

FACCT
Foundation for Accountability



Helping Americans Make
Better Health Care Decisions

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

CAHMI is a not-for-profit organization dedicated to helping Americans make better health care decisions. To achieve this goal, CAHMI 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	
<i>(Selected all that apply)</i>	(%)
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

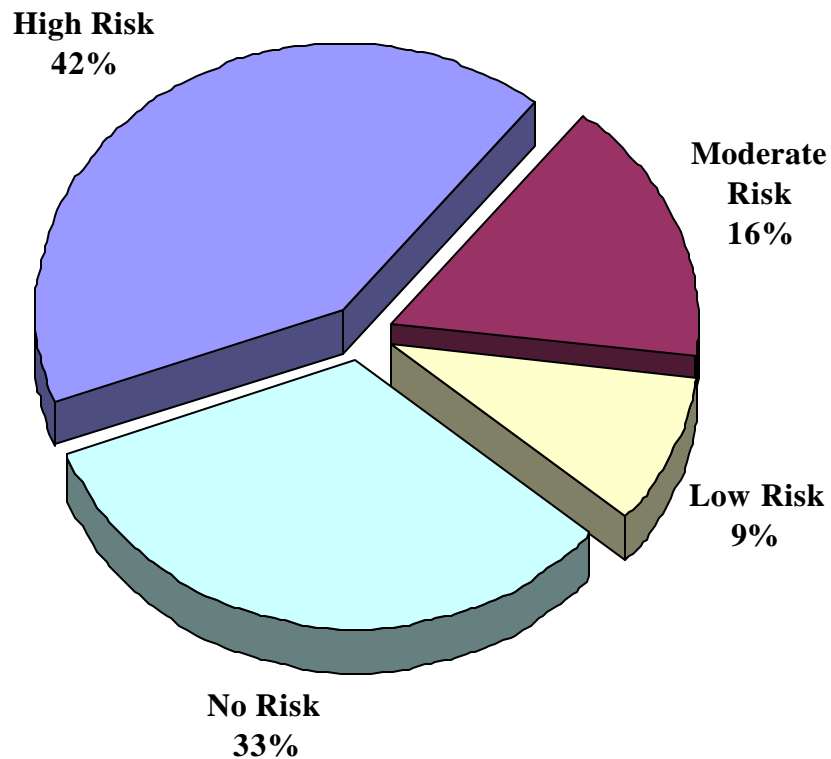
Total number of respondents	3,513
Age of Child	(%)
1 to 9 months	6.7
10 to 18 months	11.7
19 to 50 months	81.6
Gender of Child	
Male	50.9
Female	49.1
Birth Order of Child	
First born child	40.3

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? <i>(Children aged 9 months or younger)</i>	
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 (www.facct.org) for more information regarding development of the PHDS quality measures.

Quality Measures: Description

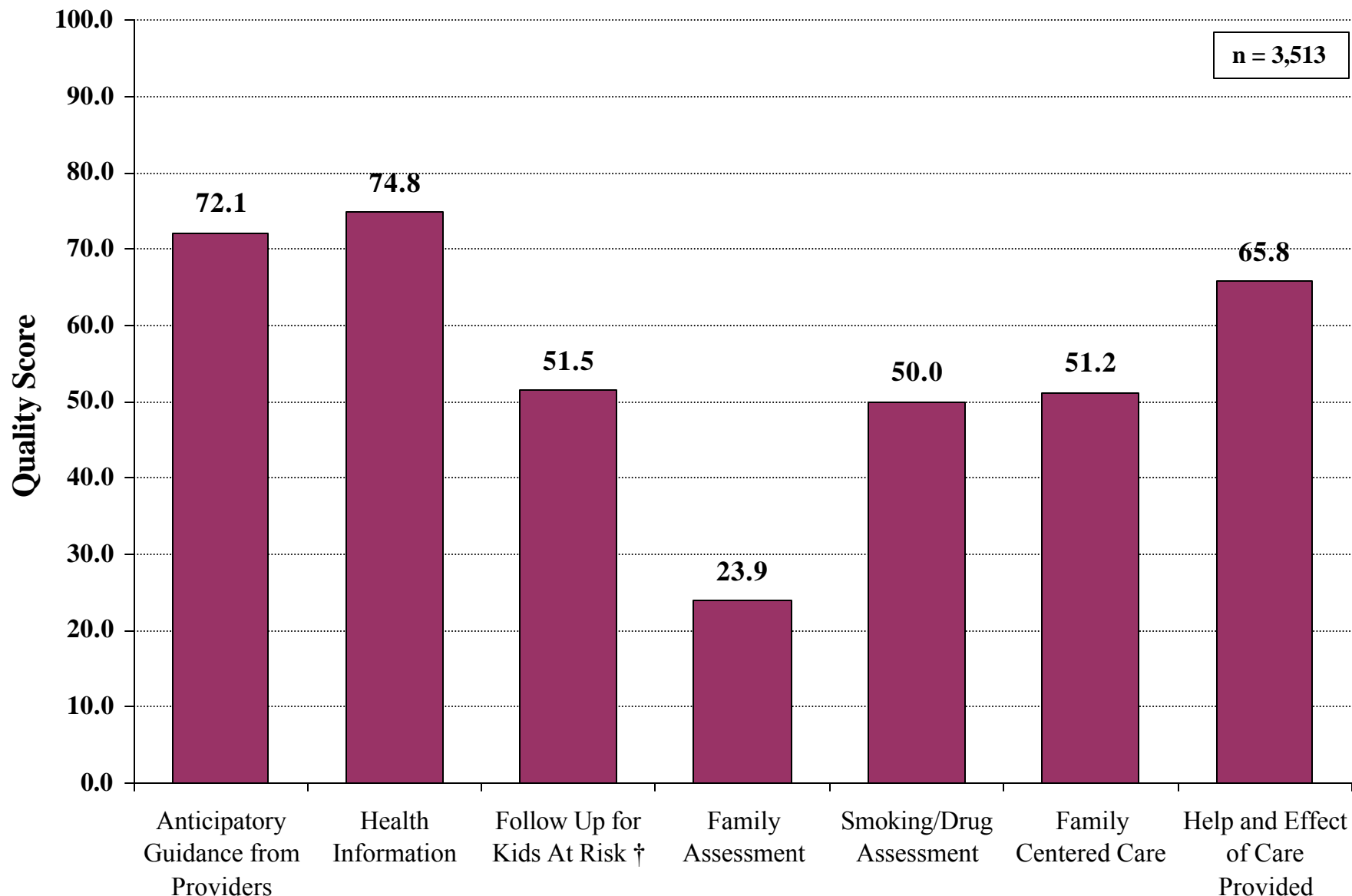
Responses from the Promoting Healthy Development Survey (PHDS) are used to create seven quality measures (see Appendix C for a detailed list of the survey items in each quality measure):

