 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?
  - a. In the last 12 months, did anyone from your child's doctor's office or clinic help coordinate your child's care among these different providers or services?

#### Section 5: Other Health Services

This section provides information about the child's enrollment in WIC and parenting classes the respondent may have taken.

- 1. Has (child) ever received WIC?
  - a. (Question only for children older than 12 months) In the last 12 months, has (child) received WIC? 1
- 2. In the last 12 months did (child's) doctors or other health providers refer you to any programs or classes?
  - a. What kinds of program (s) /classe (s) was that?
- 3. Did you attend a parenting class after the birth of (child)?
  - a. Was this parenting class paid for or covered by (child's) health insurance plan or Medicaid?
- 4. Do you have other children besides (child)?
  - a. Did you attend a parenting class after the birth of your other (CHILD/CHILDREN)? 1

# Response Code Legend

- 1 Yes, No
- 2 Open-ended response.
- A lot concerned, A little concerned, Not at all concerned
- 4 Never, Sometimes, Usually, Always 9 A lot of trouble, Some trouble, No
- **5** Not at all helpful, Somewhat helpful, Helpful, Very helpful
- **6** Excellent, Very Good, Good, Fair, Poor

- **7** Man, Woman
- **8** White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race
- trouble at all
- Mother, Father, Aunt or Uncle, Older brother or sister, Grandmother or Grandfather, Guardian, Other relative



# **Section 6: Anticipatory Guidance and Education**

This section provides information about whether key anticipatory guidance and parental education recommended in the Maternal and Child Health Bureau Bright Futures Guidelines and the American Academy of Pediatrics Guidelines for Health Supervision is provided by the doctor or other health provider.

For Parents Responding About Children 3-9 months old.

#### Section Note:

In the anticipatory guidance and education section, parents answer a core question about whether a topic was discussed in the last 12 months. Parents who answer the core question "No" are asked a follow-up question that asks whether the parent wished he/she had talked about this topic with the doctor or other health provider. Parents who answer this follow-up question "No" are then asked a second follow-up question, which asks the parent to explain why he/she did not wish to discuss the topic.

- 1. In the last 12 months, did (child's) doctors or other health providers talk with you about things you can do to help (child) grow and learn?
- 2. In the last 12 months, did (child's) doctors or other health providers talk with you about the kinds of behaviors you can expect to see as (child) gets older? •
- 3. In the last 12 months, did (child's) doctors or other health provider talk with you about breastfeeding?
- 4. In the last 12 months, did (child's) doctors or other health providers talk with you about issues related to food and feeding of (child) such as the introduction of solid foods?
- 5. In the last 12 months, did (child's) doctors or other health providers talk with you about the importance of placing (child) on (his or her) back when going to sleep?

- 6. In the last 12 months, did (child's) doctors or other health providers talk with you about night waking and fussing? ●
- 7. In the last 12 months, did (child's) doctors or other health providers talk with you about how (child) communicates (his or her) needs?
- 8. In the last 12 months, did (child's) doctors or other health providers talk with you about what (child) is able to understand? 

  1
- 9. In the last 12 months, did (child's) doctors or other health providers talk with you about how (child) responds to you, other adults, and caregivers? •
- 10. In the last 12 months, did (child's) doctors or other health providers talk with you about how to avoid burns to (child), such as changing the hot water temperature in your home?
- 11. In the last 12 months, did (child's) doctors or other health providers talk with you about using a car-seat? ①
- 12. In the last 12 months, did (child's) doctors or other health providers talk with you about how to make your house safe? •
- 13. In the last 12 months, did (child's) doctors or other health providers talk with you about the importance of showing a picture book to or reading with (child)?
- 14. In the last 12 months, did (child's) doctors or other health providers talk with you about the issues related to childcare?

#### For parents responding about children 10-18 months.

#### Section Note:

In the anticipatory guidance and education section, parents answer a core question about whether a topic was discussed in the last 12 months. Parents who answer the core question "No" are asked a follow-up question that asks whether the parent wished he/she had talked about this topic with the doctor or other health provider. Parents who answer this follow-up question "No" are then asked a second follow-up question, which asks the parent to explain why he/she did not wish to discuss the topic.

- 1. In the last 12 months, did (child's) doctors or other health providers talk with you about things you can do to help (child) grow and learn?
- 2. In the last 12 months, did (child's) doctors or other health providers talk with you about the kinds of behaviors you can expect to see in (child) as he/she gets older?
- 3. In the last 12 months, did (child's) doctors or other health providers talk with you about vitamins and foods (child) should eat?
- 4. In the last 12 months, did (child's) doctors or other health providers talk with you about (child) bed and naptime routines?
- 5. In the last 12 months, did (child's) doctors or other health providers talk with you about words and phrases (child) uses and understands?
- 6. In the last 12 months, did (child's) doctors or other health providers talk with you about night waking and fussing?
- 7. In the last 12 months, did (child's) doctors or other health providers talk with you about (child's) sleeping with a bottle? •
- 8. In the last 12 months, did (child's) doctors or other health providers talk with you about weaning (child) from a bottle?
- 9. In the last 12 months, did (child's) doctors or other health providers talk with you about weaning (child) from breastfeeding?

- 10. In the last 12 months, did (child's) doctors or other health providers talk with you about how (child) may start to explore away from you?
- 11. In the last 12 months, did (child's) doctors or other health providers talk with you about guidance and discipline techniques to use with (child)?
- 12. In the last 12 months, did (child's) doctors or other health providers talk with you about toilet training?
- 13. In the last 12 months, did (child's) doctors or other health providers talk with you about what you should do if (child) swallows certain kinds of poison?
- 14. In the last 12 months, did (child's) doctors or other health providers talk with you about using a car-seat? ●
- 15. In the last 12 months, did (child's) doctors or other health providers talk with you about how to make your house safe? 

  15. In the last 12 months, did (child's) doctors or other health providers talk with you about how to make your house safe?
- 16. In the last 12 months, did (child's) doctors or other health providers talk with you about the importance of reading with (child)? ●
- 17. In the last 12 months, did (child's) doctors or other health providers talk with you about issues related to childcare?
- 18. In the last 12 months, did (child's) doctors or other health providers talk with you about WIC? ■



#### For parents responding about children 19-48 months.

#### Section Note:

In the anticipatory guidance and education section, parents answer a core question about whether a topic was discussed in the last 12 months. Parents who answer the core question "No" are asked a follow-up question that asks whether the parent wished he/she had talked about this topic with the doctor or other health provider. Parents who answer this follow-up question "No" are then asked a second follow-up question, which asks the parent to explain why he/ she did not wish to discuss the topic.

- 1. In the last 12 months, did (child's) doctors or other health providers talk with you about things you can do to help (child) grow and learn?
- 2. In the last 12 months, did (child's) doctors or other health providers talk with you about the kinds of behaviors you can expect to see as (child) gets older?
- 3. In the last 12 months, did (child's) doctors or other health providers talk with you about issues related to food and feeding (child)?
- 4. In the last 12 months, did (child's) doctors or other health providers talk with you about (child's) bedtime routines and how many hours of sleep (child) needs?
- 5. In the last 12 months, did (child's) doctors or other health providers talk with you about toilet training?
- 6. In the last 12 months, did (child's) doctors or other health providers talk with you about the words and phrases (child) uses and understands?
- 7. In the last 12 months, did (child's) doctors or other health providers talk with you about how (child) is learning to get along with other children?
- 8. In the last 12 months, did (child's) doctors or other health providers talk with you about guidance and discipline techniques to use with (child)?

- 9. In the last 12 months, did (child's) doctors or other health providers talk with you about ways to teach (child) about dangerous situations. places, and objects [examples include electrical sockets, the stove. climbing on things, running into the street?]
- 10. In the last 12 months, did (child's) doctors or other health providers talk with you about using a car-seat? 1
- 11. In the last 12 months, did (child's) doctors or other health providers talk with you about how to make your house safe? •
- 12. In the last 12 months, did (child's) doctors or other health providers talk with you about what you should do if (child) swallows certain kinds of poisons? 1
- 13. In the last 12 months, did (child's) doctors or other health providers talk with you about the importance of reading with (child)?
- 14. In the last 12 months, did (child's) doctors or other health providers talk with you about the issues related to childcare? 1
- 15. In the last 12 months, did (child's) doctors or other health providers talk with you about WIC?

# **Response Code Legend**

- 1 Yes. No
- Open-ended response.
- 3 A lot concerned, A little concerned, Not at all concerned
- 6 Not at all helpful. Somewhat helpful, Helpful, Very helpful
- 6 Excellent, Very Good, Good, Fair, Poor

- Man, Woman
- **8** White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race
- 4 Never, Sometimes, Usually, Always 9 A lot of trouble, Some trouble, No trouble at all
  - Mother, Father, Aunt or Uncle, Older brother or sister, Grandmother or Grandfather, Guardian, Other relative

## **Section 7: Developmental Assessment**

This section provides information about whether a developmental assessment may have occurred, whether parents have concerns about their child's learning, development, and/or behavior, and whether doctors or other health care providers ask about and/or address parents concerns.

- 1. Did (child's) doctors or other health providers ever tell you that they were doing what doctors call a "developmental assessment" or test of (child's) development? •
- 2. Did (child's) doctors or other health providers ever have (child) rollover, pick up small objects, stack blocks, throw a ball, or recognize different colors?
- 3. In the last 12 months, did (child's) doctors or other health providers have you fill out a survey or checklist about concerns you may have had about (child's) learning, development, or behavior?
- 4. In the last 12 months, did (child's) doctor or other health care providers have you fill out a survey or checklist about avtivities that (child) may be able to do such as certain physical tasks, whether (child) can draw certain objects, or ways (child) can communicate with you?
- 5. The next section asks about specific concerns some parents (if grandparent: grandparents) may have. Please tell me if you are currently a lot, a little, or not at all concerned about the following:

How your child talks and makes speech sounds? 3

How your child sees? 3

How your child hears? 3

How your child understands what you say? 3

How your child uses his or her hands and fingers to do things? §

How your child uses his or her arms and legs? 3

How your child behaves?

How your child gets along with others?

How your child is learning to do things for himself/herself? 3

How your child is learning preschool or school skills?

How your child is behind others or can't do what other kids can? §

- 6. In the last 12 months, did (child's) doctors or other health providers ask if you have concerns about (child's) learning, development, or behavior?
- 7. In the last 12 months, did you have any concerns about (child's) learning, development, or behavior? 3
  - a. In the last 12 months, did (child's) doctors or other health providers give you specific information to address these concerns?

# Section 8: Follow-Up for Children at Risk for Developmental/Behavioral Delays

This section provides information about follow-up services the child may have received.

1. In the last 12 months did (child's) doctors or other health providers do any of the following...

Refer (child) to another doctor or other health provider?

Test (child's) learning and behavior?

Note a concern about (child) that should be watched carefully?

Refer (child) for speech-language or hearing testing?

•



## **Section 9: Family Centered Care**

This section provides information about communication and the respondent's experience of care.

- 1. In the last 12 months, how often did (child's) doctors or other health providers take time to understand the specific needs of (child). Would you say never, sometimes, usually, or always?
- 2. In the last 12 months, how often did (child's) doctors or other health providers respect you as an expert about (child)?
- 3. In the last 12 months, how often did (child's) doctors or other health providers build your confidence as a parent (if grandparent: grandparent)?
- 4. In the last 12 months, how often did (child's) doctors or other health providers help you feel like a partner in your child's care?
- 5. In the last 12 months, how often did (child's) doctors or other health providers explain things in a way you can understand?
- 6. In the last 12 months, how often did (child's) doctors or other health providers show respect for your family's values, customs, and how you prefer to raise your child?

# Section 10: Health Provider Assessment of Risks in the Family

This next section provides information about whether the doctor or other health provider screens families for risk factors to the child's health.

- 1. In the last 12 months, did (child's) doctors or other health providers ask you if you or someone in your household smokes? •
- 2. In the last 12 months, did (child's) doctors or other health providers ask you if you or someone in your household drinks alcohol or uses other substances?
- 3. In the last 12 months, did (child's) doctors or other health providers ask you if you ever feel depressed, sad, or have crying spells? •
- 4. In the last 12 months, did (child's) doctors or other health providers ask you if you have someone to turn to for emotional support?
- 5. In the last 12 months, did (child's) doctors or other health providers ask you if you have any firearms in your home? 1

#### **Response Code Legend**

- 1 Yes, No
- 2 Open-ended response.
- 3 A lot concerned, A little concerned, Not at all concerned
- **6** Not at all helpful, Somewhat helpful, Helpful, Very helpful
- 6 Excellent, Very Good, Good, Fair, Poor

- Man, Woman
- **8** White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race
- 4 Never, Sometimes, Usually, Always 9 A lot of trouble, Some trouble, No trouble at all
  - Mother, Father, Aunt or Uncle, Older brother or sister, Grandmother or Grandfather, Guardian, Other relative

#### **Section 11: Health Information**

This section captures information about whether the respondent has read or seen specific kinds of health information.

In the last 12 months did you see or hear any information about the following:

- 1. Safety information, such as how to make your house and car safe for (child).
- 2. Health care information, such as when and how often (child) should see the doctor or reminders about immunizations.
- 3. Developmental information, such as things you can do with (child) to help (him/her) grow and learn.

#### Section 12: Helpfulness of Care Provided

This section provides information about how helpful the care provided is in specific aspects of parenting.

In thinking about all of the care provided from (child's) doctors or other health providers in the last 12 months, how helpful has it been in the following areas:

- 1. Understanding (child's) behavior?
- 2. Learning how to protect (child) from injuries? §
- 3. Giving you the information you needed when you needed it?
- 4. Learning how to meet your own needs while caring for (child)? §

#### Section 13: Child's Health: Overall Health Status

1. Overall, how would you rate (child's) health in the last 12 months?

# **Response Code Legend**

- 1 Yes, No
- 2 Open-ended response.
- 3 A lot concerned, A little concerned, Not at all concerned
- 4 Never, Sometimes, Usually, Always 9 A lot of trouble, Some trouble, No
- **5** Not at all helpful, Somewhat helpful, Helpful, Very helpful
- **6** Excellent, Very Good, Good, Fair, Poor

- **7** Man, Woman
- **8** White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race
- trouble at all
- Mother, Father, Aunt or Uncle, Older brother or sister, Grandmother or Grandfather, Guardian, Other relative

#### Section 14: Children with Special Health Care Needs

This section identifies children who have a special health care need.

- 1. Does (child) currently need or use medicine, other than vitamins, prescribed by a doctor?
  - a. Is this because of ANY medical, behavioral, or other health condition?
  - b. Is this a condition that has lasted or is expected to last for at least 12 months? •
- 2. Does (child) need or use more medical care, mental health, or educational services than is usual for most children of the same age?
  - a. Is this because of ANY medical, behavioral, or other health condition?
  - b. Is this a condition that has lasted or is expected to last for at least 12 months? •
- 3. Is (child) limited or prevented in any way in his or her ability to do the things most children of the same age can do?
  - a. Is this because of ANY medical, behavioral, or other health condition?
  - b. Is this a condition that has lasted or is expected to last for at least 12 months?
- 4. Does (child) need or get special therapy, such as physical, occupational, or speech therapy?
  - a. Is this because of ANY medical, behavioral, or other health condition?
  - b. Is this a condition that has lasted or is expected to last for at least 12 months? •
- 5. Does (child) have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?
  - a. Has this problem lasted or is it expected to last for at least 12 months?

#### Section 15: Child Health Characteristics

This section provides information about the child's health characteristics.

- 1. Was (child) born prematurely, that is, more than 4 weeks early?
- 2. What was the birth weight of (child)?
- 3. Was (child) breastfed for any length of time? 1
  - a. For how many months was (child) breastfed?

#### Section 16: Personal Doctor or other Health Provider

This section provides information about whether the child has a personal doctor or health provider.

- 1. A personal doctor or nurse is the health provider who knows your child best. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician assistant. Do you have one person you think of as (child's) personal doctor or nurse?
- a. What kind of health provider is this person? 2
- b. And is this person a man or woman?

#### **Section 17: Respondent Health**

The next section provides information about the respondent's health.

- 1. Overall, in the last 12 months, how would you rate your health? Would you say....
- 2. For how many days, during the past 30 days, would you say your physical health was not good?
- 3. For how many days, during the past 30 days, would you say your mental health was not good?
- 4. How many days in the last week have you felt depressed?
- 5. In the past year, have you had two weeks or more during which you felt sad, blue, depressed, or lost pleasure in things that you usually cared about or enjoyed?
- 6. Have you had two or more years in your life when you felt depressed or sad most days, even if you felt okay sometimes? 1

#### Response Code Legend

- 1 Yes. No
- 2 Open-ended response.
- 3 A lot concerned, A little concerned, Not at all concerned
- 4 Never, Sometimes, Usually, Always 9 A lot of trouble, Some trouble, No
- **S** Not at all helpful, Somewhat helpful, Helpful, Very helpful
- **6** Excellent, Very Good, Good, Fair, Poor

- Man, Woman
- **8** White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race
- trouble at all
- Mother, Father, Aunt or Uncle, Older brother or sister, Grandmother or Grandfather, Guardian, Other relative



#### **Section 18: Parenting Behaviors**

This section provides information about family activities.

 For each of the following, tell me if you have ever done this in your home.

Put locks on cabinets where things such as cleaning agents or medicines are kept. •

Put padding around hard surfaces or sharp edges.

Put stoppers or plugs in electrical outlets.

Turned down the hot water thermostat setting.

Kept the Poison Control Center phone number on or near your phone. ●

Kept Syrup of Ipecac in your home.

- 2. How many days in a typical week do you or other family members read stories to (child)? ②
- 3. How many days in a typical week do you or other family members play music or sing songs with (child)?
- 4. How many days in a typical week does (child) have a set or regular routine? 2

#### **Section 19: Socio-Demographic Items**

This section provides descriptive information about respondent and family of the child.

- 1. Including (child) how many children and or young adults under the age of 18 live in your household? ②
- 2. Is (child) your first child?
- 3. Is (child) of Hispanic or Latino origin or descent? 1
- 4. Now I am going to read a list of categories. Please choose one or more of the following categories to describe (child's) race. Is (child) White, Black or African American, Native American, Alaska native, Asian, Native Hawaiian or other Pacific Islander, or another race?
  - a. Which of these groups would you say best represents (child's) race? §
- 5. The next questions ask how much trouble you have had paying for particular kinds of expenses. For each of the items in the list, please tell me if you had a lot of trouble, some trouble, or no trouble at all paying for that item.

Prenatal care during pregnancy? 
How about the medical expenses for (child's) birth? 
How about (child's) health and medical expenses? 
How about supplies like formula, food, diapers, clothes, and shoes? 
How about healthcare for yourself?

- 6. What is your age now? 2
- 7. How long have you lived in the United States? 2
- 8. Which language do you speak most comfortably?
- 9. What is the highest grade or level of school that you have completed?
- 10. Are you/is (child's) mother now married, divorced, separated, or have you/has she never been married?

#### (INSERT STATE SYMBOL)

(INSERT ADDRESS) (insert Web site)

DATE

Dear Parent or Guardian of (Child):

We need your help on an exciting project about health care for young children. You have been randomly selected to take part in a telephone survey. The survey will help us improve the health care services young children get from Medicaid.

This is what to expect:

- \* During (Month), you will be called to answer questions for the survey.
- \* The parent or guardian who takes (child) to the doctor most often should be the one who answers the questions.
- \* You will be asked to give (child's) height and weight.
- \* All of the information you give us will be kept private and never be matched to your name or (child's) name.

The answers we get from everyone who participates in the survey will be added together and put in a report that will be used to help us improve services for young children in (State).

The survey is being done for us by a private research organization (insert QIO name). If you have questions about the survey or how your answers will be used or if you would like to set up a time to do the survey you may call (QIO name) on this toll-free number (insert number) or e-mail at (insert email).

We thank you in advance for your help. Without your help, it is hard for us to improve health care for children. So please take 15 to 20 minutes to answer the questions when we call.

Sincerely,

INSERT NAME Insert Title

DIAL.SCREEN DS.

PHONE NUMBER ---> ( ### ) ### - ####

Hello, I'm calling on behalf of the (INSERT STATE NAME AND DEPARTMENT) You may have received a letter informing you of the survey we are doing regarding health care for young children.

May I please speak to the person in the household who is most often responsible for taking [CHILD] [LNAME] to the doctor to get health care?

(IF NEEDED: "The information gathered through this survey will be used to improve the care provided in (INSERT STATE NAME AND DEPARTMENT).")

(IF NEEDED: "The questions in this survey ask about the health care that [CHILD] [LNAME] has received in the past year or since (he/she) was born.")

(IF NEEDED: "The interview is completely voluntary and confidential, and will not affect your health care or benefits in any way.")

(IF NEEDED: "This is purely a scientific survey -- we are NOT trying to sell anything or conduct any sort of business with you/them.")