Description of Quality Measure	Numerator & Denominator for the Quality Measure	Scoring Used
Quality Measure #1: Anticipatory guidance and parental education from doctor or other health provider		
<p><u>All Respondents Items (3a-h)</u>: 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.</p> <p>Age Specific Items: <u>1-9 Months (5.1a-e, 5.2a-e)</u>: 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. <u>10-18 Months (6.1a-f, 6.2a-f)</u>: Talk/get information about: nutrition, sleeping/napping, preventing bottle mouth, child’s communication, child’s independence, guidance and discipline techniques, Syrup of Ipecac, toilet training, reading with the child. <u>19-48 Months (7.1a-f, 7.2a-e)</u>: 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.</p>	<p><u>Numerator</u>: 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.</p> <p><u>Denominator</u>: All survey respondents who report that their child has seen a doctor or other health provider in the last 12 months.</p>	<p>✓ Mean score on multi-item scale.</p> <p>Points obtained for each response:</p> <p>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.</p>
Quality Measure #2: Health information		
<p><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.</p>	<p><u>Numerator</u>: 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.</p> <p><u>Denominator</u>: All survey respondents.</p>	<p>✓ Average proportion answering “yes” to the four items.</p> <p>Points obtained for each response:</p> <p>Yes: 100 pts. No: 0 pts.</p>

Description of Quality Measure	Numerator & Denominator for the Quality Measure	Scoring Used
Quality Measure #3: Follow up for children with an indication of risk for developmental problems		
<p><u>Items 13a-d, 14a-d, 15a-c</u> 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.</p>	<p><u>Numerator:</u> Number of respondents identified as at high/moderate risk who received follow-up.</p> <p><u>Denominator:</u> Number of parents whose children are identified as high or moderate risk.</p>	<p>✓ Proportion identified as high/moderate risk that received some form of appropriate follow up. (<i>Risk specific scoring algorithm used for question 20</i>)</p> <p>Points obtained for each response:</p> <p>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.</p>
Quality Measure #4: Assessment of well-being of parent(s) and safety within the family		
<p><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</p>	<p><u>Numerator:</u> 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.</p> <p><u>Denominator:</u> All survey respondents.</p>	<p>✓ Average proportion answering “yes” to each survey item.</p> <p>Points obtained for each response: Yes: 100 pts. No: 0 pts.</p>
Quality Measure #5: Assessment of smoking and drug use in the family		
<p><u>Items 21c-d:</u> Provider(s) asks parent about smoking and drug use.</p>	<p><u>Numerator:</u> 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.</p> <p><u>Denominator:</u> All survey respondents.</p>	<p>✓ Average proportion answering “yes” to each survey item.</p> <p>Points obtained for each response: Yes: 100 pts. No: 0 pts.</p>

Description of Quality Measure	Numerator & Denominator for the Quality Measure	Scoring Used
Quality Measure #6: Family centered care (<i>Communication and relationship with providers</i>)		
<p><u>Items 8a-d, 9a-f:</u> 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.</p>	<p><u>Numerator:</u> 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.</p> <p><u>Denominator:</u> All survey respondents who report that their child has seen a doctor or other health provider in the last 12 months.</p>	<p>✓ Mean score on a multi-item scale</p> <p>Points obtained for each response: Never: 0 pts. Sometimes: 33 pts. Usually: 67 pts. Always: 100 pts.</p>
Quality Measure #7: Helpfulness and effect of anticipatory guidance and counseling on confidence as a parent		
<p><u>Item 10a-d, 11a-d:</u> 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.</p>	<p><u>Numerator:</u> 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.</p> <p><u>Denominator:</u> All survey respondents who report that their child has seen a doctor or other health provider in the last 12 months.</p>	<p>✓ Mean score on a multi-item scale.</p> <p>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</p> <p>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.</p>

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
1. 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

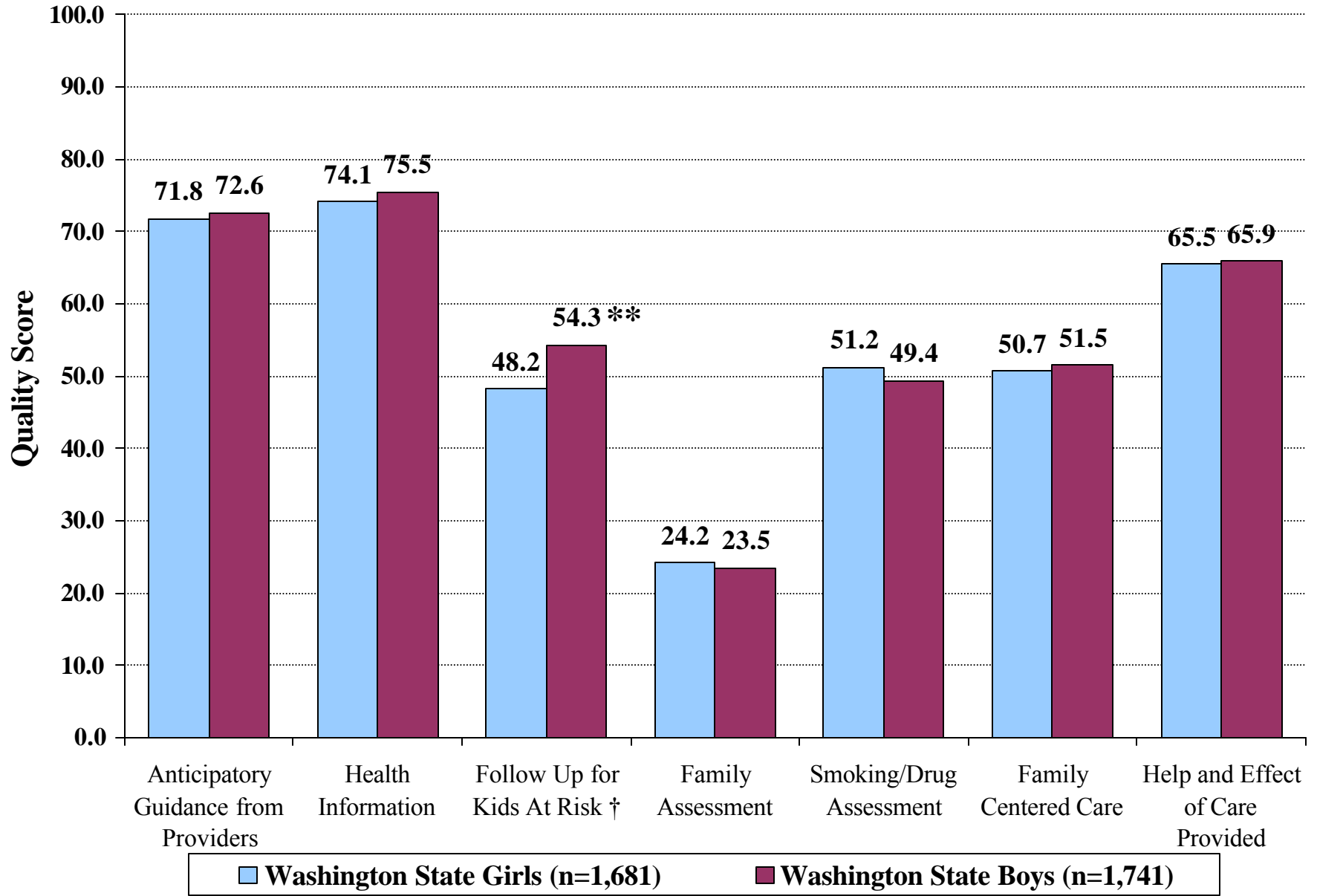
PHDS Quality Measure	AUSH n=289	CHPW n=346	CUP n=299	GHC n=363	KFHP n=301	MLNA n=367	NWMB n=401	PBC n=369	RBS n=386	PCCM n=70	FFS n=311	Significance of Variation among Plans
1. Anticipatory Guidance and Education from Providers	71.6	74.6	69.2	68.9	68.4	70.7	76.9	70.8	71.4	76.9	76.5	F =4.8 (p = .00)
2. 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

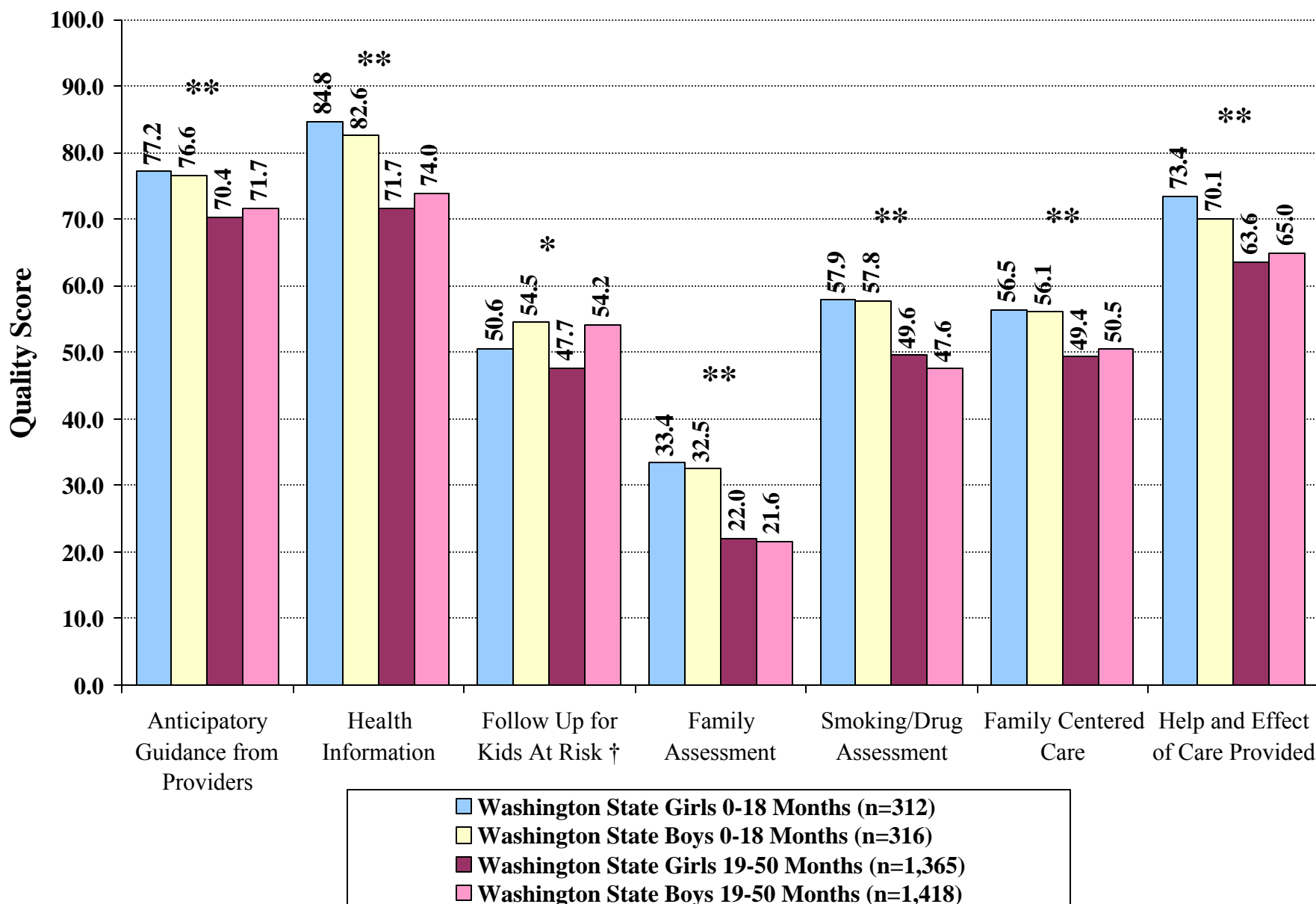
MLNA = Molina Healthcare of Washington, Inc.
 NWMB = Northwest Washington Medical Bureau
 PBC = Premera Blue Cross
 RBS = Regence Blue Shield
 PCCM = Primary Care Case Management
 FFS = Fee-For-Service