- 01. CONTINUE
- 03. NEW PHONE NUMBER
- 04. REFUSAL
- 05. APPOINTMENT (Who should I ask for?>
- 06. NEVER HEARD OF CHILD
- 07. KNOWS CHILD BUT HAS NO NEW NUMBER FOR CHILD'S HOUSEHOLD
- 08. RNA, ANS MACH, RETURN TO COVERSHEET
- 09. LANGUAGE PROBLEM

IF DIAL.SCREEN = 01 OR 02 THEN GO TO RE.INTRO

IF DIAL.SCREEN = 03, ENTER NEW PHONE NUMBER AND RE-DIAL

IF DIAL.SCREEN = 04 - 09, RETURN TO COVERSHEET

RE.INTRO

RE.INTRO. (INTERVIEWER: READ PARENS TEXT IF R ISN'T PERSON WHO ANSWERED PHONE OR HAS NOT HEARD IT YET )

(Hello, I'm calling on behalf of the (INSERT STATE NAME AND DEPARTMENT). You may have received a letter informing you of the survey we are doing regarding health care for young children.)

(IF R ASKS: "How long will this take?", EXPLAIN: "The questions should take about 15-20 minutes to answer.")

(IF NEEDED: "The information gathered through this survey will be used to improve the care provided in (INSERT STATE NAME AND DEPARTMENT).")

(IF NEEDED: "The questions in this survey ask about the health care that [CHILD] [LNAME] has received in the past year or since (he/she) was born.")

(IF NEEDED: "The information you provide will be held in strict confidence. Participation is voluntary.")

(CLARIFY IF NEEDED: This is purely a scientific survey -- we are NOT trying to sell anything or conduct any sort of business with you/them.)

("DK" NOT ALLOWED)

- 1. CONTINUE
- 2. APPOINTMENT (RECORD NAME OF TARGET R IN CALL NOTES)
- 3. REFUSAL
- 4. LANGUAGE PROBLEM
- 7. RETURN TO CS

IF RE.INTRO = 1, GO TO I1.LTR
IF RE.INTRO = 2, 3, 4 OR 7, GO TO COVERSHEET

I1.LTR
I1.LTR

A letter describing this study was sent to your home recently. Do you remember seeing the letter?

(IWER: IF R FOR A NEW LETTER TO BE SENT, CLARIFY: "I'm sorry that part of the survey is over. I do have an 800# you can call for more information. Would you like that number: INSERT TOLL FREE NUMBER.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

I3A.INTRO
I3A.INTRO

(As the letter explained, the/The) purpose of the survey is to collect information about the quality of health care for young children. The information gathered through this survey will be used to improve the care provided in (INSERT STATE NAME AND DEPARTMENT). The information you provide will be used for research purposes only and will be held in strict confidence. Participation is voluntary.

T.5

I5. From the information that I have, it looks like [CHILD]'s birth date is (CHILD's BIRTH DATE FROM SAMPLE). Is that correct?

(IWER: IF R REFUSES, CLARIFY: "I would like to assure you that ALL information will be kept in strict confidence and will be summarized for research purposes only. We only ask for children's birth dates in order to determine into what age range they fall and to help research the type of medical care that children of various ages have received.")

(DO NOT READ LIST) ("DON'T KNOW" NOT ALLOWED)

- 1. YES ----> CK.16
- 2. NO
- 9. REFUSED --> MRS.DAY.Q

INTRO.DOB

INTRO.DOB. Could you tell me what the correct birthdate for [CHILD] is?

(IWER: IF R REFUSES/DK, CLARIFY: "I would like to assure you that ALL information will be kept in strict confidence and will be summarized for research purposes only. We only ask for children's birth dates in order to determine into what age range they fall and to help research the type of medical care that children of various ages have received.")

(IWER: IF R STILL REFUSES, CLARIFY: "If you could at least tell me the month and year of [CHILD]'s birth, that would be extremely helpful and we could proceed with that information.")

(DO NOT READ)

- 1. WILL GIVE BIRTHDATE \_\_\_\_\_ (SPECIFY)
  9. REFUSES TO GIVE BIRTHDATE -----> MRS.DAY.Q
- DK -----> MRS.DAY.O

DOB1. (IWER: IF NECESSARY, ASK: "What is [CHILD]'s birth date?")

(IWER: DK/REF NOT ALLOWED FOR BIRTH MONTH -OR- BIRTH YEAR. IF DK/REF FOR BIRTH MONTH -OR- BIRTH YEAR, F9 TO INTRO.DOB AND ENTER APPROPRIATE RESPONSE CATEGORY.)

(BIRTH DD ONLY: 98=DON'T KNOW -OR- 99=REFUSED)

IWER: ENTER [ MM / DD / YYYY ]

\_\_ / \_\_ / \_\_\_\_

IF DOB1 MONTH/YEAR = DON'T KNOW/REFUSED, GO TO MRS.DAY.Q

- IF CHILD IS 0 TO 48 MONTHS OLD, GO TO CK.16
- IF CHILD IS 48 MONTHS OLD OR OLDER, GO TO TOO.OLD

MRS.DAY.Q

MRS.DAY.Q I understand your concerns. Would you feel comfortable telling me which of the following age groups [CHILD] is in? Please stop me when I get to the correct category.

(IWER: IF NECESSARY, CLARIFY: "For the purposes of our study, the following example describes how we calculate a child's age: If a child is 10 1/2 or 10 3/4 months old, the child is considered 10 months old.")

(READ LIST)

- 1. 3 MONTHS OR OLDER BUT YOUNGER THAN 10 MONTHS,
- 2. 10 MONTHS OR OLDER BUT YOUNGER THAN 19 MONTHS,
- 3. 19 MONTHS OR OLDER BUT YOUNGER THAN 36 MONTHS,
- 4. 36 MONTHS OR OLDER BUT YOUNGER THAN 48 MONTHS OR
- 5. 48 MONTHS OR OLDER? -----> TOO.OLD
- 9. REFUSED (DO NOT READ) -----> DKREF.AGE
- DK (DO NOT READ) -----> DKREF.AGE

IF MRS.DAY.Q = 1 - 4, GO TO CK.I6

TOO.OLD:

IF CHILD IS OLDER THAN 48 MONTHS:

At this time we are only collecting information about the health of children less than 48 months old.

I'd like to thank you on behalf of the (INSERT STATE NAME AND DEPARTMENT) for the time you spent answering these questions.

Have a good day/evening.

RETURN TO COVERSHEET

#### DKREF.AGE:

At this time we are only collecting information about the health of children who we can verify to be less than 48 months old.

I'd like to thank you on behalf of the (INSERT STATE NAME AND DEPARTMENT) for the time you spent answering these questions.

Have a good day/evening.

RETURN TO COVERSHEET

#### CK.I6

THE "MONTHCOUNT" VARIABLE IS COMPUTED BASED ON BIRTH DATE INFORMATION OR MRS.DAY.Q. MONTHCOUNT IS USED TO CONTROL TEXT FILLS AND SKIP PATTERNS THROUGHOUT THE QUESTIONNAIRE.

Т6

17. / I6. How are you related to [CHILD]?

(DO NOT READ LIST)

- 01. MOTHER (STEP, FOSTER, ADOPTIVE) or FEMALE GUARDIAN
- 02. FATHER (STEP, FOSTER, ADOPTIVE) or MALE GUARDIAN
- 03. SISTER OR BROTHER (STEP/FOSTER/HALF/ADOPTIVE)
- 04. IN-LAW OF ANY TYPE
- 05. AUNT/UNCLE
- 06. GRANDPARENT
- 07. OTHER FAMILY MEMBER (SPECIFY)
- 08. FRIEND
- 99. REFUSED

т7

18. / I7. Is it correct that [CHILD] is a (male/female)?

(IWER: YOU ARE ENTERING THE CORRECT GENDER - NOT YES/NO)

(DO NOT READ LIST)

- 1. MALE
- 2. FEMALE
- 9. REFUSED

I8

19. / I8. Is it also correct that [CHILD] is currently enrolled in (INSERT STATE NAME FOR THE MEDICAI PROGRAM - USE PARENT FRIENDLY TERMS)?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. OTHER \_\_\_\_\_ SPECIFY
- 9. REFUSED

DK

TRA

21./I8A. So I'll know how to refer to [CHILD] during the interview, is it alright with you that I continue to use [CHILD]'s first name?

(DO NOT READ LIST)

- 1. YES --> INTRO.U
- 2. NO

TRE

21./I8B. What name or initial would you like me to use during the interview?

\_\_\_\_\_

INTRO.U

24. / INTRO.U

The first questions ask about the health care [CHILD] may have received (in the last 12 months/since (his/her) birth).

U1

25. / U1.

(In the last 12 months/Since [CHILD]'s birth), not counting times [CHILD] went to an emergency room, how many times did (he/she) go to a DOCTORS OFFICE or CLINIC?

(IWER: RECORD NUMBER OF OFFICE/CLINIC VISITS)

999. REFUSED

```
U2
26. / U2.
       (In the last 12 months/Since [CHILD]'s birth), how many times did [CHILD]
       go to an EMERGENCY ROOM?
       (IWER: RECORD NUMBER OF EMERGENCY ROOM VISITS)
       999. REFUSED
       DK
UЗ
27. / U3.
       (In the last 12 months/Since [CHILD]'s birth), how many times was [CHILD]
       a patient in a hospital overnight or longer?
       (IWER: RECORD NUMBER OF OVERNIGHT VISITS)
       999. REFUSED
       DK
U4
28. / U4.
        (In the last 12 months/Since [CHILD]'s birth), has [CHILD] needed care
        right away for an illness or injury?
        (DO NOT READ LIST)
        1. YES
        2. NO ----> A1
        9. REFUSED --> A1
        DK ----> A1
U4A
29. / U4A.
        When [CHILD] needed care right away for an ILLNESS OR INJURY, how often
        did (he/she) get this care as soon as you wanted? Would you say...
        (READ LIST)
        1. NEVER,
        2. SOMETIMES,
        3. USUALLY, OR
        4. ALWAYS?
        9. REFUSED (DO NOT READ)
        DK (DO NOT READ)
```

A1 31. / A1

(In the last 12 months/Since [CHILD]'s birth), was there any time that [CHILD] needed health care but did NOT get it?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> A2
- 9. REFUSED --> A2 DK -----> A2

A3.2 32. / A3.2.

Why did [CHILD] need health care? Was it for...

(IWER: IF NECESSARY: "Please think about the most recent experience.")

(IWER: IF R MENTIONS A SPECIFIC REASON (EX. BROKEN ARM) IT IS OKAY TO CODE IN THE APPROPRIATE CATEGORY.)

(READ LIST) (SELECT ONE ONLY)

- 1. A REGULAR or ROUTINE VISIT,
- 2. A MEDICAL PROBLEM or CONCERN,
- 3. A BEHAVIORAL PROBLEM or CONCERN, OR
- 4. A SPEECH and/or LANGUAGE PROBLEM or CONCERN?
- 5. ANOTHER REASON (SPECIFY)
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

A4.2 33. / A4.2.

Why didn't [CHILD] receive care (for a regular or routine visit /for a medical problem or concern /for a behavioral problem or concern /for a speech or language problem or concern /for [A3.2 Other Reason])? Was it because...

(READ LIST) (PAUSE AFTER EACH OPTION) (SELECT ALL THAT APPLY)

(PROBE: "Would that be YES or NO?")

- 01. YOU COULDN'T AFFORD IT OR HAD NO HEALTH INSURANCE?
- 02. YOU HAD NO DOCTOR TO GO TO FOR [CHILD]?
- 03. [CHILD]'s DOCTOR DID NOT CONSIDER IT A PROBLEM?
- 04. [CHILD]'s DOCTOR HAD NO ONE TO REFER [CHILD] TO?
- 05. YOU HAD TRANSPORTATION OR CHILDCARE PROBLEMS?
- 06. PROBLEMS RELATED TO WORK?
- 07. INSURANCE DID NOT COVER THE VISIT?
- 08. THE DOCTOR'S SCHEDULE WAS FULL (THERE WERE NO AVAILABLE APPTMENTS)?
- 09. ANY OTHER REASON \_\_\_\_\_ (SPECIFY)?
- 10. REFUSED (DO NOT READ)
- DK (DO NOT READ)

A5(1-3).2. (35-37). / A5(1-3).2.

Did the lack of health care (for [CHILD]'s (regular or routine visit /medical problem or concern /behavioral problem or concern /speech or language problem or concern /[A3.2 Other Reason]))...

- 1. "create concerns about (his/her) future development?"
  - 2. "create problems for (his/her) attending day care?"
  - 3. "create problems for you and/or your spouse or partner meeting work responsibilities?"

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. NOT APPLICABLE ((NO DAY CARE)/(NO WORK))
- 9. REFUSED

Α2 39. / A2

> (In the last 12 months/Since [CHILD]'s birth), was there any time that [CHILD] received care, but got the care later than you would have liked?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> MN1.CK
- 9. REFUSED --> MN1.CK DK ----> MN1.CK

A3.1B

40. / A3.1B

Why did [CHILD] need health care? Was it for ...

(IWER: IF NECESSARY: "Please think about the most recent experience.")

(READ LIST) (SELECT ONE ONLY)

- 1. A REGULAR or ROUTINE VISIT,
- 2. A MEDICAL PROBLEM or CONCERN,
- 3. A BEHAVIORAL PROBLEM or CONCERN, OR
- 4. A SPEECH and/or LANGUAGE PROBLEM or CONCERN?
- 5. ANOTHER REASON \_\_\_\_\_ (SPECIFY)
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

A4.1B 41. / A4.1B.

Why was [CHILD]'s care delayed(for a regular or routine visit /for a medical problem or concern /for a behavioral problem or concern /for a speech or language problem or concern /for [A3.1B Other Reason])? Was it because...

(READ LIST) (PAUSE AFTER EACH OPTION) (SELECT ALL THAT APPLY)

(PROBE: "Would that be YES or NO?")

- 01. YOU COULDN'T AFFORD IT OR HAD NO HEALTH INSURANCE?
- 02. YOU HAD NO DOCTOR TO GO TO FOR [CHILD]?
- 03. [CHILD]'s DOCTOR DID NOT CONSIDER IT A PROBLEM?
- 04. [CHILD]'s DOCTOR HAD NO ONE TO REFER [CHILD] TO?
- 05. YOU HAD TRANSPORTATION OR CHILDCARE PROBLEMS?
- 06. PROBLEMS RELATED TO WORK?
- 07. INSURANCE DID NOT COVER THE VISIT?
- 08. THE DOCTOR'S SCHEDULE WAS FULL (THERE WERE NO AVAILABLE APPOINTMENTS)?
- 09. ANY OTHER REASON \_\_\_\_\_ (SPECIFY)?
- 10. REFUSED (DO NOT READ)
- DK (DO NOT READ)

A5(1-3).1B. (43-45). / A5(1-3).1B.

Did the delay in getting health care (for [CHILD]'s (regular or routine visit /medical problem or concern /behavioral problem or concern /speech or language problem or concern /[A3.1B Other Reason]))...

- 1. "create concerns about [CHILD]'s future development?"
  - 2. "create problems for [CHILD] attending day care?"
  - 3. "create problems for you and/or your spouse or partner meeting work responsibilities?"

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. NOT APPLICABLE ((NO DAY CARE)/(NO WORK))
- 9. REFUSED

IF (U1 = 0 DOCTOR VISITS) AND (U2 = 0 EMERGENCY ROOM VISITS) AND (U3 = 0 OVERNIGHT HOSPITAL VISITS), GO TO GO TO A6A

A6A

46. / A6A.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD] get care from more than one kind of health care provider or use more than one kind of health care service?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> LA.CK
- 9. REFUSED --> LA.CK DK ----> LA.CK

A7 47. / A7.

(In the last 12 months/Since [CHILD]'s birth), did anyone from [CHILD]'s doctor's office or clinic help coordinate (his/her) care among these different providers or services?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. CHILD DIDN'T GET CARE FROM DIFFERENT PROVIDER/USE MORE THAN 1 SERVICE
- 9. REFUSED

DK

INTRO.WIC

48. / INTRO.WIC

The next questions ask about the Women, Infants and Children's or "WIC" Program.

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

WIC1

49. / WIC1

Has [CHILD] ever received WIC?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers

for food, health care referrals, and nutrition education.")
(DO NOT READ LIST)

1. YES
2. NO -----> MN.CK

3. DON'T KNOW ABOUT THE PROGRAM --> MN.CK

IF MONTHCOUNT = 0 TO 9 MONTHS OLD, GO TO MN.CK

9. REFUSED -----> MN.CK

WIC2 50. / WIC2

(In the last 12 months/Since [CHILD]'s birth), has [CHILD] received WIC?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

INTRO.S
51. / INTRO.S

The next questions ask about other health care services children and families sometimes receive from their doctors or other health providers. A health provider can be a general doctor, a specialist doctor, a nurse practitioner, a physician assistant, a nurse, or anyone else your child would see for health care.

```
S1
52. / S1.
       (In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or
       other health providers refer you to any programs or classes?
       (DO NOT READ LIST)
       1. YES
       2. NO ----> S2
       9. REFUSED --> S2
       DK ----> S2
S1A
53. / S1A.
       What kind of program or class was that?
       (DO NOT READ LIST) (SELECT ALL THAT APPLY)
       (PROBE: "Any others?")
       1. BREASTFEEDING OR LACTATION
       2. PARENTING
       3. CHILD DEVELOPMENT
       4. OTHER CLASS _____ (SPECIFY)
       5. REFUSED (DO NOT READ)
       DK (DO NOT READ)
S2
54. / S2.
       Did you attend a parenting class after the birth of [CHILD]?
       (DO NOT READ LIST)
       1. YES
       2. NO ----> S3
       9. REFUSED --> S3
       DK ----> S3
```

S2A 55. / S2A

Was this parenting class paid for or covered by [CHILD]'s health insurance plan or Medicaid?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

s3 56. / s3.

Do you have other children besides [CHILD]?

(IWER, IF R ASKS ABOUT STEP/FOSTER/ADOPT CHILDREN, CLARIFY: "For the purposes of this question, other children would include any child whose health and development is your responsibility.")

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> VISIT.CK
- 9. REFUSED --> VISIT.CK DK -----> VISIT.CK

S3B 57. / S3B.

Did you attend a parenting class after the birth of your other child or children?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

```
VISIT.CK
IF (U1 = 0 DOCTOR VISITS) AND (U2 = 0 EMERGENCY ROOM VISITS)
  AND (U3 = 0 OVERNIGHT HOSPITAL VISITS), GO TO INTRO.DSERIES
*******************
ANTICIPATORY GUIDANCE AND EDUCATION
*******************
INTRO.G
58. / INTRO.G
        The next questions ask about topics that
        (parents/grandparents/caretakers) and health providers sometimes talk
        about.
IF MONTHCOUNT = 3 TO 9 MONTHS OLD, GO TO GA1
IF MONTHCOUNT = 10 TO 18 MONTHS OLD, GO TO GB1
IF MONTHCOUNT = 19 TO 48 MONTHS OLD, GO TO GC1
GA1
60. / GA1.
       (In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or
       other health providers talk with you about things you can do to help
       [CHILD] grow and learn?
       (IWER CLARIFY: "It doesn't matter who initiated the discussion.")
       (DO NOT READ LIST)
       1. YES ----> GA2
       2. NO
       9. REFUSED --> GA2
       DK
GA1A
61. / GA1a.
       Do you wish that they had talked with you about things you can do to
       help [CHILD] grow and learn?
       (DO NOT READ LIST)
       1. YES ----> GA2
       2. NO
       9. REFUSED --> GA2
```

GA1AI

62. / GAlai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GA2 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T ----> GA2 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

GA2

63. / GA2.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the kinds of behaviors you can expect to see as [CHILD] gets older?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA3
- 2. NO
- 9. REFUSED --> GA3

GA2A

64. / GA2a.

Do you wish that they had talked with you about the kinds of behaviors you can expect to see as [CHILD] gets older?

(DO NOT READ LIST)

- 1. YES ----> GA3
- 2. NO
- 9. REFUSED --> GA3
  DK

GA2AI

65. / GA2ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GA3 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GA3 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

```
GA3
66. / GA3.
```

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about breastfeeding?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA4
- 2. NO
- 9. REFUSED --> GA4 DK

GA3A

67. / GA3a.

Do you wish that they had talked with you about breastfeeding?

(DO NOT READ LIST)

- 1. YES ----> GA4
- 2. NO
- 9. REFUSED --> GA4 DK

GA3AI

68. / GA3ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I BREASTFED AND DIDN'T NEED TO TALK ABOUT IT
- 11. I DID NOT BREASTFEED
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

GA4

69. / GA4.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about issues related to food feeding of [CHILD] such as the introduction of solid foods?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DODO NOT READ LIST)

- 1. YES ----> GA5
- 2. NO
- 9. REFUSED --> GA5

DK

GA4A

70. / GA4a.

Do you wish that they had talked with you about issues related to food and feeding?

(DO NOT READ LIST)

- 1. YES ----> OH.CK
- 2. NO
- 9. REFUSED --> OH.CK DK

## GA4AI

71. / GA4ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD HAS NO ISSUES RELATED TO FOOD AND FEEDING
- 12. OTHER (SPECIFY)
- 13. REFUSED

GA5 72. / GA5.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the importance of placing [CHILD] on (his/her) back when going to sleep?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA6
- 2. NO
- 9. REFUSED --> GA6

GA5A

73. / GA5a.

Do you wish that they had talked with you about placing [CHILD] on (his/her) back?