Quality Measures (0 to 100 Scale) by Gender of Child: Washington State



* p <= .05; ** p <= .01; † Girls n=905, Boys n=1,041

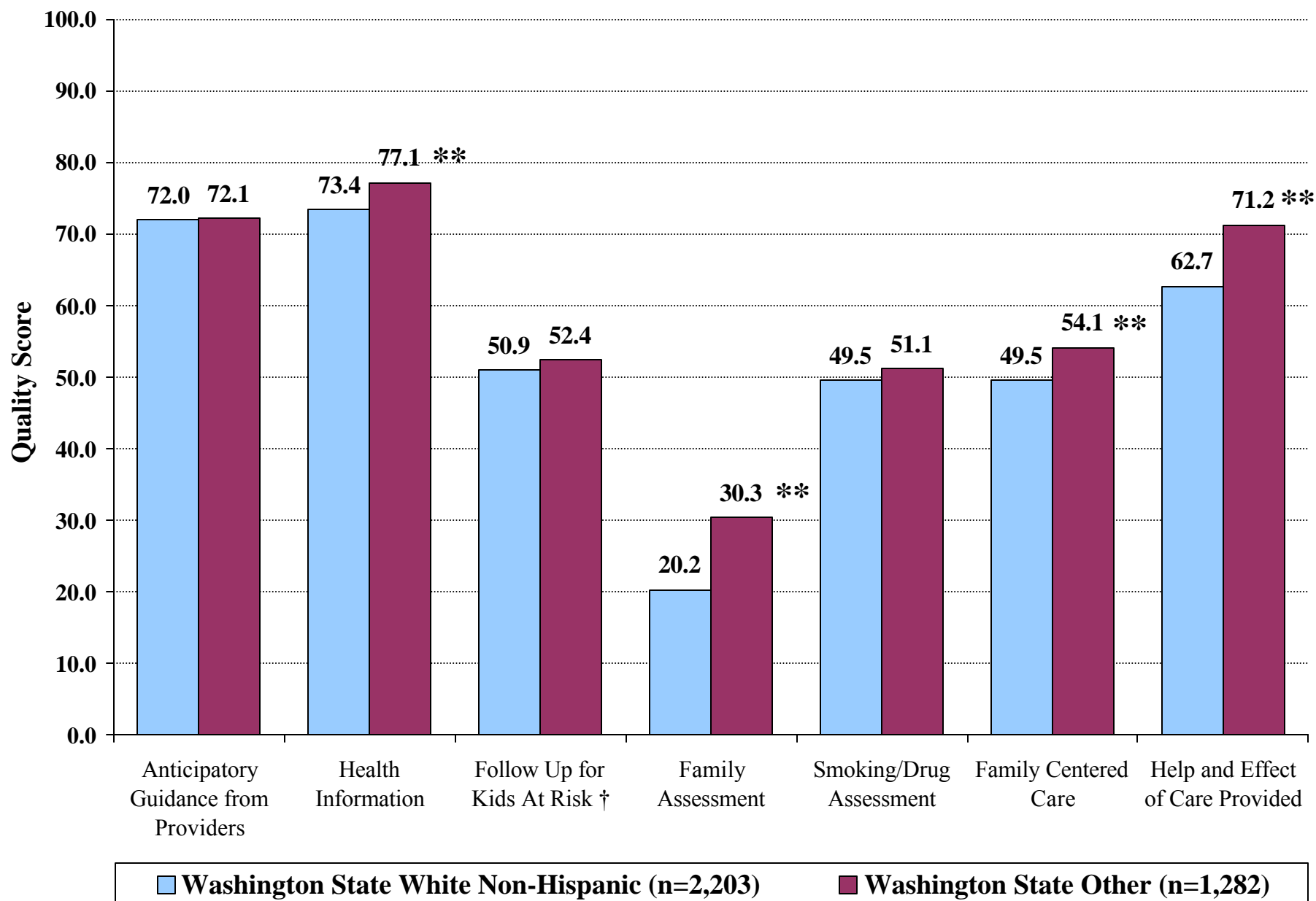
Quality Measures (0 to 100 Scale) by Age and Gender of Child: Washington State



* p <= .05; ** p <= .01 (ANOVA among the four groups)

† 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



* p <= .05; ** p <= .01; † White Non-Hispanic n=1,265, Other n=735

Quality Improvement Opportunities

Summary of Highest and Lowest Quality Ratings: Washington State

Questionnaire items receiving highest quality of care ratings

Questionnaire items receiving lowest 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”)

- | | |
|--|---|
| <ul style="list-style-type: none"> • Talk about your child’s growth and development (81.6%) • Talk about kinds of behaviors to expect to see in your child (62%) | <ul style="list-style-type: none"> • 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 (15.4%) |
|--|---|

Measure 1: Anticipatory Guidance and Education from Providers—0-9 Months

(Percentage saying “yes, all questions answered”)

(Percentage saying “no, but I wish we had discussed that”)

- | | |
|---|---|
| <ul style="list-style-type: none"> • Talk about issues related to food and feeding (83.5%) • Talk about the importance of placing your child on his or her back when going to sleep (80.2%) | <ul style="list-style-type: none"> • Talk about what your child is able to understand (22.4%) • 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”)

- | | |
|--|--|
| <ul style="list-style-type: none"> • Talk about vitamins and foods your child should eat (66.9%) • Talk about sleeping with a bottle (64.0%) | <ul style="list-style-type: none"> • Talk about the use of Syrup of Ipecac if your child swallows some poison (34.2%) • 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”)

- | | |
|--|--|
| <ul style="list-style-type: none"> • Talk about issues related to food and feeding (54.4%) • Talk about words or phrases your child uses and understands (43.7%) | <ul style="list-style-type: none"> • Talk about the use of Syrup of Ipecac if your child swallows some poison (32.9%) • Talk about guidance and limit setting techniques (28.9%) |
|--|--|

**Questionnaire items receiving
highest quality of care ratings**

**Questionnaire items receiving
lowest quality of care ratings**

Measures 4 and 5: Family Psychosocial Assessment

(Percentage saying “yes” doctor/other provider did ask)

(Percentage saying “no” doctor/other provider did not ask)

- Whether anyone in your family smokes (63.6%)
- If a family member uses alcohol or other drugs or substance excessively (36.6%)
- How your own childhood experiences may impact your relationship with your child (91.3%)
- If you have firearms in the your home (81.3%)

Measure 6: Family Centered Care

(Percentage saying doctors/other providers “always” do this)

(Percentage saying doctors/other providers “never” do this)

- Respect that you are the expert on your child (51.8%)
- Builds confidence as a parent (51.2%)
- Talk about childcare arrangements (61.3%)
- 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 <u>learning, development, or behavior</u>	43.4 %
✓ How their child <u>gets along with others</u>	37.7 %
✓ How their child <u>talks</u> and makes speech sounds	36.4 %
✓ How their child is learning <u>pre-school skills</u>	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 not receive information to address these concerns.

In the last 12 months, did your child's doctors or other health providers ask about your concerns related to your child's learning, development, and behavior?

	Yes	No	I Don't Remember
Parents with 4 or more concerns	44.8 %	39.1 %	16.1 %
Parents with 1 to 3 concerns	49.4 %	33.7 %	16.9 %
Parents without concerns	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?

	Yes	No	I Don't Remember
Parents with 4 or more concerns	45.5 %	38.1 %	16.4 %
Parents with 1 to 3 concerns	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 <u>doctor</u> or other <u>health provider</u>	67.3	72.8 **

* p <= .05; ** p <= .01

References and Appendices

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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 | 6.1a: Vitamins and foods your child should eat |
| 3b: The kinds of behaviors you can expect to see in your child | 6.1b: Your child's bed and nap time routine |
| 3c: How to dress, bathe, and feed your child | 6.1c: The words or phrases your child uses and understands |
| 3d: Things you can do to help your child grow and learn | 6.1d: Night waking and fussing |
| 3e: The importance of talking to, reading to, and playing with your child. | 6.1e: Sleeping with the bottle |
| 3f: Ways to keep your child from being injured | 6.1f: Weaning your child from a bottle |
| 3g: How to make your house safe | 6.2a: How your child may start to explore away from you |
| 3g: How to make your car safe (e.g. car seats) | 6.2b: How your child "gets into things" |
| 5.1a: Breast feeding | 6.2c: Guidance and limit setting techniques to use with your child |
| 5.1b: Issues related to food and feeding (such as the introduction of solid food) | 6.2d: Toilet training |
| 5.1c: The importance of placing your child on his or her back when going to sleep | 6.2e: The use of Syrup of Ipecac if your child swallows some poison |
| 5.1d: Where your child sleeps (such as the location and type of crib, whether there are stuffed animals in the crib, etc) | 6.2f: The importance of reading with your child |
| 5.1e: Night waking and fussing | 7.1a: Issues related to food and feeding |
| 5.2a: How your child responds to you, other adults, and caregivers | 7.1b: Bed time routing and how many hours of sleep your child needs |
| 5.2b: How your child communicates his or her needs | 7.1c: Things your child may start to do for himself or herself, like washing or dressing |
| 5.2c: What your child is able to understand | 7.1d: Toilet training |
| 5.2d: How to avoid burns, such as changing the hot water temperature in your home | 7.1e: The words or phrases your child uses and understands |
| 5.2e: The importance of showing a picture book and reading to your child. | 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 |

<p><u>PV2: Information from the Health Plan</u></p> <p>In the last 12 months did you see or read information about: (<i>Response Choice B</i>)</p> <p>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</p>	<p><u>PV3: Follow Up for Children at Risk for Developmental Delays</u></p> <p>Did your child's doctors or other health providers ever: (<i>Response Choice B</i>)</p> <p>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</p>
<p><u>PV4: Assessment of Family Well Being and Safety</u></p> <p>In the last 12 months, have your child's doctors or other health providers asked you: (<i>Response Choice B</i>)</p> <p>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</p>	<p><u>PV5: Assessment of Smoking and Substance Abuse in the Family</u></p> <p>In the last 12 months, have your child's doctors or other health providers asked you: (<i>Response Choice B</i>)</p> <p>22c: If a family member of the child smokes 22d: If a family member uses alcohol or other drugs or substances excessively</p>

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 you 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.⁵⁵ 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 twenty times 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 eight times more likely to have disabilities than children from 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® 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.

Age of Child	Risk Category			
	High Risk	Moderate Risk	Low Risk	No Risk
0-17 months old	Child identified as “high risk” if parent noted “A lot” or “A little” concern to two or more of the following: <ul style="list-style-type: none"> ➤ 13a ➤ 13b ➤ 13c ➤ 14d ➤ 15c 	Child identified as “moderate risk” if parent noted “A lot” or “A little” concern to one of the following: <ul style="list-style-type: none"> ➤ 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: <ul style="list-style-type: none"> ➤ 13d ➤ 14a ➤ 14b ➤ 14c ➤ 15a ➤ 15b 	Child identified as “no risk” if parent noted “not all concerned” to all PEDS® items: <ul style="list-style-type: none"> ➤ 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 two or more of the following: <ul style="list-style-type: none"> ➤ 13a ➤ 13b ➤ 13c ➤ 13d ➤ 15c 	Child identified as “moderate risk” if parent noted “A lot” or “A little” concern to one of the following: <ul style="list-style-type: none"> ➤ 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: <ul style="list-style-type: none"> ➤ 14a ➤ 14b ➤ 14c ➤ 14d ➤ 15a ➤ 15b 	Child identified as “no risk” if parent noted “not all concerned” to all PEDS® items: <ul style="list-style-type: none"> ➤ 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: <ul style="list-style-type: none"> ➤ 13a ➤ 13b ➤ 13c ➤ 13d ➤ 14b ➤ 15c 	Child identified as “moderate risk” if parent noted “A lot” or “A little” concern to one of the following: <ul style="list-style-type: none"> ➤ 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: <ul style="list-style-type: none"> ➤ 14a ➤ 14c ➤ 14d ➤ 15a ➤ 15b 	Child identified as “no risk” if parent noted “not all concerned” to all PEDS® items: <ul style="list-style-type: none"> ➤ 13a-d ➤ 14 a-d ➤ 15 a-c

Appendix E: The PHDS Questionnaire, with Topline Results

Entered 6.30.00

Your Voice Counts

A Survey About the Health Care Experiences of Families with Young Children

Instructions

1. In this survey, the word child is used to refer to the child or foster child named in the letter that came with this survey. Answer all the questions in the survey for only that child.
2. Please have the parent or guardian who is the most involved with your child's medical care fill out this survey.
3. Answer all the questions by checking the box like this:

Yes

No

4. You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow and then a note that tells you what question to answer next, like this:

Yes ↓

No → (Go to page 8 and continue with question 12)

So, if you choose to answer "No" to this question, then you will go to page 8 of this survey and continue the survey with question #12.

Before you begin, please answer this question:

Do you have a child that is between the ages of 1 month and 50 months old?

Yes → (Go to page 2 and
continue with question 1)

No → (Please STOP NOW and
RETURN this survey)

**Thank you for your help with this survey on
health care experiences of families with young children!**

SECTION I: BACKGROUND INFORMATION

Please answer all the questions in this survey by checking the box that fits your answer.

1. Is your child a boy or a girl?

50.9%	49.1%
(N=1741)	(N=1681)
Boy	Girl

A doctor or other health provider could be a general doctor, a specialist doctor, a pediatrician, a nurse practitioner, a physician assistant, a nurse, or any one else you would see for health care.

2. In the **last 12 months**, has your child been to see a doctor or other health provider?

96.4%	3.6%
(N=3300)	(N=123)
Yes ↓	No → (Go to page 8 and continue with question 12).

3. In the **last 12 months**, did your child's doctors or other health providers talk with you about the following:

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Your child's growth and development	81.6% (N=2684)	4.5% (N=148)	6.5% (N=215)	7.4% (N=242)
b) The kinds of behaviors you can expect to see in your child	62% (N=2024)	4% (N=130)	15.4% (N=501)	18.6% (N=608)
c) How to dress, bathe, and feed your child	34.4% (N=1125)	1.4% (N=45)	5.5% (N=180)	58.8% (N=1923)
d) Things you can do to help your child grow and learn	51.4% (N=1679)	2.8% (N=92)	16.5% (N=541)	29.3% (N=957)
e) The importance of talking to, reading to, and playing with your child	48.4% (N=1582)	1.5% (N=49)	10.7% (N=349)	39.4% (N=1289)
f) Ways to keep your child from being injured	47.6% (N=1549)	2.0% (N=66)	12.2% (N=396)	38.3% (N=1246)
g) How to make your house safe	41.9% (N=1370)	1.3% (N=44)	11.6% (N=380)	45.2% (N=1477)
h) How to make your car safe (e.g. car seats)	42.7% (N=1395)	1.2% (N=39)	9.3% (N=304)	46.9% (N=1532)