(DO NOT READ LIST)

- 1. YES ----> GA6
- 2. NO
- 9. REFUSED --> GA6

GA5AI

74. / GA5ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I PUT MY CHILD ON HIS BACK AND DIDN'T NEED TO TALK ABOUT
- 12. OTHER \_\_\_\_\_ (SPECIFY)

13. REFUSED DK

GA6 75. / GA6.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about night waking and fussing?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA7
- 2. NO
- 9. REFUSED --> GA7 DK

GA6A

76. / GA6a.

Do you wish that they had talked with you about night waking and fussing?

(DO NOT READ LIST)

- 1. YES ----> GA7
- 2. NO
- 9. REFUSED --> GA7 DK

GA6AI

77. / GA6ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD DOES NOT NIGHT WAKE OR FUSS, SO THIS ISN'T AN ISSUE FOR ME
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GA7

78. / GA7.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how [CHILD] communicates (his/her) needs?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA8
- 2. NO
- 9. REFUSED --> GA8

GA7A

79. / GA7a.

Do you wish that they had talked with you about how [CHILD] communicates?

(DO NOT READ LIST)

- 1. YES ----> GA8
- 2. NO
- 9. REFUSED --> GA8 DK

GA7AI

80. / GA7ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD COMMUNICATES GREAT, THIS ISN'T AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GA8 81. / GA8.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about what [CHILD] is able to understand?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA9
- 2. NO
- 9. REFUSED --> GA9 DK

GA8A

82. / GA8a.

Do you wish that they had talked with you about what [CHILD] is able to understand?

(DO NOT READ LIST)

- 1. YES ----> GA9
- 2. NO
- 9. REFUSED --> GA9

GA8AI

83. / GA8ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD IS TOO YOUNG TO BE THINKING ABOUT THAT
- 11. MY CHILD UNDERSTANDS WHAT I SAY
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

GA9

84. / GA9.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how [CHILD] responds to you, other adults, and caregivers?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA10
- 2. NO
- 9. REFUSED --> GA10

GA9A

85. / GA9a.

Do you wish that they had talked with you about how [CHILD] responds to people?

(DO NOT READ LIST)

- 1. YES ----> GA10
- 2. NO
- 9. REFUSED --> GA10 DK

GA9AI

86. / GA9ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD HAS NO PROBLEM IN RESPONDING TO PEOPLE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GA10 87. / GA10.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how to avoid burns to [CHILD], such as changing the hot water temperature in your home?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA11
- 2. NO
- 9. REFUSED --> GA11 DK

GA10A

88. / GA10a.

Do you wish that they had talked with you about how to avoid burns?

(DO NOT READ LIST)

- 1. YES ----> GA11
- 2. NO
- 9. REFUSED --> GA11 DK

GA10AI 89. / GA10ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I ALREADY CHANGED THE HOT WATER TEMPERATURE IN MY HOME
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GA11 90. / GA11.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about using a car-seat?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA12
- 2. NO
- 9. REFUSED --> GA12

GA11A

91. / GA11a.

Do you wish that they had talked with you about car seats?

(DO NOT READ LIST)

- 1. YES ----> GA12
- 2. NO
- 9. REFUSED --> GA12

GA11AI

92. / GAllai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I HAVE A CAR SEAT AND USE IT CORRECTLY
- 11. I DON'T HAVE A CAR SO THIS IS NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

```
GA12
93. / GA12.
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(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how to make your house safe?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA13
- 2. NO
- 9. REFUSED --> GA13 DK

GA12A

94. / GA12a.

Do you wish that they had talked with you about house safety?

(DO NOT READ LIST)

- 1. YES ----> OH2.CK
- 2. NO
- 9. REFUSED --> OH2.CK DK

GA12AI 95. / GA12ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> OH2.CK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T ----> OH2.CK BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GA13 96. / GA13.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the importance of showing a picture book to or reading with [CHILD]?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA14
- 2. NO
- 9. REFUSED --> GA14 DK

GA13A

97. / GA13a.

Do you wish that they had talked with you about reading?

(DO NOT READ LIST)

- 1. YES ----> GA14
- 2. NO
- 9. REFUSED --> GA14 DK

GA13AI 98. / GA13ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I READ TO CHILD AND SHOW BOOKS TO HIM/HER EVERY DAY
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GA14 99. / GA14.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the issues related to childcare?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GA15
- 2. NO
- 9. REFUSED --> GA15

GA14A

100. / GA14a.

Do you wish that they had talked with you about the issues related to childcare?

(DO NOT READ LIST)

- 1. YES ----> GA15
- 2. NO
- 9. REFUSED --> GA15 DK

GA14AI

101. / GA14ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM A STAY AT HOME PARENT, THIS IS NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GA15 102. / GA15.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about WIC - the Women, Infants and Children's Program?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> D1
- 2. NO
- 9. REFUSED --> D1 DK

GA15A

103. / GA15a.

Do you wish that they had talked with you about WIC?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

(DO NOT READ LIST)

- 1. YES ----> D1
- 2. NO
- 9. REFUSED --> D1 DK

GA15AI 104. / GA15ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM ALREADY ON WIC
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GO TO D1

GB1

105. / GB1.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about things you can do to help [CHILD] grow and learn?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB2
- 2. NO
- 9. REFUSED --> GB2

GB1A

106. / GB1a.

Do you wish that they had talked with you about things you can do to help [CHILD] grow and learn?

(DO NOT READ LIST)

- 1. YES ----> GB2
- 2. NO
- 9. REFUSED --> GB2 DK

GB1AI

107. / GB1ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GB2 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GB2 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GB2 108. / GB2.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the kinds of behaviors you can expect to see in [CHILD] as (he/she) gets older?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB3
- 2. NO
- 9. REFUSED --> GB3 DK

GB2A

109. / GB2a.

Do you wish that they had talked with you about the kinds of behaviors you can expect?

- 1. YES ----> GB3
- 2. NO
- 9. REFUSED --> GB3 DK

GB2AI

110. / GB2ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GB3
  ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GB3 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

GB3

111. / GB3.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about vitamins and foods [CHILD] should eat?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> qb4
- 2. NO
- 9. REFUSED --> gb4

GB3A

112. / GB3a.

Do you wish that they had talked with you about vitamins and food?

(DO NOT READ LIST)

- 1. YES ----> OH3.CK
- 2. NO
- 9. REFUSED --> OH3.CK

GB3AI

113. / GB3ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> OH3.CK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> OH3.CK BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GB4

114. / GB4.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about [CHILD]'s bed and naptime routines?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB5
- 2. NO
- 9. REFUSED --> GB5 DK GB4A

## 115. / GB4a.

Do you wish that they had talked with you about bedtime routines?

(DO NOT READ LIST)

- 1. YES ----> GB5
- 2. NO
- 9. REFUSED --> GB5

### GB4AI

116. / GB4ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. WE HAVE A SET BED AND NAPTIME ROUTINE, THIS ISN'T AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GB5

117. / GB5.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about words and phrases [CHILD] uses and understands?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB6
- 2. NO
- 9. REFUSED --> GB6 DK

GB5A

118. / GB5a.

Do you wish that they had talked with you about words and phrases [CHILD] uses and understands?

(DO NOT READ LIST)

- 1. YES ----> GB6
- 2. NO
- 9. REFUSED --> GB6

GB5AI

119. / GB5ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD USES WORDS AND PHRASES GREAT AND UNDERSTANDS THINGS VERY WELL
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GB6

120. / GB6.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about night waking and fussing?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB7
- 2. NO
- 9. REFUSED --> GB7

GB6A

121. / GB6a.

Do you wish that they had talked with you about night waking and fussing?

(DO NOT READ LIST)

- 1. YES ----> GB7
- 2. NO
- 9. REFUSED --> GB7 DK

GB6AI

122. / GB6ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD DOES NOT NIGHT WAKE OR FUSS THIS ISN'T AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GB7 123. / GB7.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about [CHILD]'s sleeping with a bottle?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB8
- 2. NO
- 9. REFUSED --> GB8 DK

GB7A

124. / GB7a.

Do you wish that they had talked with you about [CHILD] sleeping with a bottle?

- 1. YES ----> GB8
- 2. NO
- 9. REFUSED --> GB8 DK

GB7AI

125. / GB7ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD DOESN'T SLEEP WITH A BOTTLE ANYMORE
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GB8

126. / GB8.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about weaning [CHILD] from a bottle?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB9
- 2. NO
- 9. REFUSED --> GB9

GB8A

127. / GB8a.

Do you wish that they had talked with you about weaning [CHILD] from a bottle?

(DO NOT READ LIST)

- 1. YES ----> GB9
- 2. NO
- 9. REFUSED --> GB9 DK

GB8AI

128. / GB8ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD DOESN'T USE A BOTTLE ANYMORE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GB9 129. / GB9.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about weaning [CHILD] from breastfeeding?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB10
- 2. NO
- 9. REFUSED --> GB10 DK

GB9A

130. / GB9a.

Do you wish that they had talked with you about weaning [CHILD] from breastfeeding?

- 1. YES ----> GB10
- 2. NO
- 9. REFUSED --> GB10 DK

#### GB9AI

131. / GB9ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM NOT BREASTFEEDING ANYMORE
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

# GB10

132. / GB10.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how [CHILD] may start to explore away from you?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB11
- 2. NO
- 9. REFUSED --> GB11

GB10A

133. / GB10a.

Do you wish that they had talked with you about how [CHILD] may start to explore away from you?

(DO NOT READ LIST)

- 1. YES ----> GB11
- 2. NO
- 9. REFUSED --> GB11 DK

GB10AI

134. / GB10ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD DOES NOT EXPLORE AWAY FROM ME
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

#### GB11

135. / GB11.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about guidance and discipline techniques to use with [CHILD]?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB12
- 2. NO
- 9. REFUSED --> GB12 DK

## GB11A

136. / GB11a.

Do you wish that they had talked with you about guidance and discipline techniques?

- 1. YES ----> GB12
- 2. NO
- 9. REFUSED --> GB12 DK

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GB11AI
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137. / GB11ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GB12 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T ----> GB12 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

### GB12

138. / GB12.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about toilet training?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB13
- 2. NO
- 9. REFUSED --> GB13

GB12A

139. / GB12a.

Do you wish that they had talked with you about toilet training?

(DO NOT READ LIST)

- 1. YES ----> GB13
- 2. NO
- 9. REFUSED --> GB13

GB12AI

140. / GB12ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I HAVEN'T STARTED TOILET TRAINING AND DON'T WANT TO TALK ABOUT IT YET
- 11. MY CHILD IS TOILET TRAINED
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

### GB13

141. / GB13.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about what you should do if [CHILD] swallows certain kinds of poisons?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB14
- 2. NO
- 9. REFUSED --> GB14 DK

## GB13A

142. / GB13a.

Do you wish that they had talked with you about what to do if [CHILD] swallows certain kinds of poisons?

- 1. YES ----> GB14
- 2. NO
- 9. REFUSED --> GB14 DK

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GB13AI
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143. / GB13ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GB14 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T ----> GB14 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

### GB14

144. / GB14.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about using a car-seat?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB15
- 2. NO
- 9. REFUSED --> GB15

GB14A

145. / GB14a.

Do you wish that they had talked with you about car seats?

(DO NOT READ LIST)

- 1. YES ----> GB15
- 2. NO
- 9. REFUSED --> GB15

GB14AI

146. / GB14ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I HAVE A CAR SEAT AND USE IT CORRECTLY
- 11. I DON'T HAVE A CAR, SO THIS IS NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

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GB15
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147. / GB15.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how to make your house safe?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB16
- 2. NO
- 9. REFUSED --> GB16 DK

## GB15A

148. / GB15a.

Do you wish that they had talked with you about house safety?

- 1. YES ----> OH4.CK
- 2. NO
- 9. REFUSED --> OH4.CK DK

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GB15AI
149. / GB15ai.
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Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> OH4.CK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T ----> OH4.CK BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

# GB16 150. / GB16.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the importance of reading with [CHILD]?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB17
- 2. NO
- 9. REFUSED --> GB17 DK

## GB16A

151. / GB16a.

Do you wish that they had talked with you about reading?

- 1. YES ----> GB17
- 2. NO
- 9. REFUSED --> GB17 DK

GB16AI

152. / GB16ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I READ TO MY CHILD EVERYDAY I DON'T NEED TO TALK ABOUT IT
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GB17

153. / GB17.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about issues related to childcare?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GB18
- 2. NO
- 9. REFUSED --> GB18

GB17A

154. / GB17a.

Do you wish that they had talked with you about issues related to childcare?

(DO NOT READ LIST)

- 1. YES ----> GB18
- 2. NO
- 9. REFUSED --> GB18 DK

GB17AI

155. / GB17ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM A STAY AT HOME PARENT, THIS IS NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GB18

156. / GB18.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about WIC - the Women, Infants and Children's Program?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> D1
- 2. NO
- 9. REFUSED --> D1 DK

GB18A

157. / GB18a.

Do you wish that they had talked with you about WIC?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

- 1. YES ----> D1
- 2. NO
- 9. REFUSED --> D1 DK

GB18AI 158. / GB18ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM ALREADY ON WIC AND DON'T NEED TO TALK ABOUT IT
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GO TO D1

GC1

159. / GC1.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about things you can do to help [CHILD] grow and learn?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC2
- 2. NO
- 9. REFUSED --> GC2

GC1A

160. / GC1a.

Do you wish that they had talked with you about things you can do to help [CHILD] grow and learn?

(DO NOT READ LIST)

- 1. YES ----> GC2
- 2. NO
- 9. REFUSED --> GC2 DK

GC1AI

161. / GC1ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GC2 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GC2 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GC2 162. / GC2.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the kinds of behaviors you can expect to see as [CHILD] gets older?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC3
- 2. NO
- 9. REFUSED --> GC3 DK

GC2A

163. / GC2a.

Do you wish that they had talked with you about the kinds of behaviors you can expect to see as [CHILD] gets older?

(DO NOT READ LIST)

- 1. YES ----> GC3
- 2. NO
- 9. REFUSED --> GC3

GC2AI 164. / GC2ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GC3
  ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GC3 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

GC3 165. / GC3.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about issues related to food and feeding [CHILD]?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

- 1. YES ----> OH5.CK
- 2. NO
- 9. REFUSED --> OH5.CK

GC3A

166. / GC3a.

Do you wish that they had talked with you about issues related to food and feeding?

(DO NOT READ LIST)

- 1. YES ----> GC4
- 2. NO
- 9. REFUSED --> GC4 DK

GC3AI

167. / GC3ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I HAVE NO PROBLEM WITH ISSUES RELATED TO FOOD AND FEEDING
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GC4 168. / GC4.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about [CHILD]'s bedtime routines and how many hours of sleep [CHILD] needs?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC5
- 2. NO
- 9. REFUSED --> GC5 DK

GC4A

169. / GC4a.

Do you wish that they had talked with you about bedtime routines and hours of sleep [CHILD] needs?

(DO NOT READ LIST)

- 1. YES ----> GC5
- 2. NO
- 9. REFUSED --> GC5 DK

GC4AI

170. / GC4ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. WE HAVE A BEDTIME ROUTINE AND MY CHILD HAS NO PROBLEM GETTING SLEEP

12. OTHER \_\_\_\_\_ (SPECIFY)

13. REFUSED

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GC5
171. / GC5.
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(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about toilet training?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC6
- 2. NO
- 9. REFUSED --> GC6 DK

GC5A

172. / GC5a.

Do you wish that they had talked with you about toilet training?

- 1. YES ----> GC6
- 2. NO
- 9. REFUSED --> GC6 DK

GC5AI

173. / GC5ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD IS ALREADY TOILET TRAINED
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GC6

174. / GC6.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the words and phrases [CHILD] uses and understands?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC7
- 2. NO
- 9. REFUSED --> GC7

GC6A

175. / GC6a.

Do you wish that they had talked with you about words and phrases [CHILD] uses and understands?

(DO NOT READ LIST)

- 1. YES ----> GC7
- 2. NO
- 9. REFUSED --> GC7 DK

GC6AI

176. / GC6ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD USES WORDS AND PHRASES AND UNDERSTANDS THEM WELL
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GC7 177. / GC7.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how [CHILD] is learning to get along with other children?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC8
- 2. NO
- 9. REFUSED --> GC8 DK

GC7A

178. / GC7a.

Do you wish that they had talked with you about how [CHILD] gets along with others?

(DO NOT READ LIST)

- 1. YES ----> GC8
- 2. NO
- 9. REFUSED --> GC8

GC7AI 179. / GC7ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD HAS NO PROBLEMS GETTING ALONG WITH OTHER CHILDREN
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED DK

GC8 180. / GC8.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about guidance and discipline techniques to use with [CHILD]?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC9
- 2. NO
- 9. REFUSED --> GC9

GC8A

181. / GC8a.

Do you wish that they had talked with you about guidance and discipline techniques?

(DO NOT READ LIST)

- 1. YES ----> GC9
- 2. NO
- 9. REFUSED --> GC9 DK

GC8AI

182. / GC8ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GC9
  ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GC9 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GC9 183. / GC9.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about ways to teach [CHILD] about dangerous situations, places, and objects?

(IWER, IF R NEEDS/ASKS FOR EXAMPLES, "Such as electrical sockets, the stove, climbing on things, running into the street.")

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC10
- 2. NO
- 9. REFUSED --> GC10 DK

GC9A

184. / GC9a.

Do you wish that they had talked with you about ways to teach [CHILD] about dangerous situations, places and objects?

- 1. YES ----> GC10
- 2. NO
- 9. REFUSED --> GC10 DK

GC9AI 185. / GC9ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. MY CHILD ALREADY HAS LEARNED ABOUT THIS, THIS IS NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED DK

GC10

186. / GC10.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about using a car-seat?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC11
- 2. NO
- 9. REFUSED --> GC11

GC10A

187. / GC10a.

Do you wish that they had talked with you about car seats?

(DO NOT READ LIST)

- 1. YES ----> GC11
- 2. NO
- 9. REFUSED --> GC11

GC10AI

188. / GC10ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I HAVE A CAR SEAT AND USE IT CORRECTLY
- 11. I DON'T HAVE A CARE SO THIS IN NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

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GC11
189. / GC11.
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(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about how to make your house safe?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> OH6.CK
- 2. NO
- 9. REFUSED --> OH6.CK DK

## GC11A

190. / GC11a.

Do you wish that they had talked with you about house safety?

- 1. YES ----> OH6.CK
- 2. NO
- 9. REFUSED --> OH6.CK DK

GC11AI

191. / GC11ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> OH6.CK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T ----> OH6.CK BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

OH6.CK

IF STATE <> OHIO THEN GO TO GC12

OHLP3

191a. / OHLP3.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about [CHILD]'s risk of lead poisoning?

(DO NOT READ LIST)

- 1. YES ----> GC12
- 2. NO
- 9. REFUSED --> GC12

GC12 192. / GC12.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about what you should do if [CHILD] swallows certain kinds of poisons?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC13
- 2. NO
- 9. REFUSED --> GC13 DK

GC12A

193. / GC12a.

Do you wish that they had talked with you about what to do if [CHILD] swallows certain kinds of poisons?

- 1. YES ----> GC13
- 2. NO
- 9. REFUSED --> GC13 DK

GC12AI 194. / GC12ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK --> GC13 ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T -----> GC13 BRING IT UP
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

DK

GC13 195. / GC13.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the importance of reading with [CHILD]?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC14
- 2. NO
- 9. REFUSED --> GC14

GC13A

196. / GC13a.

Do you wish that they had talked with you about reading?

(DO NOT READ LIST)

- 1. YES ----> GC14
- 2. NO
- 9. REFUSED --> GC14

GC13AI

197. / GC13ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. WE READ EVERYDAY, THIS IS NOT AN ISSUE
- 12. OTHER \_\_\_\_\_ (SPECIFY)
- 13. REFUSED

GC14

198. / GC14.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about the issues related to childcare?

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> GC15
- 2. NO
- 9. REFUSED --> GC15 DK

GC14A

199. / GC14a.

Do you wish that they had talked with you about issues related to childcare?

- 1. YES ----> GC15
- 2. NO
- 9. REFUSED --> GC15 DK

GC14AI 200. / GC14ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM A STAY AT HOME PARENT AND THIS ISN'T A ISSUE
- 12. OTHER (SPECIFY)
- 13. REFUSED

DK

GC15 201. / GC15.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers talk with you about WIC - the Women, Infants and Children's program?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

(IWER CLARIFY: "It doesn't matter who initiated the discussion.")

(DO NOT READ LIST)

- 1. YES ----> D1
- 2. NO
- 9. REFUSED --> D1

GC15A 202. / GC15a.

Do you wish that they had talked with you about WIC?

(IWER: IF NECESSARY, "WIC is a nutrition and health program for Women, Infants, and Children. WIC benefits include food, checks or vouchers for food, health care referrals, and nutrition education.")

(DO NOT READ LIST)

- 1. YES ----> D1
- 2. NO
- 9. REFUSED --> D1 DK

GC15AI

203. / GC15ai.

Can you explain why you answered no?

(DO NOT READ LIST) (SELECT ALL THAT APPLY)

(DO NOT PROBE FOR OTHERS)

- 01. I HAD ENOUGH INFORMATION, DIDN'T NEED TO TALK ABOUT IT ANYMORE
- 02. HE/SHE ALREADY TALKED ABOUT THIS WHEN I CAME WITH MY OTHER CHILDREN
- 03. TALKED ABOUT IT BEFORE, AND DIDN'T NEED TO
  TALK ABOUT IT AGAIN (AT ANOTHER VISIT FOR [CHILD])
- 04. HE/SHE GAVE WRITTEN INFORMATION AND I UNDERSTOOD EVERYTHING
- 05. I DON'T GET/EXPECT/WANT INFO ABOUT THIS FROM DOCTORS/OTHER PROVIDER
- 06. I KNOW MORE ABOUT THIS THAN MY DOCTORS OR OTHER HEALTH PROVIDERS DO
- 07. WOULD BE INSULTING IF DOCTORS/OTHER HEALTH PROVIDERS TALKED ABOUT THIS
- 08. HE/SHE KNOWS ME AND MY FAMILY AND THAT WE DIDN'T NEED TO TALK ABOUT IT
- 09. I DIDN'T HAVE A QUESTION AND THEY DIDN'T BRING IT UP
- 10. I AM ON WIC, I DON'T NEED TO DISCUSS THIS ANY MORE
- 12. OTHER (SPECIFY)
- 13. REFUSED

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

## DEVELOPMENTAL ASSESSMENT

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

D1

204. / D1.

Did [CHILD]'s doctors or other health providers ever tell you that they were doing what doctors call a "developmental assessment" or test of [CHILD]'s development?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

IF MONTHCOUNT = 0 TO 9 MONTHS, GO TO D3

Π2

205. / D2.

Did [CHILD]'s doctors or other health providers ever have [CHILD] roll-over, pick up small objects, stack blocks, throw a ball or recognize different colors?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. CHILD TOO YOUNG TO DO THOSE KINDS OF THINGS
- 9. REFUSED

DK

D3

206. / D3.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers have you fill out a survey or checklist about concerns you may have about [CHILD]'s learning development or behavior?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. CHILD TOO YOUNG
- 9. REFUSED

D4 207. / D4.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers have you fill out a survey or checklist about activities [CHILD] may be able to do such as certain physical tasks, whether (he/she) can draw certain objects or ways (he/she) can communicate with you?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 3. CHILD TOO YOUNG TO DO THOSE KINDS OF THINGS
- 9. REFUSED

DK

## INTRO.DSERIES

208. / INTRO.DSERIES

The next section asks about specific concerns some (parents/grandparents/caretakers) may have.

D5 209. / D5.

Please tell me if you are currently A LOT, A LITTLE, or NOT AT ALL concerned with how [CHILD] talks and makes speech sounds?

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED

D6 210. / D6.

(Next/How about) how [CHILD] sees?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] sees?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

D7 211. / D7.

(Next/How about) how [CHILD] hears?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] hears?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

D8 212. / D8.

(Next/How about) how [CHILD] understands what you say?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] understands what you say?)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

D9 213. / D9.

(Next/How about) how [CHILD] uses (his/her) hands and fingers to do things?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] uses (his/her) hands and fingers to do things?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

D10 214. / D10.

(Next/How about) how [CHILD] uses (his/her) arms and legs?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] uses (his/her) arms and legs?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

IF MONTHCOUNT = 0 TO 9 MONTHS, GO TO D14.CK

D11

215. / D11.

(Next/How about) how [CHILD] behaves?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how  $[\mathtt{CHILD}]$  behaves?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

D12 216. / D12.

(Next/How about) how [CHILD] gets along with others?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] gets along with others?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

D13

217. / D13.

(Next/How about) how [CHILD] is learning to do things for (himself/herself)?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] is learning to do things for (himself/herself)?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

D14.CK

IF MONTHCOUNT = 0 TO 18 MONTHS, GO TO D15.CK

D14

218. / D14.

(Next/How about) how [CHILD] is learning preschool or school skills?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] is learning preschool or school skills?)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

D15.CK

IF MONTHCOUNT = 0 TO 9 MONTHS THEN GO TO D16.CK

D15

219. / D15.

(Next/How about) how [CHILD] is behind others or can't do what other kids can?

(Are you currently A LOT, A LITTLE, or NOT AT ALL concerned about how [CHILD] is behind others or can't do what other kids can?)

(DO NOT READ LIST)

- 1. A LOT
- 2. A LITTLE
- 3. NOT AT ALL
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

D16.CK

IF (U1 = 0 DOCTOR VISITS) AND (U2 = 0 EMERGENCY ROOM VISITS) AND (U3 = 0 OVERNIGHT HOSPITAL VISITS), GO TO INTRO.H

D16

220. / D16.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers ask if you have concerns about [CHILD]'s learning, development, or behavior?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

D17.CK

IF D5 THROUGH D15 = (A LOT or A LITTLE), GO TO D17A

D17

221. / D17.

(In the last 12 months/Since [CHILD]'s birth), did you have any concerns about [CHILD]'s learning, development, or behavior?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> INTRO.D2SERIES
- 9. REFUSED --> INTRO.D2SERIES DK -----> INTRO.D2SERIES

D17A

222. / D17A.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers give you specific information to address these concerns?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

## INTRO.D2SERIES

223. / INTRO.D2SERIES

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers do any of the following?

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D18(A-D) (224-227). / D18(A-D).
```

[(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers.../((In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers.../How about...)]

- A. "refer [CHILD] to another doctor or other health provider?"
  - B. "test [CHILD]'s learning and behavior?"

  - D. "refer [CHILD] for speech-language or hearing testing?"

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

INTRO.FSERIES

228. / INTRO.FSERIES

The next questions ask about your experience and communication with [CHILD]'s doctors or other health providers.

F(1-6) (229-234). / F(1-6).

[(In the last 12 months/Since [CHILD]'s birth), how often did [CHILD]'s doctors or other health providers.../((In the last 12 months/Since [CHILD]'s birth), how often did [CHILD]'s doctors or other health providers.../How about...)]

- 1. "take time to understand the specific needs of [CHILD]?"
  - 2. "respect you as an expert about [CHILD]?"
  - 3. "build your confidence as a (parent/grandparent/caretaker)?"
  - 4. "help you feel like a partner in [CHILD]'s care?"
  - 5. "explain things in a way that you can understand?"
  - 6. "show respect for your family's values, customs and how you prefer to raise your child?"

(READ LIST IF NECESSARY)

(Would you say...)

- 1. NEVER,
- 2. SOMETIMES,
- 3. USUALLY, OR
- 4. ALWAYS?
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

INTRO.AF
235. / INTRO.AF

The next section is about questions a child's doctors or other health providers sometimes ask about a child's family. These questions may be asked in a survey that you fill out in your child's doctors office or when you talk with your child's doctors or other health providers during a visit.

AF1

236. / AF1.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers ASK you if you or someone in your household smokes?

(IWER: CLARIFY IF NEEDED, "We want to know if you were specifically asked about this by doctors or other health providers.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

AF2

237. / AF2.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers ASK you if you or someone in your household drinks alcohol or uses other substances?

(IWER: CLARIFY IF NEEDED, "We want to know if you were specifically asked about this by doctors or other health providers.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

AF3

238. / AF3.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers ASK you if you ever feel depressed, sad, or have crying spells?

(IWER: CLARIFY IF NEEDED, "We want to know if you were specifically asked about this by doctors or other health providers.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

AF4 239. / AF4.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers ASK you if you have someone to turn to for emotional support?

(IWER: CLARIFY IF NEEDED, "We want to know if you were specifically asked about this by doctors or other health providers.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

AF5 240. / AF5.

(In the last 12 months/Since [CHILD]'s birth), did [CHILD]'s doctors or other health providers ASK you if you have any firearms in your home?

(IWER: CLARIFY IF NEEDED, "We want to know if you were specifically asked about this by doctors or other health providers.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

HEALTH INFORMATION

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

INTRO.H

242. / INTRO.H

The next questions ask about types of information you may have seen or heard (in the last 12 months/since (his/her) birth) inside or outside the doctors or other health provider's office.

H(1-3) (243-245). / H(1-3).

[(In the last 12 months/Since [CHILD]'s birth), did you see or hear anything about.../((In the last 12 months/Since [CHILD]'s birth), did you see or hear anything about... /How about...)]

- "safety information, such as how to make your house and car safe for [CHILD]?"
  - 2. "health care information, such as when and how often [CHILD] should see the doctor or reminders about immunizations?"
  - 3. "developmental information, such as things you can do with [CHILD] to help (him/her) grow and learn?"

(IWER: IF NECESSARY, "Information can be given to you in written pamphlets, videos in the waiting room, recorded information over the telephone, or information over the internet.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED DK

IF (U1 = 0 DOCTOR VISITS) AND (U2 = 0 EMERGENCY ROOM VISITS) AND (U3 = 0 OVERNIGHT HOSPITAL VISITS), GO TO INTRO.GCH

INTRO.E
246. / INTRO.E

The next questions ask about the helpfulness of all the health care  $[\mathtt{CHILD}]$  has received (in the last 12 months/since (his/her) birth).

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E(1-4) (247-250). / E(1-4).
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[In thinking about all of the care provided from [CHILD]'s doctors or other health providers (in the last 12 months/since (his/her) birth), how helpful has it been in.../(In thinking about all of the care provided from [CHILD]'s doctors or other health providers (in the last 12 months/since (his/her) birth), how helpful has it been in.../How about)]

- 1. "understanding [CHILD]'s behavior?"
  - 2. "learning how to protect [CHILD] from injuries?"
  - 3. "giving you the information you needed when you needed it?"
  - 4. "learning how to meet your own needs while caring for [CHILD]?"

(READ LIST IF NECESSARY)

(Would you say...)

- 1. NOT AT ALL HELPFUL,
- 2. SOMEWHAT HELPFUL,
- 3. HELPFUL, OR
- 4. VERY HELPFUL?
- 5. WE DID NOT DISCUSS (VOLUNTEERED)
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

251. / INTRO.GCH

The next questions are about [CHILD]'s health.

GCH1 252. / GCH1.

> Overall, how would you rate [CHILD]'s health in the last 12 months. Would you say...

(READ LIST)

- 1. EXCELLENT,
- 2. VERY GOOD,
- 3. GOOD,
- 4. FAIR, or
- 5. POOR?
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

L1 253. / L1.

Does [CHILD] currently need or use medicine, other than vitamins, prescribed by a doctor?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> L2
- 9. REFUSED --> L2 DK ----> L2

L1A 254. / L1a.

Is this because of ANY medical, behavioral or other health condition?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> L2
- 9. REFUSED --> L2 DK ----> L2

L1B 255. / L1b.

Is this a condition that has lasted or is expected to last for at least 12 months?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

L2 256. / L2.

Does [CHILD] need or use more medical care, mental health or educational services than is usual for most children of the same age?

- 1. YES
- 2. NO ----> L3
- 9. REFUSED --> L3
- DK ----> L3

```
L2A
257. / L2a.
```

Is this because of ANY medical, behavioral or other health condition?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> L3
- 9. REFUSED --> L3 DK ----> L3

L2B 258. / L2b.

Is this a condition that has lasted or is expected to last for at least 12 months?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED DK

L3 259. / L3.

Is [CHILD] limited or prevented in any way in (his/her) ability to do the things most children of the same age can do?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> L4
- 9. REFUSED --> L4 DK -----> L4

L3A 260. / L3a.

Is this because of ANY medical, behavioral or other health condition?

- 1. YES
- 2. NO ----> L4
- 9. REFUSED --> L4 DK ----> L4

```
L3B
261. / L3b.
       Is this a condition that has lasted or is expected to last for at least
       12 months?
       (DO NOT READ LIST)
       1. YES
       2. NO
       9. REFUSED
       DK
L4
262. / L4.
       Does [CHILD] need or get special therapy, such as physical, occupational
       or speech therapy?
       (DO NOT READ LIST)
       1. YES
       2. NO ----> L5
       9. REFUSED --> L5
       DK ----> L5
L4A
263. / L4a.
       Is this because of ANY medical, behavioral or other health condition?
       (DO NOT READ LIST)
       1. YES
       2. NO ----> L5
       9. REFUSED --> L5
       DK ----> L5
L4B
264. / L4b.
       Is this a condition that has lasted or is expected to last for at least
       12 months?
       (DO NOT READ LIST)
       1. YES
       2. NO
       9. REFUSED
```

```
L5
265. / L5.
```

Does [CHILD] have any kind of emotional, developmental or behavioral problem for which he or she needs or gets treatment or counseling?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> C1
- 9. REFUSED --> C1 DK ----> C1

L5A 266. / L5a.

Has this problem lasted or is it expected to last for at least 12 months?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

C1

267. / C1.

Was [CHILD] born prematurely, that is, more than 4 weeks early?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK (DO NOT PROBE)

```
C2
268. / C2.
        Please tell me what was the birth weight of [CHILD]?
        (PROBE: "What is your best estimate?")
                                           [1/8 \text{ and } .125 = \text{ONE EIGHTH}]
                 POUNDS/OUNCES/GRAMS
                                            [ 1/4 and .25 = ONE FOURTH ]
         999 OZ REFUSED
                                            [1/2 \text{ and .5}] = \text{ONE HALF}
                                            [ 3/4 and .75 = THREE FOURTHS ]
         LB=POUNDS RANGE = 3.125 LB - 12.50 LB
         OZ=OUNCES RANGE = 050 OZ - 200 OZ
         GM=GRAMS RANGE = 1425 GM - 5680 GM
C3.CK
IF MONTHCOUNT > 9 MONTHS OLD, GO TO PD1
C3
  272. / C3.
       Was [CHILD] breastfed for any length of time?
        (DO NOT READ LIST)
        1. YES
        2. NO ----> PD1
        9. REFUSED --> PD1
        DK ----> PD1
C4
  273. / C4.
       For how many months was [CHILD] breastfed?
        (DO NOT READ LIST)
        1. LESS THAN A MONTH
        2. MORE THAN A MONTH
        3. NOT BREASTFED
        4. STILL BREASTFEEDING (VOLUNTEERED)
        9. REFUSED (DO NOT READ)
        DK (DO NOT READ)
```

PD1

274. / PD1.

A personal doctor or nurse is the health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician assistant.

Do you have ONE person you think of as [CHILD]'s personal doctor or nurse?

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> PD1A
- 9. REFUSED --> PD1A DK ----> PD1A

PD2A

275. / PD2A.

What kind of health provider is this person?

(DO NOT READ LIST) (SELECT ONE ONLY)

- 01. PEDIATRICIAN
- 02. FAMILY PRACTITIONER
- 03. PEDIATRIC NURSE PRACTITIONER
- 04. PHYSICIAN'S ASSISTANT
- 05. SPECIALIST
- 06. WIC NURSE
- 07. HOME VISITING NURSE
- 08. OTHER (SPECIFY)
- 99. REFUSED (DO NOT READ)
- DK (DO NOT READ)

PD2B

277. / PD2B.

And is this health provider a man or woman?

(DO NOT READ LIST)

- 1. MAN
- 2. WOMAN
- 9. REFUSED

DK

GO TO INTRO.M

PD1A 274A. / PD1a.

Do you have MORE THAN ONE person you think of as [CHILD]'s personal doctor or nurse?

(IWER, IF NECESSARY, CLARIFY: "A personal doctor or nurse is the health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician assistant.")

(DO NOT READ LIST)

- 1. YES
- 2. NO ----> INTRO.M
- 9. REFUSED --> INTRO.M DK -----> INTRO.M

PD1A.1 / PD1A.1

How many personal doctors or nurses does [CHILD] have?

99. REFUSED

IF PD1A.1 = DK/REF THEN GO INTRO.M

ASK PD2A1 AND PD2B FOR THE NUMBER OF PROVIDERS ANSWERED IN PD1A.1

PD2A1.(1-10) 275A.(1-10) / PD2A1.(1-10)

What kind of health provider is [CHILD]'s (first - tenth) personal doctor or nurse?

(DO NOT READ LIST) (SELECT ONE ONLY)

- 01. PEDIATRICIAN
- 02. FAMILY PRACTITIONER
- 03. PEDIATRIC NURSE PRACTITIONER
- 04. PHYSICIAN'S ASSISTANT
- 05. SPECIALIST
- 06. WIC NURSE
- 07. HOME VISITING NURSE
- 08. OTHER \_\_\_\_\_ (SPECIFY)
- 99. REFUSED (DO NOT READ)
- DK (DO NOT READ)

```
PD2B.(1-10)
277.(1-10) / PD2B.(1-10)
```

Is this health provider a man or woman?

(IWER: R ANSWERED [PD2A1.](1-10) TO THE PREVIOUS QUESTION)

(DO NOT READ LIST)

- 1. MAN
- 2. WOMAN
- 9. REFUSED

DK

INTRO.M

The next questions ask about YOUR OWN health.

М1

279. / M1.

Overall, in the last 12 months, how would you rate your health? Would you say...

(READ LIST)

- 1. EXCELLENT,
- 2. VERY GOOD,
- 3. GOOD,
- 4. FAIR, or
- 5. POOR?
- 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

M2 280. / M2. For how many days, during the past 30 days, would you say your physical health was not good? (DO NOT READ LIST) \_\_ DAYS 99. REFUSED DK МЗ 281. / M3. For how many days, during the past 30 days, would you say your mental health was not good? (DO NOT READ LIST) \_\_ DAYS 99. REFUSED DK M4 282. / M4. How many days in the last week have you felt depressed? Was it... (READ LIST) 1. 0 DAYS, 2. 1 TO 2 DAYS, 3. 3 TO 4 DAYS, or 4. 5 TO 7 DAYS? 9. REFUSED (DO NOT READ)

DK (DO NOT READ)

М5

283. / M5.

In the past year, have you had two weeks or more during which you felt sad, blue, depressed, or lost pleasure in things that you usually cared about or enjoyed?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

IF (M4 = 1 TO 7 DAYS) OR (M5 = YES), ASK M6, ALL OTHERS GO TO INTRO.PB1

М6

284. / M6.

Have you had two or more years in your life when you felt depressed or sad most days, even if you felt okay sometimes?

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

INTRO.PB1

For each of the following, tell me if you have ever done this in your home...

```
PB1(A-E) (286-290). / PB1(A-E).
```

[First,/(Next/How about)]

- A. "put locks on cabinets where things such as cleaning agents or medicines are kept?"
- B. "put padding around hard surfaces or sharp edges?"
- C. "put stoppers or plugs in electrical outlets?"
- D. "turned down the hot water thermostat setting?"
- E. "kept The Poison Control Center Phone Number on or near your phone?"

(Have you ever done this in your home?)

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED DK

#### INTRO.PB3

How many days in a typical week do you or other family members do the following?

```
PB3 (A-C)
(293-295). / PB3(A-C).
          [First,/(Next/How about)]
          A. "read stories to [CHILD]?"
          B. "play music or sing songs with [CHILD]?"
          C. "have a set or regular routine?"
              (How many days in a typical week does this happen?)
             PB3C ONLY: (IWER: IF R ASKS WHAT YOU MEAN, CLARIFY: 'feeding
             and sleep routines')
              (READ LIST IF NECESSARY)
              (Would you say...)
          1. EVERYDAY,
          2. 3-6 DAYS,
          3. 1-2 DAYS, or
          4. NEVER?
          9. REFUSED (DO NOT READ)
          DK (DO NOT READ)
*******************
SOCIO-DEMOGRAPHIC ITEMS
******************
INTRO.SD
       I have just a few more questions for you.
SD1
 297. / SD1.
       Including [CHILD], how many children and/or young adults under the age
       of 18 live in your household?
```

NUMBER OF PEOPLE 18 OR UNDER

99. REFUSED

DK

IF I6 <> MOTHER AND I6 <> FATHER THEN GO TO SD3

SD2

298. / SD2.

Is [CHILD] your first child?

(IWER, IF R ASKS ABOUT STEP/FOSTER/ADOPT CHILDREN, CLARIFY: "For the purposes of this question, first child means any child whose health and development has been your responsibility.")

(DO NOT READ LIST)

- 1. YES
- 2. NO
- 9. REFUSED

DK

SD3

299. / SD3.

Is [CHILD] of Hispanic or Latino origin or descent?

(DO NOT READ LIST)

- 1. HISPANIC OR LATINO
- 2. NOT HISPANIC OR LATINO
- 9. REFUSED

DK

SD4

300. / SD4.

Now I am going to read a list of categories. Please choose one or more of the following categories to describe [CHILD]'s race. Is [CHILD]...?

(IWER: IF NECESSARY PROBE: "In this question, we're asking about your RACE as opposed to your nationality or ethnicity." RE-ASK Q, IF R SAYS HISPANIC AGAIN, ENTER UNDER OTHER SPECIFY)

(READ LIST) (SELECT ALL THAT APPLY)

- 1. WHITE,
- 2. BLACK OR AFRICAN AMERICAN,
- 3. AMERICAN INDIAN,
- 4. ASIAN,
- 5. NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, or
- 6. SOME OTHER RACE? \_\_\_\_\_ (SPECIFY)
- 7. REFUSED (DO NOT READ)
- DK (DO NOT READ)

#### CIRC.CK

IF RESPONDENT HAS CHOSEN ONLY ONE ANSWER FOR SD4 OR DK/REF, GO TO INTRO.SD5

IF RESPONDENT HAS CHOSEN MULTIPLE OPTIONS, ONLY THOSE OPTIONS WILL BE DISPAYED IN SD4B.

#### SD4B

302. / SD4B.

Which do you feel BEST describes [CHILD]'s race.