SECTION II: AGE SPECIFIC QUESTIONS

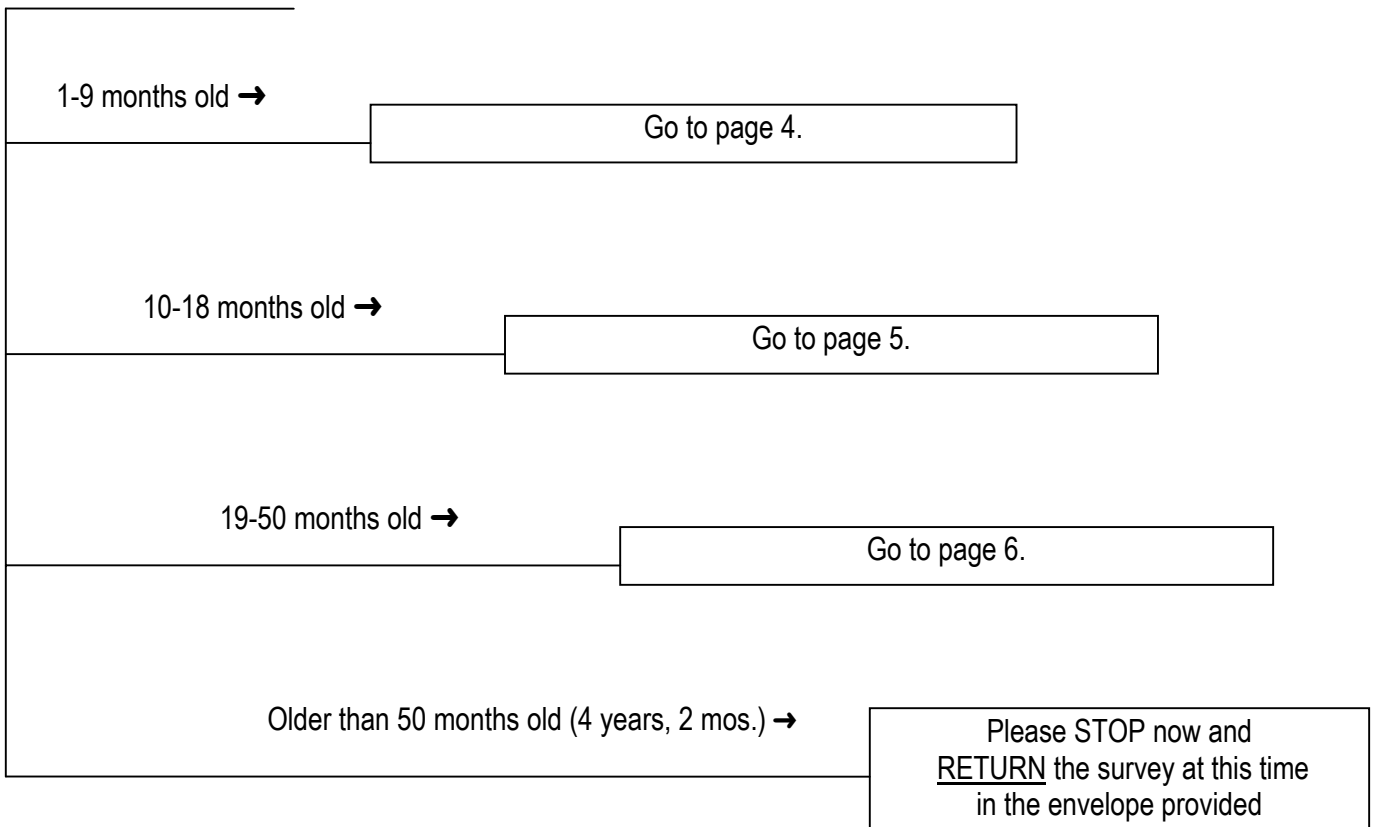
4. How old is your child:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<i>Years</i>		<i>Months</i>	

Your child’s doctors or other health providers may talk with you about certain topics that are important for you child’s development and growth. Some topics are specific to your child’s age. The next questions ask you about these age-specific topics and whether your child’s doctors or other health providers talked about them .

Use the diagram below and please find the page that matches the age of your child. Turn to this page and answer **ONLY** the questions found on this page. Then continue with the rest of the survey on page 7.

How old is your child?



5.0 79.2%(N=252) Yes, my child is 1-9 months old (Go to question 5.1 and complete this page↓)
 20.8%(N=66) No, my child is older than 9 months (Go to the page 5→)

5.1 In the last 12 months, did your child's doctors or other health providers talk with you about the following:

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Breast feeding	76.9% (N=263)	2.0% (N=7)	2.9% (N=10)	18.1% (N=62)
b) Issues related to food and feeding (such as the introduction of solid foods)	83.5% (N=283)	3.8% (N=13)	4.7% (N=16)	8.0% (N=27)
c) The importance of placing your child on his or her back when going to sleep	80.2% (N=271)	0.6% (N=2)	7.4% (N=25)	11.8% (N=40)
d) Where your child sleeps (such as the location and type of crib, whether there are stuffed animals in the crib, etc.)	62.2% (N=211)	1.8% (N=6)	12.1% (N=41)	23.9% (N=81)
e) Night waking and fussing	55.9% (N=189)	4.4% (N=15)	16.3% (N=55)	23.4% (N=79)

5.2 In the last 12 months, did your child's doctors or other health providers talk with you about the following:

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) How your child communicates his or her needs	67.8% (N=229)	2.1% (N=7)	12.4% (N=42)	17.8% (N=60)
b) What your child is able to understand	57.6% (N=196)	2.1% (N=7)	22.4% (N=76)	17.9% (N=61)
c) How your child responds to you, other adults, and caregivers	57.7% (N=195)	2.4% (N=8)	18% (N=61)	21.9% (N=74)
d) How to avoid burns, such as changing the hot water temperature in your home	54.1% (N=185)	1.5% (N=5)	17.3% (N=59)	27.2% (N=93)
e) The importance of showing a picture book and reading to your child	57.1% (N=196)	2.0% (N=7)	12.5% (N=43)	28.3% (N=97)

Now go to question 8 on page 7.

6.0 86.8%(N=413) Yes, my child is 10-18 months old (Go to question 6.1 and complete this page ↓)
 13.2%(N=63)No, my child is older than 18 months (Go to page 6→)

6.1 In the last 12 months, did your child’s doctors or other health providers talk with you about the following:

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Vitamins and foods your child should eat	66.9% (N=361)	4.3% (N=23)	15.7% (N=85)	13.1% (N=71)
b) Your child’s bed and nap time routine	45.1% (N=243)	2.2% (N=12)	20% (N=108)	32.7% (N=176)
c) The words or phrases your child uses and understands	52.2% (N=281)	3.5% (N=19)	18.6% (N=100)	25.7% (N=138)
d) Night waking and fussing	43.5% (N=233)	3.2% (N=17)	22.4% (N=120)	31% (N=166)
e) Sleeping with a bottle	64% (N=340)	1.3% (N=7)	8.1% (N=43)	26.6% (N=141)
f) Weaning your child from a bottle	51% (N=272)	2.1% (N=11)	15.2% (N=81)	31.7% (N=169)

6.2 In the last 12 months, did your child’s doctors or other health providers talk with you about the following:

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) How your child may start to explore away from you	38.9% (N=206)	2.6% (N=14)	29.5% (N=156)	28.9% (N=153)
b) How your child “gets into things”	47.3% (N=251)	2.4% (N=13)	19.6% (N=104)	30.7% (N=163)
c) Guidance and discipline techniques to use with your child	36.7% (N=194)	1.9% (N=10)	27.8% (N=147)	33.6% (N=178)
d) Toilet training	26.9% (N=140)	2.1% (N=11)	33% (N=172)	38% (N=198)
e) The use of syrup of Ipecac if your child swallows some poison	42.5% (N=224)	1.7% (N=9)	34.2% (N=180)	21.6% (N=114)
f) The importance of reading with your child	52.1% (N=276)	1.3% (N=7)	12.5% (N=66)	34.2% (N=181)

Now go to question 8 on page 7.