(IWER: DO NOT PROBE DK/REF)

(READ LIST) (SELECT ONE ONLY)

XX. OPTION CHOSEN IN SD4, (OR)

XX. OPTION CHOSEN IN SD4, (OR)

XX. OPTION CHOSEN IN SD4, (OR)

XX. OPTION CHOSEN IN SD4?

9. REFUSED (DO NOT READ)

DK (DO NOT READ)

#### INTRO.SD5

The next questions ask how much trouble you have had paying for particular kinds of expenses. For each of the following items, please tell me if you had A LOT OF TROUBLE, SOME TROUBLE or NO TROUBLE at all paying for that item?

```
SD5 (A-E)
(305-309). / SD5(A-E). [First,/(Next/How about)]
           A. "prenatal care during pregnancy?"
               "the medical expenses for [CHILD]'s birth?"
           C. "[CHILD]'s health and medical expenses?"
               "supplies like formula, food, diapers, clothes,
                and shoes?"
           E. "health care for yourself?"
                (Did you have A LOT OF TROUBLE, SOME TROUBLE or NO TROUBLE at
                all paying for this?)
                (DO NOT READ LIST)
            1. A LOT OF TROUBLE
            2. SOME TROUBLE
            3. NO TROUBLE
            9. REFUSED (DO NOT READ)
           DK (DO NOT READ)
SD6
 310. / SD6.
       What is your age now?
        (IWER: IF NEEDED CLARIFY, "Please answer based on your age as of your
       last birthday.")
        (READ LIST IF NEEDED, "Are you...")
        01. UNDER 18,
        02. 18 TO 24,
        03. 25 TO 34,
        04. 35 TO 44,
        05. 45 TO 54,
        06. 55 TO 64,
        07. 65 TO 74, OR
        08. 75 OR OLDER?
        99. REFUSED (DO NOT READ)
        DK (DO NOT READ)
```

SD7

311. / SD7.

How long have you lived in the United States?

(PROBE: "Please round up to the nearest year.")

YEARS

997. ALL MY LIFE

999. REFUSED

DK

SD8

312. / SD8

What language do you speak most comfortably?

(DO NOT READ LIST) (ENTER ONE ONLY)

- 1. ENGLISH
- 2. SPANISH
- 7. SOME OTHER LANGUAGE \_\_\_\_\_ (SPECIFY)
- 9. REFUSED

DK

SD9

313. / SD9.

What is the highest grade or level of school that you have COMPLETED?

(IWER: IF R SAYS HE/SHE HAD NON-ACADEMIC TRAINING, SUCH AS TRADE SCHOOL, PROBE: "Did you receive a high school diploma or GED?")

(IWER: ACADEMIC TRAINING BEYOND A HIGH SCHOOL DIPLOMA THAT DOES NOT LEAD TO A BACHELORS DEGREE, SHOULD BE CODED "4". IF R WENT TO BUSINESS SCHOOL OR GOT A 3-YEAR NURSING DEGREE, ENTER "4")

(IWER: IF R OFFERS MORE THAN ONE RESPONSE, FOR EXAMPLE: "SOME HIGH SCHOOL OR GED", ENTER THE HIGHEST NUMBER THAT APPLIES.)

(READ LIST IF NEEDED, "Did you complete...")

- 1. 8TH GRADE OR LESS,
- 2. SOME HIGH SCHOOL, BUT DID NOT GRADUATE,
- 3. HIGH SCHOOL GRADUATE OR GED,
- 4. SOME COLLEGE OR 2-YEAR DEGREE,
- 5. 4-YEAR COLLEGE GRADUATE, OR
- 6. MORE THAN A 4-YEAR COLLEGE DEGREE?
- 9. REFUSED (DO NOT READ)
- DK (DO NOT READ)

SD10

314. / SD10.

(Are you/Is [CHILD]'s mother) now MARRIED, DIVORCED, SEPARATED, or (have you/has she) NEVER BEEN MARRIED?

(DO NOT READ LIST)

- 1. MARRIED
- 2. WIDOWED (VOLUNTEERED)
- 3. DIVORCED
- 4. SEPARATED
- 5. NEVER MARRIED
- 6. DECEASED (VOLUNTEERED)
- 9. REFUSED

DK

ALL.DONE
THANKS.SCREEN.

Those are all of the question I have. I'd like to thank you again on behalf of the (INSERT STATE NAME AND DEPARTMENT) for the time and effort you've spent answering these questions.

# ISSUE BRIEF: QUALITY OF EPSDT SERVICES IN (INSERT STATE NAME)



Hearing from Parents in (Insert State Name):

Results from a
Survey of
Preventive and
Developmental
Health Care
Recommended
for Young
Children

## Project Background:

(Insert State Name) Medicaid participated in a project led by the CAHMI and supported by The Commonwealth Fund.
This project, called the Promoting Healthy
Development State Learning
Network (PHDSLN), is a network of four states focused on measuring and improving preventive and developmental health care for young children (0–3 years old).

In November 2003—January 2004, (Insert State Name) Medicaid, in collaboration with the Child and Adolescent Health Measurement Initiative (CAHMI), administered a survey to parents of young children continuously enrolled in Medicaid about the EPSDT services their child received here in (Insert State Name). This survey captured reliable, valid, and specific information about discussions and information parents received from their child's health care providers during EPSDT and other visits. This issue brief provides a summary of the survey results.

#### MAIN FINDINGS IN (INSERT STATE NAME)

Nearly all continuously enrolled children under age 4 represented in this survey have had one or more visits with their health care provider. However, few children received recommended preventive and developmental services during their office visits.

- Less than one of five children received preventive and developmental services that met a basic threshold of quality across each of the seven aspects of care assessed (15 percent).
  - The highest levels of quality of care were reported in the areas of written health information and assessment for smoking and substance abuse in the family. The lowest levels of quality were reported in the areas of assessment of psychosocial well-being and safety within the family and anticipatory guidance and parental education.
- A majority of continuously-enrolled children report having a personal dector or nurse. Nine of 10 parents (93 percent) reported that their child had one or more personal doctors or nurses.
- A significant number of children are at risk for developmental, behavioral and/or social delays. More than one of two children (58 percent) was identified at significant risk for behavioral, developmental, or social delays based on the Parental Evaluation of Developmental Status® tool developed by Frances Glascoe, Ph.D.
  - No follow-up steps were taken to track and assess possible problems for nearly one
    out every two children (45 percent) identified at significant risk for developmental,
    behavioral, or social delays.
- Only one of five parents of young children received information or counseling on a range of the most basic and essential parent education and counseling topics recommended by the American Academy of Pediatrics, federal Maternal and Child Health Bureau, and EPSDT guidelines.
  - Three of five parents who reported that their child's health care providers did not talk
    with them about one or more key topics indicated that they wished they had received
    information about these topics.
  - Health care providers were more likely to address issues related to **injury prevention** (53 percent) and **physical care** of the child (45 percent) than to address topics related to the **child's development**, **behavior**, **and social growth** (31 percent).

# Project Background (cont):

The CAHMI was established in 1998 as a national collaboration to develop and implement a comprehensive set of consumer-centered quality measurement tools. The CAHMI provides leadership and resources for measuring and communicating information about the quality of health care for children and adolescents. For more information, visit the **CAHMI** Web site http://www.cahmi.org or email cahmi@ohsu.edu.

#### About the Survey:

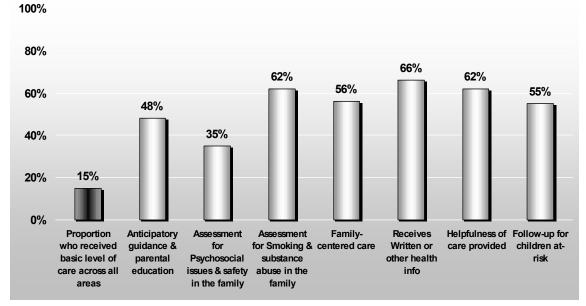
The **Promoting Healthy Development Survey-**PLUS (PHDS-PLUS) is a reliable and valid survey to parents of young children administered by telephone that collects information about preventive and developmental health care quality. The PHDS-PLUS was administered to parents of eligible Medicaid clients the under age of four during (insert time period) with assistance from (where applicable, insert vendor name). In order to be eligible for the survey, the child had to be currently and continuously enrolled in Medicaid for the previous 12 months or since the child was born. (Insert Number) PHDS-PLUS surveys were completed and collected in (Insert State Name). The data was then weighted to represent the population of continuously-enrolled children in (Insert State Name) Medicaid (N=insert number).

# QUALITY OF EPSDT SERVICES FOCUSED ON PREVENTIVE AND DEVELOPMENTAL HEALTH CARE IN (INSERT STATE NAME)

National guidelines recommend that children see a health care provider approximately 12 times during the first three years of life for routine, well-child care services. The PHDS-PLUS assesses the level and quality of care that is recommended to occur during a child's office visits by the American Academy of Pediatrics and the federal Maternal and Child Health Bureau and as recommended in EPSDT guidelines. The PHDS-PLUS measures seven core components of these recommendations. (Insert State Name)'s findings are detailed in the chart below.

#### QUALITY OF EPSDT SERVICES IN (INSERT STATE NAME) FOCUSED ON PREVENTIVE AND DEVELOPMENTAL HEALTH CARE FOR YOUNG CHILDREN

Proportion of children receiving a threshold level of quality care:



#### **KEY FINDINGS**

- Toddlers were less likely than infants or older youngsters to receive comprehensive services.
- Parents with a high school education or less were significantly more likely to receive a basic level of assessment for psychosocial issues, safety, smoking, and substance abuse in the family compared with parents who reported higher levels of education.
- A little more than one out of two parents (56 percent) reported that their child's health
  care provider "usually or always" provided family-centered care in each of the six areas.
   Parents who reported that care was family-centered were nearly twice as likely to

receive anticipatory guidance and parental education (72 percent vs. 45 percent).

# DIFFERENCES IN THE QUALITY OF CARE PROVIDED BY (INSERT STATE NAME) MEDICAID

Insert chart of quality care findings by a groups of state-specific interest.

### (Insert State Name)'s Team:

 Insert members of your state team

# Other State Medicaid Agencies Who Have Used the PHDS-PLUS:

- Louisiana
- Maine
- Minnesota
- Mississippi
- North Carolina
- Ohio
- Vermont
- Washington

#### **National Data:**

A majority of the items in the PHDS-PLUS were included in the National Survey of Early Childhood Health (NSECH).

#### **Funding Source**

This project received primary funding from The Commonwealth Fund, a private foundation that supports independent research on health and social issues and makes grants to improve health care practice and policy. The Fund is dedicated to helping people become more informed about their health care, and improving care for vulnerable populations such as children, elderly people, low-income families, minority Americans, and the uninsured. Visit http://www.cmwf.org.

## HOW (INSERT STATE) COMPARES TO OTHER STATES, NATIONAL DATA

Insert chart of quality care findings comparing State, Other States (Contact CAHMI Staff), and National Survey of Early Childhood Health findings.

<sup>\* 2004</sup> CAHMI PHDS-PLUS Data, (Insert State Name) Medicaid Beneficiaries, Weighted Data (Raw N=1993, Weighted N=70178)

<sup>\*\* 2001-2004</sup> CAHMI PHDS-PLUS Data from Six States (VT, NC, WA, MN, LA, OH)

<sup>\*\*\* 2001</sup> National Survey of Early Childhood Health. Children 35 months old or younger whose parents reported receiving public insurance.

### Health Care Utilization:

- Three out of five (61 percent) children had visited an emergency room at least once in the past year.
- One of five children (20 percent) had at least one overnight hospital stay.

#### **Access to Care:**

 One of 10 parents reported their child had a problem getting necessary care OR did not receive needed health care.

#### Of these children:

- One-third of parents reported lack of/delay in care because there were no free appointments in the doctor's office.
- Two of five parents noted that it caused a problem for the parent to meet work responsibilities.
- Three of 10 parents noted that it caused concern about their child's development.

#### FINDINGS RELATED TO CHILD AND FAMILY HEALTH

While most low-income children were healthy, many experienced health problems.

- Nearly seven out of 10 young children had "excellent" or "very good" health status according to parent reports (65 percent).
- One of 10 children were born with a low birth weight (11 percent) and/or prematurely (13 percent). These children had poorer health status compared with children with a normal birth weight and gestation.

#### Parents were concerned about their child's development.

• Seven out of 10 parents (74 percent) raised at least one concern about their child's social, emotional, behavioral, and cognitive development.

#### Nineteen percent of children have a special health care need (CSHCN).

 Nearly one of five (19 percent) children have a special health care need as defined by the federal Maternal and Child Health Bureau.

#### Many parents of low-income young children experienced health problems.

- On average, parents reported **4.6 poor physical or mental health** days in the last 30 days.
- Nineteen percent of parents with high school level of education or less reported seven or more poor physical health days, compared with 14 percent of parents with a greater than high school level of education. This compares with 11.7 percent in the general U.S. population of women under age 45.

#### CHILD AND PARENT HEALTH CHARACTERISTICS

Proportion of children/or parents with the following health characteristic: 58% 60% □ Child ■ Parent 40% 27% 19% 17% 20% 13% 11% 0% Child at significant Child has a Child was a low Child born Parent report 7 + Parent reported special health birth weight baby symptoms of poor physical prematurely developmental. health days depression care need behavioral or social delays

# WHY SCREENING AND ASSESSMENT MATTER: RELATIONSHIP BETWEEN A CHILD'S HEALTH AND HIS/HER PARENT'S HEALTH

One out of four (27 percent) parents experienced symptoms of depression.

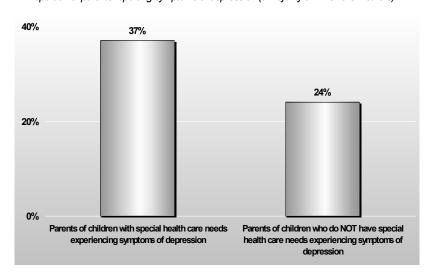
 Three out of five parents (61 percent) who experienced symptoms of depression in the past year said that they were not asked about their mental and emotional well-being by their child's health care provider during this time.

Three out of five parents (62 percent) reported being asked about **smoking**, **alcohol**, **and drug abuse** in the home.

 Health care providers were more likely to ask racial minorities than whites about smoking, alcohol, and drug use (67 percent versus 54 percent) despite lack of evidence that these issues are more likely to occur among racial minorities.

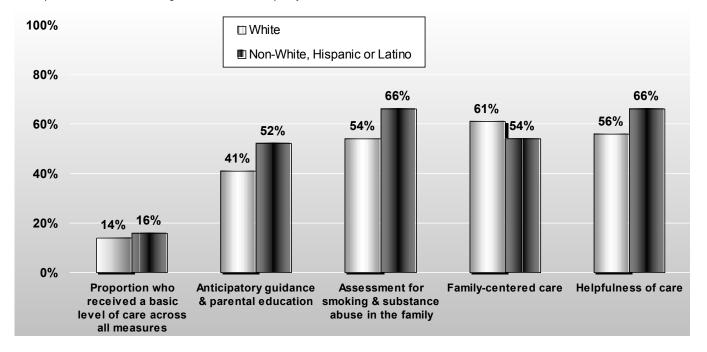
# PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS ARE MORE LIKELY TO EXPERIENCE SYMPTOMS OF DEPRESSION

•Proportion of parents reporting symptoms of depression (a majority of which are mothers):



#### **VARATIONS IN QUALITY OF CARE BY CHILD'S RACE-ETHNICITY**

Proportion of children receiving a threshold level of quality care:



#### CONCLUSIONS AND IMPLICATIONS OF THE FINDINGS

Findings from the PHDS-PLUS in (Insert State Name) reveal important opportunities to improve the health of young children. This study indicated that the health care system has significant room for improvements in the delivery of preventive and developmental services for young children. It is important to note that the findings shown present a "best case" scenario due to the positivity bias inherent in a telephone survey, conducted only in English to parents of children who are continuously enrolled in Medicaid. Key conclusions from this study include the following:

- Parents have significant concerns about the development and health of their children that are not addressed by their child's health care providers.
- Few children receive comprehensive preventive and developmental services and care is often worse for those whose parents have the greatest number and most serious concerns about their child's development and health.
- Higher quality of care is provided to children with a personal doctor or nurse who knows the child well, reflecting the importance of continuity of care.
- In addition to the child, more attention needs to be given to the health of the parent and family. This is especially true for mothers who report symptoms of depression and/or who have children with chronic conditions and other special health care needs. Health care coverage for parents is essential.
- For many parents, care is not family-centered, nor responsive to their personal needs and concerns.

Everyone has a role to play in promoting the healthy development of young children. Improvements in care require a comprehensive strategy that involves every level of society—state purchasers and policymakers, the family, the health care provider, the health care system, the community, and society at large. For each of these levels, information is essential to change. Results of this study demonstrate the value of surveying parents about the quality of health care their child receives and the richness of information that can be obtained through this type of methodology. The information is essential to understand the degree to which health care is meeting the needs of children and whether efforts to improve the quality of care make a difference. The findings emphasize that parent-reported assessments of preventive and developmental services for young children provide valid and valuable information to guide efforts to improve the quality of their health care.

AUTHORS: Christina Bethell, PhD, MPH, MBA; Colleen Peck Reuland, MS; and Brooke Latzke of the CAHMI.

**ADDITIONAL INFORMATION ABOUT THE CAHMI AND THE PHDS-PLUS:** Additional information about the CAHMI and the PHDS-PLUS can be found on the CAHMI Web site at www.cahmi.org. Information about the NSECH can be found at www.cdc.gov/nchs/about/major/slaits/nsech.htm.

#### ADDITIONAL RESOURCES ABOUT PREVENTIVE AND DEVELOPMENTAL HEALTH CARE:

www.aap.org • brightfutures.aap.org/web/ • www.zerothree.org • www.nichq.org • www.ncchildhealth.org/

**QUESTIONS?** Insert state-specific resources

<sup>&</sup>lt;sup>1</sup> National Center for Health Statistics. Hyattsville, Maryland: Public Health Service, 2000.

# Snapshot of Quality of Care Findings in (insert state name)

In December 2003–January 2004, (insert state name) Medicaid implemented a survey to parents of young children (0-3 years old). This survey, the Promoting Healthy Development Survey, assesses whether national recommendations for health promotion and developmental services are provided by pediatric clinicians.

We've since compiled the data, analyzed them by a number of variables, and are now sharing some of the results.

(Insert number) parents or guardians of children enrolled in (insert state name) Medicaid completed this survey. The findings were then weighted to represent the population of continuously enrolled children in (insert state name) Medicaid (N=insert number).

This report details key findings in (insert state name) related to the following measures of care:

Anticipatory Guidance and Parental Education	2
Assessment of the Family	
Addressing Parental Concerns	5
Follow-up for Children At-Risk	
Family-Centered Care	
anning contolog caremanning	•••

Additional information and resources are provided on page 7.

If you have questions about the findings presented in this report please contact (insert contact information).

More information about the Promoting Healthy Development Survey (PHDS) can be found on the Child and Adolescent Health Measurement Initiative (CAHMI) Web page at www.cahmi.org.

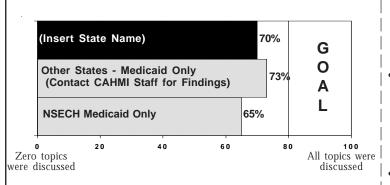
# ANTICIPATORY GUIDANCE AND PARENTAL EDUCATION

#### **DESCRIPTION**:

National recommendations for well-child care call for health care providers to provide anticipatory guidance and parental education about a number of topics related to children's development, growth, behavior, and safety. In the PHDS, parents are asked whether their child's doctor or other health care providers discussed 15 recommended age-specific anticipatory guidance and parental education topics. The response choices allow parents to indicate whether their informational needs on each topic were met:

- ✓ Yes, and my questions were answered
- ✓ No, but I wish we had talked about that
- ✓ No, but I already had information about that and did not need to talk about it any more

#### **OVERALL RESULTS**



#### **All Recommended Topics Discussed**

• 18% of parents report that their child's doctors or other health care providers talked with them about all of the age-appropriate topics.

#### **Informational Needs Met**

47% of parents report "Yes, and my questions were answered" OR "No, but I already had information about that and did not need to talk about it any more" to all of the age-appropriate topics.

#### **Informational Needs Unmet**

53% of parents noted at least once "No, but I wish we had talked about that" OR "Yes, but my questions were not answered".

#### RELATED PARENTING BEHAVIORS

To provide you with descriptive information about your patients, we asked parents to report about key parenting behaviors. Following each topic is the percentage of parents who report they did NOT do the activity:

- Did not play music or sing songs to their child every day 24%
- Did not read to their child every day 48%
- Did not turn down the hot water temperature on their water heater 41%
- Did not have the Poison Control Center phone number near the phone 16%
- $\bullet$  Did not put locks on cabinets where things such as cleaning agents or medicines are kept 25%
- Did not put padding around hard surfaces or sharp edges 46%
- Did not put <u>stoppers</u> or <u>plugs</u> in electrical outlets 5%
- Did not have a set or regular routine 24%

TOPIC-SPECIFIC FINDINGS			
<b>3–9 MONTHS OLD</b> Weighted Data** N=Insert # RAW DATA n=Insert #	<b>10–18 MONTHS OLD</b> Weighted Data** N=Insert # RAW DATA n=Insert #	<b>19–48 монтнз old</b> Weighted Data** N=Insert # RAW DATA n=Insert #	
<ul> <li>Things you can do to help child grow and learn - 83, 9, 9 (%)*</li> <li>Breastfeeding - 88, 10, 1 (%)</li> <li>Issues related to food such as the introduction of solid foods - 91, 4, 5 (%)</li> <li>Importance of placing child on back - 95, 3, 2 (%)</li> <li>Issues related to childcare - 81, 10, 9 (%)</li> <li>WIC Program - 87, 11, 3 (%)</li> </ul>	<ul> <li>Things you can do to help child grow and learn - 85, 8, 7 (%)*</li> <li>Vitamins and foods your child should eat - 92, 2, 6 (%)</li> <li>Bed and naptime routines - 64, 2, 9 (%)</li> <li>Whether child sleeps with a bottle - 82, 13, 5 (%)</li> <li>Weaning your child from a bottle - 75, 18, 7(%)</li> <li>Weaning your child from breastfeeding - 47, 48, 5 (%)</li> <li>Issues related to childcare - 73, 15, 12 (%)</li> <li>WIC Program - 83, 13, 4 (%)</li> </ul>	<ul> <li>Things you can do to help child grow and learn - 76, 13, 11 (%)*</li> <li>Issues related to food and feeding - 79, 15, 6 (%)</li> <li>Bedtime routines and how many hours of sleep child needs - 58, 28, 16 (%)</li> <li>Issues related to childcare - 67, 18, 15 (%)</li> <li>WIC Program - 65, 27, 8 (%)</li> </ul>	
<ul> <li>Kinds of behaviors you can expect to see in child as he/she gets older - 81, 9, 10 (%)*</li> <li>Night waking and fussing - 79, 12, 9 (%)</li> <li>How child communicates his/her needs - 85, 7, 9 (%)</li> <li>What your child is able to understand - 71, 9, 21 (%)</li> <li>How your child responds to you and other caregivers - 79, 9, 12 (%)</li> <li>Importance of showing a picture book to or reading with your child - 83, 6, 11 (%)</li> </ul>	<ul> <li>Kinds of behaviors you can expect to see in child as he/she gets older - 78, 11, 11 (%)*</li> <li>Words and phrases child uses and understands - 72, 14, 14 (%)</li> <li>Night waking and fussing - 71, 19, 10 (%)</li> <li>How your child may start to explore away from you - 62, 15, 22 (%)</li> <li>Guidance and discipline techniques - 61, 18, 21 (%)</li> <li>Anticipatory guidance about toilet training - 31, 41, 28 (%)</li> <li>Importance of reading with child - 85,7, 8 (%)</li> </ul>	<ul> <li>Kinds of behaviors you can expect to see in child as he/she gets older - 71, 15, 14 (%)*</li> <li>Toilet training - 53, 29, 18 (%)</li> <li>Words and phrases child uses and understand - 71, 15, 15 (%)</li> <li>How child is learning to get along with other children - 58, 20, 21 (%)</li> <li>Guidance and discipline techniques - 59, 22, 19 (%)</li> <li>Importance of reading with child - 77 11, 11 (%)</li> </ul>	
<ul> <li>How to avoid burns to your child, such as changing the hot water temperature in your home - 75, 12, 13 (%)*</li> <li>Using a car seat - 94, 3, 3 (%)</li> <li>How to make your house safe - 86, 6, 8 (%)</li> <li>* The figures following each topic represent, respectively, the points of the</li></ul>	<ul> <li>What you should do if your child swallows certain kinds of poisons - 72, 5, 23 (%)*</li> <li>Using a car seat - 89, 7, 5 (%)</li> <li>How to make your house safe - 86, 6, 8 (%)</li> </ul>	<ul> <li>Ways to teach child about dangerous situations, places and objects - 54, 19, 26 (%)*</li> <li>Using a car seat - 74, 20, 6(%)</li> <li>How to make your house safe - 71, 17, 12 (%)</li> <li>What to do if your child swallows certain kinds of poisons - 67, 8, 25 (%)</li> </ul>	

wished we had talked about that OR Yes, but I still had questions.

\*\*The data shown are based on data weighted to the population of continuously enrolled children in Medicaid.

### MEASURE: ASSESSMENT OF THE FAMILY

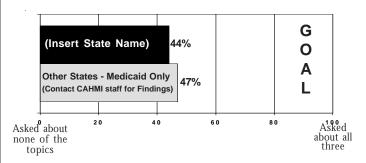
#### **DESCRIPTION:**

Parental well-being and the home environment are major determinants of the health and well-being of young children. National guidelines recommend that pediatric clinicians annually assess for the well-being of parents and safety within the family. Five items in the PHDS ask whether the child's doctors or other health care providers assess the parent and family for risks to the child's health.

#### **OVERALL RESULTS**

#### PSYCHOSOCIAL ISSUES/SAFETY TOPICS

- ✓ If the parent ever feels depressed, sad, or has crying spells
- ✓ Firearms in the home
- ✓ Changes or stressors in the home



#### **Asked About All Topics**

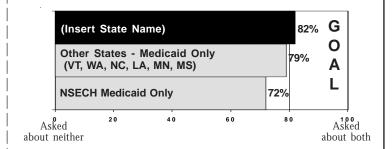
• 26% of parents report that their child's doctors or other health care providers asked about all three topics.

#### **NOT Asked About Any Topic**

 38% of parents report that their child's doctors or other health care providers did NOT ask about any of the three topics.

#### SMOKING/SUBSTANCE ABUSE TOPICS

- Smoking in the household
- ✓ Alcohol and other substance abuse in the household



#### **Asked About Both Topics**

 71% of parents report that their child's doctors or other health care providers asked about <u>both</u> topics.

#### **NOT Asked About Either Topic**

• 7% of parents report that their child's doctors or other health care providers did NOT ask about either topic.

#### **ITEM-SPECIFIC FINDINGS**

The percentage of parents reporting their child's doctors or other health care provider asked about the following topics in the last 12 months:

- If parent feels depressed, sad, or has crying spells 44%
- If there are firearms in the home 38%
- If parent has someone to turn to for emotional support 51%
- If someone in the household smokes 92%
- If someone in the household drinks alcohol or uses other substances 72%

#### RELATED ISSUES IN THE FAMILY

• **21**% of parents report experiencing symptoms of depression in the last 12 months.

Of this group, 44% were asked by their child's doctors or other health care providers if they have felt depressed, sad, or had experienced crying spells.

# ADDRESSING PARENTAL CONCERNS

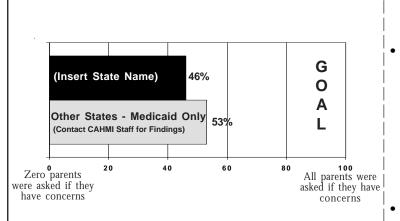
#### **DESCRIPTION:**

Research with health care providers and parents consistently finds that asking about and addressing parent concerns is one of the most important and valuable aspects of well-child care. Two items in the PHDS focus on addressing parent concerns:

- ✓ Whether their child's doctors or other health care providers asked the parent if he/she has concerns about the child's learning, development, or behavior.
- ✓ Whether parents with concerns received specific information to address those concerns.

Six items derived from the Parent's Evaluation of Developmental Status (PEDS)<sup>©\*</sup> are also included in the PHDS. These items ask parents about specific concerns they may have about their child's learning, development, or behavior.

#### **OVERALL RESULTS**



#### Parents With Concerns Who Are Asked About Their Concerns

61% of parents had one or more concerns about their child's learning, development, or behavior. Of this group, 45% of parents report that their child's doctors or other health care providers asked whether they had any concerns about their child.

### **Parents With Concerns Who Received Information to Address Their Concerns**

37% of parents with concerns report that their child's doctors or other health care providers gave them specific information to address their concerns.

#### SPECIFIC PARENT CONCERNS

The following percentages of parents report having a specific concern in the following areas:

- How the child understands what parents say 21%
- How the child talks and makes speech sounds 31%
- How the child sees -18%
- How the child hears -19%
- How the child is behind others or can't do what other kids can - 22%
- How the child is learning to do things for himself/ herself - 17%
- How the child uses his or her arms and legs 14%
- How the child behaves 37%
- How the child gets along with others 32%
- How the child uses his or her hands and fingers to do things - 13%
- How the child is learning preschool or school skills - 28%

\*Glascoe FP. Parents' Evaluation of Developmental Status. Nashville, TN: Ellsworth & Vandermeer Press, Ltd; 1998

# FOLLOW-UP FOR CHILDREN AT-RISK

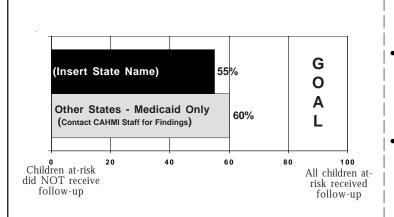
#### **DESCRIPTION**:

Parent concerns can be an indication of their child's risk for developmental, behavioral, or social delays. Adapted from the PEDS® manual\*, an age- and concern-specific scoring algorithm was used to identify children at "at risk" for a developmental/behavioral delay based on parent responses to the PEDS items included in the PHDS.

The PHDS includes five items that can indicate whether children at risk for developmental/behavioral delays received follow-up care from the child's doctors or other health care providers:

- ✓ Tested the child's learning and behavior
- ✓ Referred the child to another doctor or health care provider
- ✓ Referred the child for speech-language or hearing testing
- ✓ Noted a concern about the child that should be watched
- ✓ Gave the parent advice about how to help the child

#### **OVERALL RESULTS**



#### Children Identified At-Risk

36% of parents noted concerns that indicate their child is at significant risk for developmental, behavioral, or social delays.

#### Children At-Risk Who Received Follow-Up Care

55% of children identified at significant risk for developmental/behavioral delays whose parents report that their child received some form of follow-up care.

#### LEVEL OF FOLLOW-UP RECEIVED FOR AT-RISK GROUP

Listed below are the percentages of parents whose children were identified as at-risk by the PEDS items reporting that their child's doctor or other health care providers did one or more of the follow-up actions:

- Tested their child's learning and behavior 29%
- $\bullet$  Referred their child to another doctor or health care provider 32%
- $\bullet$  Referred their child for speech-language or hearing testing 25%
- Noted a concern about their child that should be watched - 24%

\*Glascoe FP. Parents' Evaluation of Developmental Status. Nashville, TN: Ellsworth & Vandermeer Press, Ltd; 1998

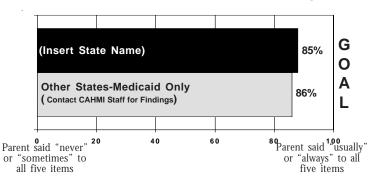
#### **FAMILY-CENTERED CARE**

#### **DESCRIPTION:**

Research demonstrates that a positive partnership with a child's doctors or other health care providers is one of the most important factors for ensuring parents get the information and support they need to promote the healthy development of their child. Five items in the PHDS assess the degree to which the care provided is family-centered by asking parents how often the child's doctor or other health care providers do the following:

- ✓ Respect the parent as an expert about their child
- ✓ Take time to understand the specific needs of the child
- ✓ Help the parent feel like a partner in their child's care
- ✓ Explain things in a way that the parent can understand
- ✓ Show respect for the family's values, customs, and how they prefer to raise their child

#### **OVERALL RESULTS**



- 64% of parents report "usually" or "always" to all of the family-centered care items.
- of parents report "never" or "sometimes" to one or more of the family-centered care items.

#### ITEM-LEVEL RESULTS

Percentage of parents reporting that their child's doctors and other health care providers "usually" or "always":

- Respect the parent as an expert about the child 82%
- Take the time to understand the specific needs of the child 77%
- Build confidence as a parent 82%

- Help the parent feel like a partner in their child's care 88%
- Explain things in a way the parent can understand 89%
- Understand how you and your family prefer to raise your child - 91%

#### ~ABOUT THE SURVEY~

The Promoting Healthy Development Survey (PHDS) was created by the Child and Adolescent Health Measurement Initiative (CAHMI) while at FACCT-Foundation for Accountability. To date, over 40,000 PHDS surveys have been collected and analyzed. The PHDS has been proven to be a reliable and valid tool for measuring preventive and developmental care. For more information about this survey and other related activities, please visit CAHMI's Web site <a href="http://www.cahmi.org">http://www.cahmi.org</a>. A majority of the items in the PHDS were included in the National Survey of Early Childhood Health. This nationally representative survey was administered to parents of children 3 years old or younger.

#### ~FOR MORE INFORMATION~

#### **About Topics Measured in the PHDS:**

- American Academy of Pediatrics Health Supervision Guidelines: http://www.aap.org
- Bright Futures Recommendations: brightfutures.aap.org/web/

#### **About Related Quality Improvement Strategies:**

- · National Initiative for Children's Healthcare Quality: www.nichq.org
- Zero to Three: www.zerotothree.org
- North Carolina Center for Children's Healthcare Improvement: www.ncchildhealth.org

**Resources in (Insert State Name):** Insert state-specific resources.

### Next visit notes:


For more information:

For additional information about the topics in this pamphlet, please visit:

insert state-specific website info www.cahmi.org www.aap.org/family www.kidshealth.org/parent www.zerotothree.org/stt\_parents.html Get the
Best
Health Care
for Your
Child . . .

be a know what to expect partnead be a partner and be a partner lin your child's health

in State X

### Be a partner in your child's health care!

We asked 2,000 parents whose children's health care is paid for by State X, Dept of X to complete the PROMOTING HEALTHY DEVELOPMENT SURVEY. This survey gathered children's health care information from parents just like you with children 3 years old or younger.

#### Why?

Your child's health and health care are important to us and we want to learn where our efforts, and the efforts of health care providers, can improve. We want to make sure your child gets the health care he or she needs to stay healthy. We are giving you this information so that you can ask questions to make sure your child gets the care he or she deserves.

#### Well-child care is important

Well-child care is preventive health care provided when your child is not sick. Also known as a "check-up," or a "routine visit," well-child care is essential to keeping your child healthy.

#### Did you know?

A national study found that most children do not get the preventive services they need to stay healthy. In fact, less than 10% of children 3 years old and younger receive all of these important services.

National recommendations for helping children stay healthy say that primary care providers should give parents information, guidance, and support.

#### Know what to expect...

#### And be a partner!

The information in this pamphlet will help you learn how to get the most out of your child's well-visits. You can make a difference in your child's health care.

# Your Child's Physical Needs

#### Areas of excellence:

Number of parents who talked with their child's health care provider about:

- Placing your child on his or her back to sleep
   9 out of 10
- Issues related to food 9 out of 10

#### Room for improvement:

Number of parents who did not talk with their child's doctor or other health care provider and wished they had talked about:

- Childcare issues 1 out of 10
- Bedtime routines 1 out of 10

Talk to your child's health care providers about:

- How to help your child learn and grow
- Vitamins and food your child should eat
- Feeding issues
- Bed- and nap-time routines and how many hours of sleep your child needs
- Issues related to childcare



### Be a partner in your child's health care!

# Your Child's Developmental Needs & Behavior

#### Areas of excellence:

Number of parents who talked with their child's health care provider about:

- Behaviors you can expect to see in your child
   9 out of 10
- The importance of reading to your child
   8 out of 10

#### Room for improvement:

Number of parents who did not talk with their child's doctor or other health care provider and wished they had talked about:

- Guidance and discipline techniques 1 out of 4
- Toilet training 1 out of 5

Talk to your child's health care providers about:

- Behaviors to expect from your child
- Words or phrases your child may use
- How often you should read to your child
- Toilet training
- Guidance and discipline techniques





#### Areas of excellence:

Number of parents who talked with their child's health care provider about:

- Car seat safety 8 out of 10
- House safety 8 out of 10

#### Room for improvement:

Number of parents who did not talk with their child's doctor or other health care provider and wished they had talked about:

- What to do if your child swallows something poisonous — 1 out of 4
- Teaching your toddler about dangerous situations, places, and objects — 1 out of 4

Talk to your child's health care providers about:

- Safety in your home and car
- Poison prevention
- Teaching your child about dangerous situations, places, and objects

#### Do You Have Concerns about Your Child's Learning, Development, or Behavior?

Before your child's office visit, think about if you have these concerns:

- How your child talks and makes speech sounds
- How your child understands what you say
- o How your child uses his or her arms and legs
- How your child behaves or gets along with others

Voicing these concerns can help your child's health care provider assess your child's risk for learning, developmental, and behavioral delays.

Parents are often the first to notice delays in their child's growth and development. Voicing your concerns can help your child's health care providers identify issues early.

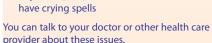


# We Care about Your Entire Family!

Your child's doctor or other health care provider should ask about family issues that affect your child's health and well-being.

Your child's health care provider should ask:

- If anyone in your household smokes
- If anyone in your household abuses alcohol or other substances
- If you feel safe at home
- If you ever feel depressed, sad, or have crying spells







### Child and Adolescent Health Measurement Initiative: Washington State Healthy Options

### Promoting Healthy Development Survey (PHDS)

2000 Results

**Washington State** 

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#### Introduction

#### Overview

This report presents the results from the 2000 fielding of the Promoting Healthy Development Survey (PHDS) to Washington State's Healthy Options Medicaid, Fee-For-Service, and Primary Care Case Management clients. The PHDS is intended to help providers, consumers, purchasers, and policymakers assess the degree to which health plans and practitioners provide recommended developmental services for children up to four years old. The PHDS was one of three surveys piloted as part of a national demonstration project through the Child and Adolescent Health Measurement Initiative, spearheaded by FACCT -- The Foundation for Accountability. Washington State Medical Assistance Administration was selected from among several agencies around the nation to participate in this statewide pilot project. The pilot included Washington State "Healthy Options" clients being served by nine managed care organizations as well as children receiving care through Washington Fee-For-Service and Primary Care Case Management programs.

#### FACCT, CAHMI, and the PHDS

FACCT is a not-for-profit organization dedicated to helping Americans make better health care decisions. To achieve this goal, FACCT creates tools that help people understand and use quality information, develops consumer-focused quality measures, advocates public education about health care quality, supports efforts to gather and provide quality information, and encourages health policy to empower and inform consumers.

The Child and Adolescent Health Measurement Initiative (CAHMI) is committed to improving the health of children and adolescents by ensuring that families, purchasers, policymakers and providers have relevant and actionable information about health care quality. The CAHMI, led by FACCT, was established in the Spring of 1998 as a collaboration including the National Committee for Quality Assurance, the American Academy of Pediatrics, Children Now, The Centers for Disease Control and Prevention, The Agency for Healthcare Research and Quality. More than 50 consumer organizations, policymakers, researchers, health care practitioners, health plans, and health care purchasers have participated in the CAHMI since May, 1998.

The PHDS quality measures were developed under the auspices of the CAHMI's Staying Healthy Task Force. The purpose of this task force was to identify or develop measures specifically focused on preventive care. The two areas of preventive care identified as most crucial were early childhood development and adolescent preventive counseling and screening. Because no quality measures focused specifically on preventive care for young children could be identified, FACCT developed and tested the PHDS to fill this need for quality information in this area.

The PHDS has undergone extensive cognitive testing, readability assessments, and has been translated into Spanish. Prior to the Washington project, the PHDS was fielded with three health plans in Maine.

#### **Methodology Overview**

The Promoting Healthy Development Survey was administered in Washington using a standardized mail administration protocol (for more detail, see Appendix B). A random sample of parents of children three months to four years old at the time the survey administration was selected. Children within this age range were eligible to be sampled if they had been continuously enrolled with Washington Medical Assistance Administration for 12 months as of 3/1/2000, allowing for a single one-month gap. If the child was younger than 12 months, then he/she was eligible to be sampled if he/she had been enrolled since the date of birth.

Statewide samples were taken from the managed care organizations and Fee-For-Service, plus a sample from PCCM clients. A total of 7,566 people were mailed the PHDS questionnaire in Washington State. If MAA records indicated the parent's primary language was Spanish, both the Spanish and English versions of the questionnaire and cover letters were sent.

#### **Response Rate**

Overall, 3,542 completed questionnaires were obtained, yielding a raw response rate of 46.8%. After removing undeliverable questionnaires (497), incorrect addresses (4), children who were not in the correct age range (52), and children who died (3), the adjusted response rate for the survey was 50.5%.

# Characteristics of Respondents and Target Child

### Respondent/Parent Characteristics: Washington State

The PHDS asked the respondent/parent to report their race/ethnicity, educational attainment, and age:

#### Washington State

Total number of respondents	3,513
Race/Ethnicity of Respondent (Selected all that apply)	(%)
White	63.2
Black	3.8
Hispanic	19.5
Asian	3.2
American Indian or Native American	3.3
Native Hawaiian or Pacific Islander	0.9
Other, or mixed race	6.1
Education of Respondent	
Less than high school	20.2
Age of Respondent	
24 years or younger	31.3
25 to 34 years	48.6
35 years or older	20.0

### Respondent/Parent Report of Child's Characteristics: Washington State

A target child was selected during the PHDS sampling process. Only one child was selected per parent, even if the parent had more than one child. The following table describes the children to whom the respondents referred when they filled out the PHDS questionnaire.