7.0 86.4%(N=2301)Yes, my child is 19-50 months old (**Go to question 7.1 and complete this page ↓**)
 0.2%(N=5)No, my child is older than 50 months (**Please STOP now return the survey at this time.**)

7.1 In the <u>last 12 months</u> , did your child’s doctors or other health providers talk with you about the following:	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Issues related to food and feeding	54.4% (N=1417)	3.6% (N=93)	12% (N=312)	30.1% (N=785)
b) Bed time routine and how many hours of sleep your child needs	32.3% (N=839)	2.6% (N=68)	24.7% (N=643)	40.4% (N=1051)
c) Things your child may start to do for himself or herself, like washing or dressing.	42% (N=1093)	2.3% (N=59)	18% (N=470)	37.7% (N=982)
d) Toilet Training	36.7% (N=953)	3.5% (N=91)	20.8% (N=541)	38.9% (N=1011)
e) The words or phrases your child uses and understands	43.7% (N=1137)	3.5% (N=90)	18.4% (N=480)	34.4% (N=896)
f) How your child is learning to get along with other children (For example at home, in play groups, at day care, or pre-school)	36.7% (N=953)	2.0% (N=51)	24.5% (N=637)	36.8% (N=956)

7.2 In the <u>last 12 months</u> , did your child’s doctors or other health providers talk with you about the following:	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) How well your child follows directions	35.3% (N=911)	2.6% (N=68)	28.2% (N=727)	33.9% (N=876)
b) Guidance and discipline techniques to use with your child	31.3% (N=809)	3.0% (N=77)	28.9% (N=747)	36.7% (N=948)
c) Ways to teach your child about dangerous situations (such as electrical sockets, the stove, hot water, pools, and the street)	29% (N=748)	1.7% (N=43)	25.4% (N=656)	43.9% (N=1131)
d) The use of syrup of Ipecac if your child swallows some poison	34.3% (N=884)	1.9% (N=50)	32.9% (N=848)	30.8% (N=795)
e) The importance of reading with your child	40.3% (N=1037)	1.4% (N=37)	11.3% (N=290)	47% (N=1211)

Now go to question 8 on page 7.

SECTION III: HEALTH COMMUNICATION AND INFORMATION

The next questions ask about your experiences with the health care your child has received from your child's doctor or other health providers in the past year. .

8. In the last 12 months, how often did your child's doctors or other health providers. . .

	Never	Sometimes	Usually	Always
a) Take time to understand the specific needs of your child	4.9% (N=164)	19.5% (N=650)	31.3% (N=1044)	44.3% (N=1477)
b) Respect you as an expert about your child	5.9% (N=197)	14.5% (N=485)	27.7% (N=924)	51.8% (N=1729)
c) Build your confidence as a parent	9.8% (N=326)	15.7% (N=523)	23.4% (N=779)	51.2% (N=1705)
d) Ask you about how you are feeling as a parent	37.1% (N=1240)	21.2% (N=707)	13.1% (N=437)	28.7% (N=958)

9. In the last 12 months, how often did your child's doctors or other health providers. . .

	Never	Sometimes	Usually	Always
a) Give you specific information to address any questions you may have about your child	10.6% (N=353)	20.7% (N=689)	27.7% (N=922)	41% (N=1365)
b) Understand your family and how you prefer to raise your child	22.8% (N=755)	16.8% (N=557)	23.1% (N=765)	37.2% (N=1231)
c) Talk to you about childcare arrangements	61.3% (N=2016)	14.7% (N=483)	8.6% (N=283)	15.4% (N=507)
d) Talk to you about the WIC program, a nutrition and health program for Women, Infants, and Children. (Benefits include food, vouchers for food, healthcare referrals, and nutrition education)	41.9% (N=1394)	15.8% (N=525)	11.6% (N=385)	30.7% (N=1021)
e) Talk to you about resources for parents and families (parent support groups, alternative health care)	59.1% (N=1960)	16.9% (N=561)	8.9% (N=294)	15.1% (N=500)
f) 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)	59.6% (N=1988)	14.9% (N=498)	9.5% (N=317)	16% (N=532)

10. In <u>last 12 months</u> , how <i>helpful</i> were your discussions with your child's doctors or other health providers in:	Very Helpful	Helpful	Somewhat Helpful	Not at all helpful	We did not discuss
a) Helping you understand your child's behavior	26.7% (N=897)	25.5% (N=856)	20.5% (N=690)	3.8% (N=128)	23.5% (N=791)
b) Helping you learn how to meet your own needs while caring for your child	20.1% (N=675)	19.8% (N=665)	15% (N=503)	5.2% (N=175)	39.9% (N=1342)
c) Learning how to protect your child from injuries	26.8% (N=899)	23.4% (N=787)	13.8% (N=463)	3.0% (N=100)	33.1% (N=1111)
d) Giving you the information you needed <u>when</u> you needed it	42.7% (N=1434)	29.2% (N=979)	16.3% (N=548)	3.5% (N=116)	8.3% (N=279)

11. Overall, do you feel more or less confident in doing the following things <u>because</u> of the information or guidance you received from your child's doctors or other health providers?	I feel a lot more confident	I feel a little more confident	I do not feel more or less confident	I feel less confident
a) Managing your parenting responsibilities	37.3% (N=1240)	18.9% (N=627)	43.2% (N=1434)	0.7% (N=22)
b) Protecting your child from injury and accidents	38.5% (N=1281)	20.4% (N=678)	40.1% (N=1333)	1.0% (N=32)
c) Doing things for your child that help him or her grow and learn such as reading and talking to your child.	42.1% (N=1401)	19.7% (N=656)	37.2% (N=1238)	1.0% (N=33)
d) Addressing any special concerns you have about your child's development and behavior	42.7% (N=1420)	25.5% (N=849)	29.8% (N=993)	2.0% (N=67)

Health information can include written pamphlets, videos you could have seen in the waiting room, recorded information over the telephone while waiting to make an appointment, or information on the Internet. You could have seen or heard this information inside or outside your doctor's office.

12. In the <u>last 12 months</u> , did you see or hear any information about:	Yes	No
a) Safety Tips: How to make your house and car safe for your child (For example: information about lead poisoning or car seats or syrup of ipecac)	68.7% (N=2395)	31.3% (N=1090)
b) Health Care Tips: When and how often your child should see the doctor, immunization reminders, information about the WIC program, information about other health care services available for your child	83.4% (N=2904)	16.6% (N=580)
c) Child Care Tips: Helpful tips about how to care for your child.	70.6% (N=2459)	29.4% (N=1024)
d) Developmental Information: Information about your child's development and how you can help your child grow and learn.	76.6% (N=2668)	23.4% (N=817)

SECTION IV: HEALTH CONCERNS ABOUT THE CHILD

The next few questions ask about concerns parents sometimes have about their child.