#### Washington State

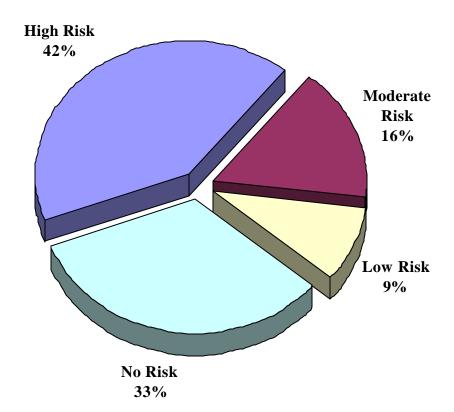
Total number of respondents	3,513
Age of Child	(%)
1 to 9 months	6.7
10 to 18 months	11.7
19 to 50 months	81.6
Gender of Child	
Male	50.9
Female	49.1
Birth Order of Child	
First born child	40.3

# Child's Risk for Developmental or Behavioral Delays

### Risk of Developmental or Behavioral Delays: Washington State

PHDS questionnaire items 13-15 can be used to identify children at risk for developmental and/or behavioral delays. These items are based on Dr. Frances Glascoe's parent-based risk assessment tool, the Parents' Evaluation of Developmental Status (PEDS®). Research using the PEDS® has shown that parents' concerns about specific aspects of their child's development and behavior at particular ages are fairly accurate predictors of their child's risk for developmental or behavioral problems later in life. Appendix D provides a detailed description of the scoring algorithm used to score parental responses to the PEDS® items into four risk groups of developmental and/or behavioral delays: 1) High Risk 2) Moderate Risk 3) Low Risk and 4) No Risk.

In Washington State, based on parental responses to items 13-15, the following percentages of children were identified as being at risk for developmental and/or behavioral delays.



**High Risk**: Child is at high risk for developmental or behavioral delays. Child should receive a developmental assessment, developmental promotion, parental guidance, and possible referral.

**Moderate Risk**: Child is at moderate risk for developmental or behavioral delays. Child should receive screening, developmental promotion, parental guidance, and observation.

**Low Risk**: Child is at low risk for developmental or behavioral delays. Parents most likely need behavioral guidance targeting their concerns.

**No Risk**: Child, based on parent's noted concerns, is at no risk for developmental or behavioral delays and should continue to receive routine monitoring through well-child visits.

# Family / Parenting Activities

### Family/Parenting Activities: Washington State

Included in the PHDS are items about family activities or parenting behaviors. These items were not included in any of the seven quality measures, but they can be useful for quality improvement and community assessment purposes.

#### Washington State

Total number of respondents	3,513
How many times in the past week did you show or read a book to your child?	(%)
Not at all, or once or twice	28.8
Several times or more	71.2
When laying your child down to sleep, in what position do you usually place your child?  (Children aged 9 months or younger)	
On back	71.4
On stomach	5.5
On side	20.5
No special position	1.8
Other	0.9
Was your child breastfed for more than a month, less than a month, or not at all?	
Less than a month, or not at all	35.2
More than a month	64.8
Does anyone in your household smoke?	
Yes	35.1

# Home Safety: Washington State

PHDS items 25-28 ask the respondents/parents if they have made four basic child-safety modifications to their home: put cleaning products out of reach, turned down the hot water heater's temperature, keep syrup of Ipecac in the home, and put up baby gates or other safety barriers.

#### Washington State

Total number of respondents	3,513
Percent responding "Yes, I have" to:	(%)
0 out of 4 questions	2.7
1 out of 4 questions	12.5
2 out of 4 questions	26.4
3 out of 4 questions	31.5
4 out of 4 questions	27.0

# **Quality Measures**

Please visit FACCT's web site (<u>www.facct.org</u>) for more information regarding development of the PHDS quality measures.

# **Quality Measures: Description**

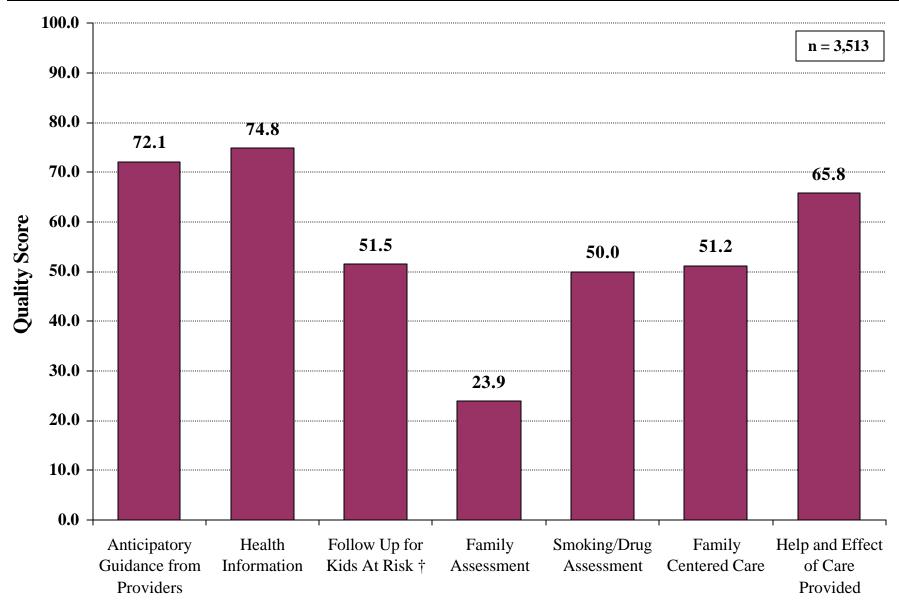
Responses from the Promoting Healthy Development Survey (PHDS) are used to create seven quality measures (see Appendix C for a detailed list of the survey items in each quality measure):

Description of Quality Measure	Numerator & Denominator for the Quality Measure	Scoring Used
Quality Measure #1: Anticipatory guidance and parental educa	tion from doctor or other health provider	
All Respondents Items (3a-h): Talking with provider(s) or otherwise having needed information about: child's growth and development, behaviors to expect, physically caring for the child, reading and playing with child and helping child grow and learn, making house and car safe and preventing child from injury.  Age Specific Items:  1-9 Months (5.1a-e, 5.2a-e): Talk/get information about: breastfeeding, issues related to food and feeding, sleeping positions and sleep area, night waking and fussing, child's responses and communication, how to avoid burns, reading a book with the child.  10-18 Months (6.1a-f, 6.2a-f): Talk/get information about: nutrition, sleeping/napping, preventing bottlemouth, child's communication, child's independence, guidance and discipline techniques, Syrup of Ipecac, toilet training, reading with the child.  19-48 Months (7.1a-f, 7.2a-e): Talk/get information about: nutrition and eating habits, child's social interactions and communication skills, child's independence, guidance and limit setting, Syrup of Ipecac and other safety issues, toilet training, and reading with the child.	Numerator: Sum of the score for each eligible, individual survey respondent who reported that their child had seen a doctor or other health provider in the last 12 months. Individual scores are calculated as the sum of the scores for question 3 and to the age specific questions divided by the number of items answered.  Denominator: All survey respondents who report that their child has seen a doctor or other health provider in the last 12 months.	✓ Mean score on multi-item scale.  Points obtained for each response:  Yes, and all my questions were answered: 100 pts.  Yes, but my questions were not answered: 25 pts.  No, but I wish we had discussed: 0 pts.  No, but I got my information from other resources and did not need to discuss it any further: 75 pts.
Quality Measure #2: Health information		
<u>Items 12a-d</u> : Information provided outside/inside the doctor's or other health provider's office (mail, in clinic pamphlets, videos, etc) on: safety tips, health care utilization tips, childcare tips, child development.	Numerator: Sum of the score for each respondent. Individual scores are calculated as the sum of the scores for each individual item divided by the number of items answered.  Denominator: All survey respondents.	<ul> <li>✓ Average proportion answering "yes" to the four items.</li> <li>Points obtained for each response:</li> <li>Yes: 100 pts.</li> <li>No: 0 pts.</li> </ul>

Description of Quality Measure	Numerator & Denominator for the	Scoring Used						
	Quality Measure	scoring escu						
Quality Measure #3: Follow up for children with an indication of risk for developmental problems								
Items 13a-d, 14a-d, 15a-c used to classify children as having and indication of risk. Follow up items (20a-e) indicate whether some type of appropriate follow up occurred. Follow up items include testing of child's learning and behavior, referral to specialist, whether a doctor or other health provider noted a concern, and whether a doctor or other health provider gave advice to the parent to address his/her concern.	Numerator: Number of respondents identified as at high/moderate risk who received follow-up.  Denominator: Number of parents whose children are identified as high or moderate risk.	✓ Proportion identified as high/moderate risk that received some form of appropriate follow up. (Risk specific scoring algorithm used for question 20)  Points obtained for each response:  High Risk: 100 pts if answered "Yes" to 20a, 20b, or 20d.  Moderate Risk: 100 pts if answered "Yes" to 20a, 20b, 20c, 20d, or 20e.						
Quality Measure #4: Assessment of well-being of parent(s) and s	safety within the family							
<u>Items 21a-b, 21e, 22a-e</u> : Provider(s) talks with parent about: depression, sadness, childhood experiences, feeling safe at home, support and stress in life, firearms, parenting along with other demands	Numerator: Sum of the score for each eligible, individual survey respondent. Individual scores are calculated as the sum of the scores for items 21a-b, 17e, 22a-e divided by the number of items answered.  Denominator: All survey respondents.	✓ Average proportion answering "yes" to each survey item.  Points obtained for each response: Yes: 100 pts. No: 0 pts.						
Quality Measure #5: Assessment of smoking and drug use in the family								
Items 21c-d: Provider(s) asks parent about smoking and drug use.	Numerator: Sum of the score for each eligible, individual survey respondent. Individual scores are calculated as the sum of the scores for items 21c-d divided by two.  Denominator: All survey respondents.	✓ Average proportion answering "yes" to each survey item.  Points obtained for each response: Yes: 100 pts.  No: 0 pts.						

Description of Quality Measure	Numerator & Denominator for the Quality Measure	Scoring Used							
Quality Measure #6: Family centered care (Communication and relationship with providers)									
Items 8a-d, 9a-f: Parent reports that provider(s) takes time to understand unique qualities and needs of child and family, respects and builds confidence in parent, asks about responds to parent's feelings, concerns and preferences, and shares about resources that may help the child, parent and/or family.	Numerator: Sum of the score for each eligible, individual survey respondent who reported that their child had seen a doctor or other health provider in the last 12 months. Individual scores are calculated as the sum of the scores for 8a-d, 9a-f divided by the number of items answered.  Denominator: All survey respondents who report that their child has seen a doctor or other health provider in the last 12 months.	Points obtained for each response: Never: 0 pts. Sometimes: 33 pts. Usually: 67 pts. Always: 100 pts.							
Quality Measure #7: Helpfulness and effect of anticipatory guid	ance and counseling on confidence as a par	ent							
Item 10a-d, 11a-d: Family report of helpfulness of guidance, counseling and education. Reported increase/decrease in confidence in certain parenting actions because of information or counseling obtained from a doctor or other health provider.	Numerator: Sum of the score for each eligible, individual survey respondent who reported that their child had seen a doctor or other health provider in the last 12 months. Individual scores are calculated as the sum of the scores for survey items 10a-d, 11a-d divided by the number of survey items answered.  Denominator: All survey respondents who report that their child has seen a doctor or other health provider in the last 12 months.	Points obtained for each response: Not all Helpful: 0 pts. Somewhat Helpful: 33 pts. Helpful: 67 pts. Very Helpful: 100 pts. We do not discuss: Coded as Missing  I feel a lot more confident: 100 pts. I feel a little more confident: 67 pts. I do not feel more or less confident: 33 pts. I feel less confident: 0 pts.							

# **Quality Measures (0 to 100 Scale): Washington State**



† n = 2,012

# **Quality Measures (0 to 100 Scale) by County**

Quality measures for counties with more than 100 respondents to the PHD Survey are shown below:

PHDS Quality Measure	Clark County n=530	Cowlitz County n=104	King County n=513	Pierce County n=334	Skagit County n=167	Snohomish County n=205	Spokane County n=301	Whatcom County n=220	Yakima County n=232	Significance of Variation Among Counties
Anticipatory Guidance and Education from Providers	68.2	74.0	72.5	71.5	79.9	73.5	69.8	75.7	71.0	F = 4.74 (p = .000)
2. Health Information	67.6	79.8	77.9	76.2	80.3	74.1	72.0	77.5	73.7	F = 4.74 (p = .000)
3. Follow Up for Kids At Risk for Behavioral/ Developmental Problems	44.3% (n=309)	54.2% (n=59)	56.2% (n=306)	49.7% (n=191)	61.5% (n=91)	50.4% (n=125)	57.2% (n=173)	54.6% (n=108)	41.8% (n=141)	$X^2 = 21.2$ (p = .007)
4. Family Assessment	18.5	20.0	27.7	22.4	32.4	25.4	17.9	24.9	29.5	F = 8.91 (p = .000)
5. Smoking/Drug Assessment	53.2	50.0	49.4	51.2	56.6	51.0	44.5	46.6	50.6	F = 1.85 $(p = .064)$
6. Family Centered Care	44.9	49.9	52.7	51.2	61.4	52.5	49.3	52.7	50.5	F = 7.75 (p = .000)
7. Help and Effect of Care Provided	59.5	62.7	68.0	64.4	74.8	66.3	61.6	64.8	70.9	F = 9.75 (p = .000)

## Quality Measures (0 to 100 Scale) by Plan

PHDS Quality Measure	AUSH n=289	CHPW n=346	CUP n=299	GHC n=363	KFHP n=301	MLNA n=367	NWMB n=401	PBC n=369	RBS n=386	PCCM n=70	FFS n=311	Significance of Variation among Plans
Anticipatory     Guidance and     Education from     Providers	71.6	74.6	69.2	68.9	68.4	70.7	76.9	70.8	71.4	76.9	76.5	F =4.8 (p = .00)
2. Health Information	75.5	78.9	68.8	72.6	68.1	74.1	78.6	74.4	73.1	83.6	80.8	F =4.7 (p = .00)
3. Follow Up for Kids At Risk for Behavioral/ Developmental Problems	53.8% (n=160)	47.6% (n=231)	55.4% (n=175)	59.5% (n=210)	34.5% (n=168)	48.1% (n=212)	59.3% (n=204)	48.9% (n=223)	52.9% (n=208)	42.5% (n=40)	56.4% (n=181)	$X^2 = 37.3$ (p = .00)
4. Family Assessment	20.0	34.6	19.4	21.0	17.2	21.4	26.3	21.2	24.6	33.0	30.4	F =11.8 (p = .00)
5. Smoking/Drug Assessment	43.1	57.7	45.3	54.3	59.5	44.6	50.3	43.3	47.1	65.9	53.2	F = 7.3 (p = .00)
6. Family Centered Care	47.4	57.4	44.7	48.7	46.1	50.1	55.9	50.2	50.9	60.2	56.8	F =9.8 (p = .00)
7. Help and Effect of Care Provided	63.8	74.5	59.5	60.6	59.9	65.0	68.5	65.3	66.1	72.1	72.2	F =12.6 (p = .00)

#### Health plan abbreviations:

AUSH = Aetna US Healthcare of Washington

CHPW = Community Health Plan of Washington

CUP = Columbia United Providers GHC = Group Health Cooperative

KFHP = Kaiser Family Health Plan

MLNA = Molina Healthcare of Washington, Inc.

NWMB = Northwest Washington Medical Bureau

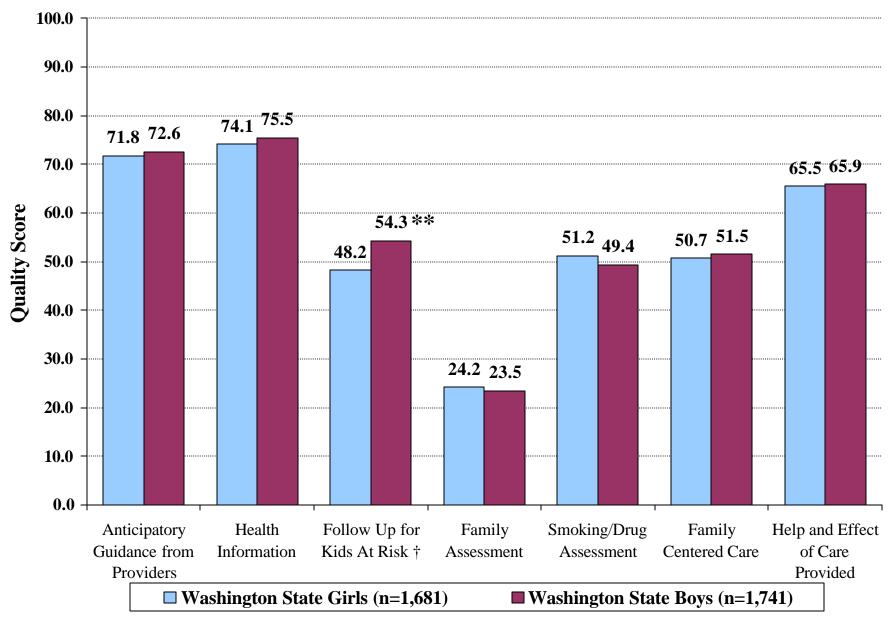
PBC = Premera Blue Cross

RBS = Regence Blue Shield

PCCM = Primary Care Case Management

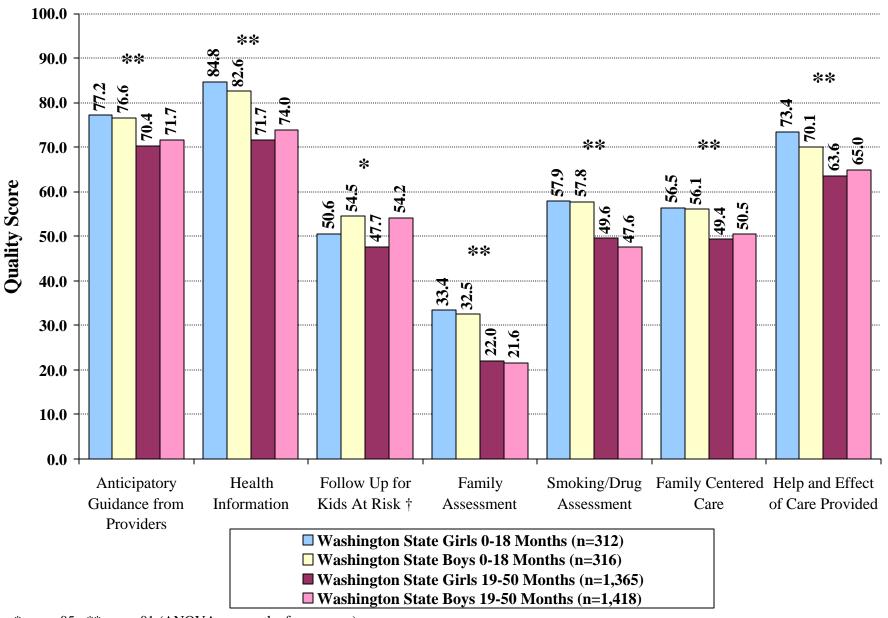
FFS = Fee-For-Service

## Quality Measures (0 to 100 Scale) by Gender of Child: Washington State



<sup>\*</sup> p <= .05; \*\* p <= .01; † Girls n=905, Boys n=1,041

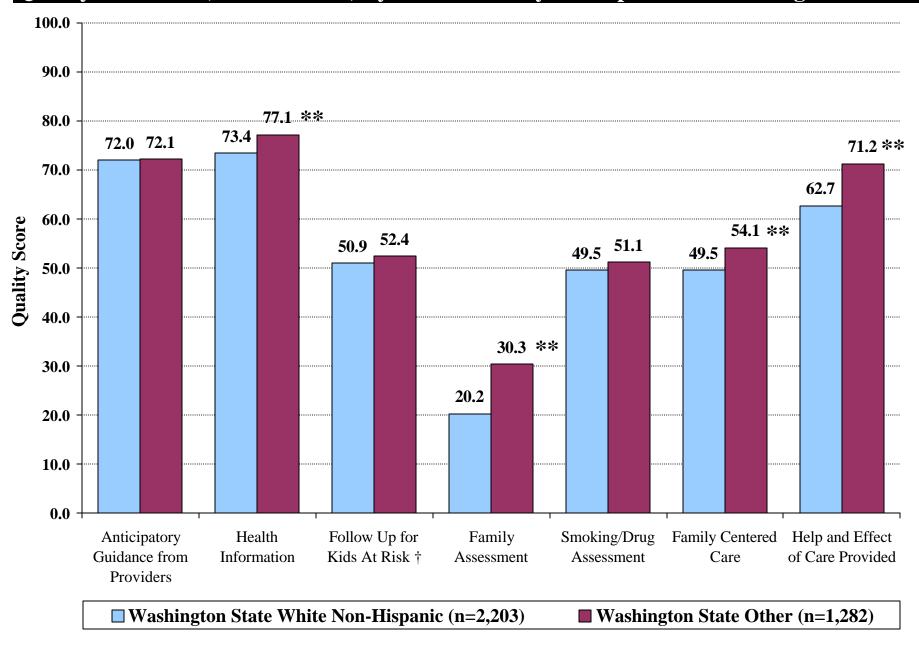
# Quality Measures (0 to 100 Scale) by Age and Gender of Child: Washington State



<sup>\*</sup>  $p \le 0.05$ ; \*\*  $p \le 0.01$  (ANOVA among the four groups)

<sup>†</sup> Girls 0-18 n=160, Boys 0-18 n=176, Girls 19-50 n=745, Boys 19-50 n=865

## Quality Measures (0 to 100 Scale) by Race/Ethnicity of Respondent: Washington State



<sup>\*</sup> p <= .05; \*\* p <= .01; † White Non-Hispanic n=1,265, Other n=735

# **Quality Improvement Opportunities**

# Questionnaire items receiving highest quality of care ratings

# **Questionnaire items receiving lowest quality of care ratings**

Talk about guidance and limit setting techniques (28.9%)

highest quality of care ratings	<u>lowest</u> quality of care ratings					
Measure 1: Anticipatory Guidance and Education from Providers—All Ages						
(Percentage saying "yes, all questions answered")	(Percentage saying "no, but I wish we had discussed that")					
• Talk about your child's growth and development (81.6%)	• Talk about things to do to help your child grow and learn (16.5%)					
• Talk about kinds of behaviors to expect to see in your child (62%)	• Talk about kinds of behaviors to expect to see in your child (15.4%)					
Measure 1: Anticipatory Guidance and	d Education from Providers—0-9 Months					
(Percentage saying "yes, all questions answered")	(Percentage saying "no, but I wish we had discussed that")					
• Talk about issues related to food and feeding (83.5%)	• Talk about what your child is able to understand (22.4%)					
• Talk about the importance of placing your child on his or her back when going to sleep (80.2%)	• Talk about how your child responds to you, other adults, and caregivers (18.0%)					
Measure 1: Anticipatory Guidance and	Education from Providers—10-18 Months					
(Percentage saying "yes, all questions answered")	(Percentage saying "no, but I wish we had discussed that")					
• Talk about vitamins and foods your child should eat (66.9%)	• Talk about the use of Syrup of Ipecac if your child swallows some poison (34.2%)					
• Talk about sleeping with a bottle (64.0%)	• Talk about toilet training (33.0%)					
Measure 1: Anticipatory Guidance and Education from Providers—19-50 Months						
(Percentage saying "yes, all questions answered")	(Percentage saying "no, but I wish we had discussed that")					
• Talk about issues related to food and feeding (54.4%)	• Talk about the use of Syrup of Ipecac if your child swallows some poison (32.9%)					

Talk about words or phrases your child uses and understands (43.7%)

# **Questionnaire items receiving**<a href="https://doi.org/10.2007/j.jup/1

# **Questionnaire items receiving lowest** quality of care ratings

Measures 4 and 5: Family Psychosocial Assessment							
(Percentage saying "yes" doctor	other provider <u>did</u> ask)		(Percentage saying "no" doctor/other provider did not ask)				
• Whether anyone in your family smokes (63.6%)		•	How your own childhood experiences may impact your relationship with your child (91.3%)				
• If a family member uses alcohol or other drugs or substance excessively (36.6%)			• If you have firearms in the your home (81.3%)				
	Measure 6: Family Centered Care						
(Percentage saying doctors/other pr	oviders "always" do this)		(Percentage saying doctors/other providers "never" do this)				
Respect that you are the expert on your cl	nild (51.8%)	•	Talk about childcare arrangements (61.3%)				
• Builds confidence as a parent (51.2%)		•	Talk to you about issues in your community that may affect your child's health and development (59.6%)				

## **Parents' Concerns: Washington State**

Items 13-15 of the PHDS ask about specific concerns parents may currently have about their child's growth, development, and behavior. The top five concerns about child development and behavior reported by Washington State parents of children aged 1 to 50 months old are:

# Percentage of parents who said they are "a lot" or "a little" concerned about this

✓	How their child <u>behaves</u>	44.8 %
✓	Their child's learning, development, or behavior	43.4 %
✓	How their child gets along with others	37.7 %
✓	How their child talks and makes speech sounds	36.4 %
✓	How their child is learning pre-school skills	32.8 %

## Providers' Response to Parents' Concerns: Washington State

Overall, a large number of parents with numerous concerns (items 13-15) are not having their needs for information and guidance met. As can be seen from the tables below, many parents are not asked if they have concerns about their child's learning, development, and behavior. In addition, many of the parents who noted in items 13-15 that they have concerns about their child did <u>not</u> receive information to address these concerns.

In the last 12 months, did your child's doctors or other health providers <u>ask about your concerns</u> related to your child's learning, development, and behavior?

Parents with 4 or more concerns

Parents with 1 to 3 concerns

Parents without concerns

Yes	No	I Don't Remember
44.8 %	39.1 %	16.1 %
49.4 %	33.7 %	16.9 %
52.7 %	35.2 %	12.1 %

(Of parents with concerns (items 13-15)) In the last 12 months, did your child's doctors or other health providers give you specific information to address your concerns?

Parents with 4 or more concerns

Parents with 1 to 3 concerns

Yes	No	I Don't Remember
45.5 %	38.1 %	16.4 %
61.3 %	25.1 %	13.6 %

# Children with Special Health Care Needs: Washington State

The Promoting Healthy Development Survey includes five questions to identify children with special health care needs. Termed the "CAHMI/CSHCN screener," this tool uses consequences-based criteria to screen returned PHDS questionnaires for children with special health care needs. The screener consists of PHD survey items 32-36. To qualify as having a special health care need, the following set of conditions must be met:

- The child currently experiences a specific consequence.
- The consequence is due to a medical or other health condition.
- 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 (Question 32)
- 2) Above average use or need of medical, mental health or educational services (Question 33)
- 3) Functional limitations compared with others of same age (Question 34)
- 4) Use or need of specialized therapies (Occupational Therapy, Physical Therapy, speech, etc.) (Question 35)
- 5) Treatment or counseling for emotional, behavioral or developmental problems (Question 36)

The second and third parts (screener question #36 has only 2 parts) of each screener question ask those responding "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 of at least one screener question (or in the case of question 36, the two parts) must be answered "yes" in order for a child to meet CSHCN screening tool criteria for having a special health care need.

In the Washington State PHDS sample, 11.6% of the children were identified as having special health care needs. Overall quality measure scores between these children and children without special health care needs were similar within and across counties. However, some disparity and room for improvement is evident in the area of "Anticipatory Guidance":

	Children with SHCN (n=384)	Children without SHCN (n=2,936)
Quality Measure #1:  Getting needed anticipatory guidance and education from doctor or other health provider	67.3	72.8 **
* p <= .05; ** p <= .01		

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## **Appendix A: Background on the Promoting Healthy Development Survey**

The Promoting Healthy Development Survey was developed under the auspices of the Child and Adolescent Health Measurement Initiative's (CAHMI) Staying Healthy Task Force. The development of the Promoting Healthy Development Survey has been largely funded by FACCT—The Foundation for Accountability through grant support from The David and Lucile Packard Foundation and The Commonwealth Fund. The Promoting Healthy Development Survey is formally endorsed by the Advisory Committee of the Child and Adolescent Health Measurement Initiative (CAHMAC).

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 considered how such measures could 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 Promoting Healthy Development sampling strategy, survey items and measures:

Kathryn Taaffe McLearn PhD, The Commonwealth Fund Edward Schor, MD, Iowa Department of Public Health Jessica Reich, Children Now Margo Kaplan-Sanoff, EdD, Boston Medical Center Peter Gorski, MD, MPA, Massachusetts Caring for Children Foundation Frances Glascoe, PhD, Vanderbilt University Jan Hanson, PHD, Institute for Family Centered Care (prev.) Neal Halfon, MD, MPH, UCLA School of Medicine and Public Health James Cameron, PhD, Preventive Ounce Steve Black, MD, Permanente Medical Group, Inc. Barbara Yawn, MD, Olmsted Medical Center

Christina Bethell, PhD, Senior Vice President at FACCT-The Foundation for Accountability, is Director of the CAHMI and principle investigator for the development and testing of the Promoting Healthy Development Survey. Colleen Peck, MS served as the research associate for the Promoting Healthy Development Survey. Debbie Levy provided administrative and research assistance.

### **Appendix B: Summary Methodology**

#### **Sampling Methodology**

The Promoting Healthy Development Survey was administered in Washington using a standardized mail administration protocol. A random sample of parents of children three months to four years old at the time the survey administration was selected. Children within this age range were eligible to be sampled if they had been continuously enrolled with Washington Medical Assistance Administration for 12 months as of 3/1/2000, allowing for a single one-month gap. If the child was younger than 12 months, then he/she was eligible to be sampled if he/she had been enrolled since the date of birth.

Statewide samples were taken from the managed care organizations and Fee-For-Service, plus a sample from PCCM clients. A total of 7,566 people were mailed the PHDS questionnaire in Washington State. If MAA records indicated the parent's primary language was Spanish, both the Spanish and English versions of the questionnaire and cover letters were sent.

#### **Administration Protocol**

The protocol for conducting the survey was as follows:

Activity	Date
Pre-notification letter sent to all survey participants	April 12
Initial questionnaire sent to all survey participants	April 19-25
Reminder postcard sent to non-respondents	May 2
Second copy of questionnaire sent to non-respondents	May 17
Reminder postcard sent to non-respondents	May 23
End of data collection	June 14

#### **Response Rate**

Overall, 3,542 completed questionnaires were obtained, yielding a raw response rate of 46.8%. After removing undeliverable questionnaires (497), incorrect addresses (4), children who were not in the correct age range (52), and children who died (3), the adjusted response rate for the survey was 50.5%.

#### **Notes on Significance Testing**

Statistics in this report are of two kinds primarily: a) percentages or counts, and b) means. Statistical significance testing of percentages is accomplished using the *chi-square test*. The chi-square test examines tallies within each of the mutually exclusive categories in question and tests whether or not these patterns are likely the result of chance. If the chi-square test indicates that we can be at least 95% certain the patterns observed are not due to simple random variation, then we conclude there is a statistically significant result.

Statistical significance testing of means is accomplished using the *Analysis of Variance* (ANOVA). Similar to the chi-square test, the ANOVA examines means for each of the groups in question and tests whether or not these patterns are likely the result of chance. If the ANOVA indicates that we can be at least 95% certain the patterns observed are not due to simple random variation, then we conclude there is a statistically significant result.

When conducting significance tests, it is important to consider the sample sizes of the groups being compared. The greater the sample size, the better the sample statistic represents the true population value (assuming the sample was selected randomly from that population). Another way to phrase this is that the accuracy of the estimate increases as the sample size increases. This means that differences that are not statistically significant using sample sizes of 20 may turn out to be statistically significant if those samples were increased to 100. The inverse of this also is true: statistically significant differences using large sample sizes may not be significant if the samples were very small. Above all, the reader must evaluate the practical importance of the statistics and of any group differences reported.

#### **Roles of the Organizations**

FACCT – The Foundation for Accountability. FACCT spearheaded the development and testing of the PHDS, under the auspices of the national Child and Adolescent Health Measurement Initiative. FACCT provided the survey materials and analyzed the resulting data. FACCT provided hands-on consultation and technical assistance to Washington Medical Assistance Administration (MAA) and its subcontractors during administration of the PHDS. FACCT also provided MAA with grant funding to serve as a national pilot site for the PHDS.

Washington Medical Assistance Administration (MAA). MAA oversaw the statewide study and provided the survey population. MAA played a key role in fostering interest and buy-in among the key stakeholders and the managed care organizations in Washington.

Oregon Medical Peer Review Organization (OMPRO). OMPRO coordinated the survey administration. They hired the survey subcontractor, cleansed and transmitted survey data, and oversaw the survey operations.

Washington State University, Social and Economic Sciences Research Center (SESRC). SESRC was responsible for actual survey administration.

# **Appendix C: PHDS Items Scored in Quality Measures**

#### Response Choice Options:

- A) Yes, and all my questions were answered; Yes but my questions were not answered completely; No, but I wish we had discussed; No, but I already had information about this topic and did not need to discuss it any more
- B) Yes: No
- C) Never; Sometimes; Usually; Always
- D) Very Helpful; Helpful; Somewhat Helpful; Not at all Helpful; We did not discuss
- E) I feel a lot more confident; I feel a little more confident; I do not feel more or less confident; I feel less confident

#### PV1: Anticipatory Guidance and Education from Health Care Providers

In the last 12 months did your child's doctors or other health providers talk with you about the following: (Response Choice A)

- 3a: Your child's growth and development
- 3b: The kinds of behaviors you can expect to see in your child
- 3c:How to dress, bathe, and feed you child
- 3d:Things you can do to help your child grow and learn
- 3e:The importance of talking to, reading to, and playing with your child.
- 3f: Ways to keep your child from being injured
- 3g: How to make your house safe
- 3g: How to make your car safe (e.g. car seats)
- 5.1a: Breast feeding
- 5.1b: Issues related to food and feeding (such as the introduction of solid food)
- 5.1c: The importance of placing your child on his or her back when going to sleep
- 5.1d: Where your child sleeps (such as the location and type of crib, whether there are stuffed animals in the crib, etc)
- 5.1e: Night waking and fussing
- 5.2a: How your child responds to you, other adults, and caregivers
- 5.2b: How your child communicates his or her needs
- 5.2c: What your child is able to understand
- 5.2d: How to avoid burns, such as changing the hot water temperature in your home
- 5.2e: The importance of showing a picture book and reading to your child.

- 6.1a: Vitamins and foods your child should eat
- 6.1b: Your child's bed and nap time routine
- 6.1c: The words or phrases your child uses and understands
- 6.1d: Night waking and fussing
- 6.1e: Sleeping with the bottle
- 6.1f: Weaning your child from a bottle
- 6.2a: How your child may start to explore away from you
- 6.2b: How your child "gets into things"
- 6.2c: Guidance and limit setting techniques to use with your child
- 6.2d: Toilet training
- 6.2e: The use of Syrup of Ipecac if your child swallows some poison
- 6.2f: The importance of reading with your child
- 7.1a: Issues related to food and feeding
- 7.1b: Bed time routing and how many hours of sleep your child needs
- 7.1c: Things your child may start to do for himself or herself, like washing or dressing
- 7.1d: Toilet training
- 7.1e: The words or phrases your child uses and understands
- 7.1f: How your child is learning to get along with other children (For example: at home, in play groups, at day care, or pre-school)
- 7.2a: How well your child follows directions
- 7.2b: Guidance and limit setting techniques to use with your child
- 7.2c: Ways to teach your child about dangerous situations (such as electrical sockets, the stove, hot water, pools, and the street)
- 7.2d: The use of Syrup of Ipecac if your child swallows some poison
- 7.2e: The importance of reading with your child

#### PV2: Information from the Health Plan

In the last 12 months did you see or read information about: (*Response Choice B*)

11a: Safety Tips: How to make your house and car safe for your child (For example: information about lead poisoning or car seats) 11b: Health Care Tips: When and how often your child should see the doctor, immunization reminders, information on other health care services available for your child

11c: Child Care Tips: Information about caring for your child 11d: Developmental Information: Information about your child's development

#### PV3: Follow Up for Children at Risk for Developmental Delays

Did your child's doctors or other health providers ever: (*Response Choice B*)

20a: Make a referral to another doctor or other health provider

20b: Test your child's learning and behavior

20c: Note a concern that should be watched carefully

20d: Make a referral for speech-language or hearing testing

16e: Give you advice about how to help your child

#### PV4: Assessment of Family Well Being and Safety

In the last 12 months, have your child's doctors or other health providers asked you: (*Response Choice B*)

21a: If you ever felt depressed, sad, or had crying spells

21b: To discuss your own childhood experiences with him or her and how they relate to your interaction with your child

21e: If you felt safe at home

22a: If you have someone to turn to for emotional support

22b: To talk about any changes or new stressors in your family or home

22c: If you had firearms in your home

22d: How parenting works into your daily activities and future plans

22e: To discuss how your and your family are enjoying raising your child

#### PV5: Assessment of Smoking and Substance Abuse in the Family

In the last 12 months, have your child's doctors or other health providers asked you: (*Response Choice B*)

22c: If a family member of the child smokes

22d: If a family member uses alcohol or other drugs or substances excessively

# PV6: Family Centered Care: Communication and Experience of Care

In the last 12 months how often did your child's doctors or other health providers: (*Response Choice C*)

8a: Take time to understand the specific needs of your child

8b: Respect you as an expert on your child

8c: Build your confidence as a parent

8d: Ask you about how you are feeling as a parent

9a: Give you specific information to address any questions you may have about your child.

9b: Understand your family and how your prefer to raise your child

9d: Talk to you about the WIC program, a nutrition and health program for Woman, Infants, and Children. (Benefits include food, vouchers for food, healthcare referrals, and nutrition education)

9e: Talk to you about resources that are available to support you (parent support groups, childcare, alternative health care)
9f: Talk to you about issues in your community that may affect your child's health and development (such as lead poisoning, pool safety, community violence, gun safety, or window guards)

#### PV7: Helpfulness and Effect of Care Provided

In the last 12 months, how helpful were your discussions with your child's doctors or other health providers in: (*Response Choice D*)

10a: Helping you understand your child's behavior

10b: Helping you learn to meet your own needs while caring for your child

10c: Learning how to protect your child from injuries

10d: Giving you information you needed when you needed it.

Overall, how much more or less confident do you feel in doing the following things because of the information or guidance you received from your child's doctors or other health providers: (Response Choice E)

11a: Managing your parenting responsibilities

11b: Protecting your child from injuries and accidents

11c: Doing things for your child to help him or her grow and learn such as reading and talking to your child.

11d: Addressing any special concerns you have about your child's development and behavior and how you can help your child grow and learn.

# Appendix D: The Parental Evaluation of Developmental Status (PEDS®)

#### Overview

The PEDS® instrument identifies 74-80% of children ages 0-8 years old with developmental disabilities and identifies 70-80% of children without disabilities. Approximately 90% of parents can complete PEDS® independently, having been standardized on 971 families from various backgrounds, including varied ethnicity, income and educational levels and at a reading grade of fifth grade.

**High Risk**: About one in ten parents will have two or more significant concerns-concerns that are predictive of disabilities. Children who fall into the high-risk category are <u>twenty times</u> more likely to have disabilities than children for whom there are no concerns. Further research has shown that this indicates that 50% of children indicated with high risk have disabilities and an additional 20% perform well below average in areas critical to school success. Therefore, seventy percent of children identified as high risk will be disabled or below average. The positive predicative value for high risk children identified via the PEDS® is 52%. The odds of disabilities are 20.1 with a value less than .0001.

**Moderate Risk**: About two in ten parents will have only one of the concerns shown to be significant predictors of problems. These children are <u>eight times</u> more likely to have disabilities than children form whom there are no significant concerns. One in three children whose parents have a significant concern will found, upon further testing, to have a disability. Therefore, 46% of children identified as moderate risk will be either disabled or below average. The positive predicative value for moderate risk children identified via the PEDS<sup>®</sup> is 28%. The odds of a disability are 7.6 with p value less than .0001.

#### Key notes regarding sampling and survey administration of the PEDS®:

Difference based on **Income**: There were significant differences in the overall frequency of parent's concerns on the basis of the parent's income. Low-income parent had an average of 1.5 concerns while higher income parents had an average of 1.2 concerns. Further, low-income parents had significantly more concerns about several specific areas of children's development, all of which were significant, even after controlling for children's age. On the other hand, there were no significant differences between gender, birth order, and number of children, marital status, and educational levels.

## PEDS® Scoring Algorithm

The PEDS® has an age and concern specific scoring algorithm. The following table describes the scoring algorithm used to identify children as high, moderate, low, and no risk of developmental/behavioral delays. Overall, there are three age-specific algorithms that apply to the PHDS® age parameter for children sampled: 0-17 months, 18-36 months, and 37-50 months.

	Risk Category			
Age of Child	High Risk	Moderate Risk	Low Risk	No Risk
<b>0-17</b> months old	Child identified as "high risk" if parent noted "A lot" or "A little" concern to two or more of the following:  > 13a > 13b > 13c > 14d > 15c	Child identified as "moderate risk" if parent noted "A lot" or "A little" concern to <b>one</b> of the following:  > 13a  > 13b  > 13c  > 14d  > 15c	Child identified as "low risk" if parent noted "A lot" or "A little" concern to one or more of the following:  > 13d > 14a > 14b > 14c > 15a > 15b	Child identified as "no risk" if parent noted "not all concerned" to all PEDS® items:  > 13a-d > 14 a-d > 15 a-c
18-35 months old	Child identified as "high risk" if parent noted "A lot" or "A little" concern to <b>two</b> or more of the following:  > 13a > 13b > 13c > 13d > 15c	Child identified as "moderate risk" if parent noted "A lot" or "A little" concern to <b>one</b> of the following:  > 13a  > 13b  > 13c  > 13d  > 15c	Child identified as "low risk" if parent noted "A lot" or "A little" concern to one or more of the following:  > 14a > 14b > 14c > 14d > 15a > 15b	Child identified as "no risk" if parent noted "not all concerned" to all PEDS® items:  > 13a-d > 14 a-d > 15 a-c
36-50 months old	Child identified as "high risk" if parent noted "A lot" or "A little" concern to two or more of the following:  > 13a > 13b > 13c > 13d > 14b > 15c	Child identified as "moderate risk" if parent noted "A lot" or "A little" concern to <b>one</b> of the following:  > 13a  > 13b  > 13c  > 13d  > 14b  > 15c	Child identified as "low risk" if parent noted "A lot" or "A little" concern to one or more of the following:  > 14a > 14c > 14d > 15a > 15b	Child identified as "no risk" if parent noted "not all concerned" to all PEDS® items:  > 13a-d > 14 a-d > 15 a-c

Appendix E: The PHDS Questionnaire, with Topline Results						