13. * Do you have any concerns about . . .	Yes	A little	Not at all
a) Your child's learning, development or behavior?	18.9% (N=660)	24.5% (N=857)	56.6% (N=1978)
b) How your child talks and makes speech sounds?	19.4% (N=678)	17% (N=595)	63.6% (N=2224)
c) How your child sees or hears ?	18.4% (N=644)	11.8% (N=413)	69.8% (N=2439)
d) How your child understands what you say?	18.1% (N=632)	13.9% (N=486)	68% (N=2374)

14. * Do you have any concerns about . . .	Yes	A little	Not at all
a) How your child uses his or her hands and fingers to do things?	9.1% (N=319)	4.9% (N=173)	85.9% (N=3008)
b) How your child uses his or her arms and legs?	11.3% (N=397)	4.9% (N=173)	83.7% (N=2932)
c) How your child behaves?	19% (N=663)	25.8% (N=902)	55.2% (N=1930)
d) How your child gets along with others?	16.8% (N=587)	20.8% (N=728)	62.3% (N=2177)

15. * Do you have any concerns about	Yes	A little	Not at all
a) How your child is learning to do things for himself/herself?	12.3% (N=432)	13% (N=454)	74.7% (N=2612)
b) How your child is learning pre-school skills?	14.5% (N=499)	18.3% (N=630)	67.2% (N=2313)
c) How your child is behind others (can't do what other kids can)?	8.9% (N=310)	11.9% (N=414)	79.1% (N=2743)

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16. In the last 12 months, did your child’s doctors or other health providers ask if you have concerns about your child’s learning, development, and behavior?

48.7% (N=1706) 36.3% (N=1271) 15% (N=525)
 Yes No I don’t remember

17. In the last 12 months, did your child’s doctors or other health providers give you specific information to address your concerns?

40.2% (N=1396) 22.1% (N=767) 10% (N=348) 27.8% (N=965)
 Yes No I don’t remember I did not have any concerns

18. In the last 12 months, did your child’s doctors or other health providers tell you that they were doing an assessment or test of your child’s development?

22.8% (N=799) 66% (N=2309) 11.2% (N=392)
 Yes No I don’t remember

19. In the last 12 months, did your child’s doctors or other health providers have your child pick up small objects, stack blocks, throw a ball or recognize different colors?

21.3% (N=745) 75.0% (N=2620) 3.7% (N=128)
 Yes No I don’t remember

20. Did your child’s doctors or other health providers ever:

	Yes	No
a) Refer your child to another doctor or other health provider	27.4% (N=951)	72.6% (N=2525)
b) Test your child’s learning and behavior	21% (N=733)	79% (N=2762)
c) Note a concern about your child that should be watched carefully	15.6% (N=545)	84.4% (N=2956)
d) Refer your child for speech-language or hearing testing	10.9% (N=382)	89.1% (N=3114)
e) Give you advice about how to help your child	39.3% (N=1372)	60.7% (N=2119)

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SECTION V: YOUR FAMILY

A child's doctors or other health providers sometimes ask questions about a child's family. These questions help provide the best care possible for your child. These questions can be asked in a survey that you fill out before the visit, in the waiting room, or when you talked with your child's doctor or other health provider during your child's visit.

21. In the last 12 months have your child's doctors or other health providers asked you :

	Yes	No
a) If you ever feel depressed, sad, or have crying spells	19% (N=664)	81% (N=2834)
b) To talk about your own childhood experiences with him or her and how they relate to your interaction with your child	8.7% (N=303)	91.3% (N=3184)
c) If any family member of the child smokes	63.6% (N=2226)	36.4% (N=1272)
d) If a family member uses alcohol or other drugs or substances excessively	36.6% (N=1280)	63.4% (N=2219)
e) If you feel safe at home	27.8% (N=970)	72.2% (N=2524)

22. In the last 12 months have your child's doctors or other health providers asked you :

	Yes	No
a) If you have someone to turn to for emotional support	30.4% (N=1064)	69.6% (N=2434)
b) To talk about any changes or new stressors in your family or home	27.2% (N=950)	72.8% (N=2544)
c) If you have any firearms in your home	18.7% (N=654)	81.3% (N=2839)
d) How parenting works into your daily activities and future plans in life	22.5% (N=786)	77.5% (N=2704)
e) To talk about how you and your family are enjoying raising your child	36.3% (N=1270)	63.7% (N=2225)

SECTION VI: HOUSEHOLD ACTIVITIES AND INFORMATION

These next questions ask about some of the activities in your family.

23. When laying your child down to sleep at night or for a nap, in what position do you usually place your child ?

48.5% (N=1638) 4.3% (N=146) 17.9% (N=604) 23.5% (N=792) 5.7% (N=194)
 On Back On Stomach On Side No Special Position Other _____

23a. 0-9 Months

71.4% (N=157) 5.5% (N=12) 20.5% (N=45) 1.8% (N=4) 0.9% (N=2)
 On Back On Stomach On Side No Special Position Other _____

24. How many times in the past week did you look at or read a book with your child?

7.6% (N=263) 21.3% (N=741) 25.7% (N=894) 23.3% (N=811) 22.2% (N=774)
 Not at all Once or Twice Several Times About once a day More than once a day

Have you	Yes	No
25. Put household cleaning products or medicines out of reach or in a locked cabinet?	91% (N=3191)	9% (N=314)
26. Turned down the hot water temperature on your hot water heater?	61.3% (N=2138)	38.7% (N=1347)
27. Kept syrup of Ipecac in your home?	57.2% (N=1908)	42.8% (N=1426)
28. Put up baby gates or other safety barriers in your home?	62% (N=2161)	38% (N=1322)

29. How long did you breastfeed your child?

21.4% (N=736) 13% (N=448) 57.9% (N=1992) 7.7% (N=264)
 My child was not breastfed Less than a month More than a month I am still breastfeeding

30. Does anyone living in your household smoke?

35.1% (N=1228) 64.9% (N=2271)
 Yes No

--

These next questions help us to better understand your child and his or her health care needs.

31. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?

16.6%

83.4%

Yes → Go to Question 31a

No → Go to Question 32

31 a. Is this because of ANY medical, behavioral or other health condition?

64.5%

35.5%

Yes → Go to Question 31b

No → Go to Question 32

31b. Is this a condition that has lasted or is expected to last for at least 12 months?

52.9%

7.1%

Yes

No

32. Does your child need or use more **medical care , mental health or educational services** than is usual for most children of the same age?

9.4%

90.6%

Yes → Go to Question 32a

No → Go to Question 33

32a. Is this because of ANY medical, behavioral or other health condition?

64.9%

35.1%

Yes → Go to Question 32b

No → Go to Question 33

32b. Is this a condition that has lasted or is expected to last for at least 12 months?

61%

39%

Yes

No

33. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?

4.2%

95.8%

Yes → Go to Question 33a

No → Go to Question 34

33a. Is this because of ANY medical, behavioral or other health condition?

45.2%

54.8%

Yes → Go to Question 33b

No → Go to Question 34

33b. Is this a condition that has lasted or is expected to last for at least 12 months?

50.9%

49.1%

Yes

No

[Empty box for Confidential ID Code]

34. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
 4.7% 95.3%
 Yes → Go to Question 34a No → Go to Question 35

34a. Is this because of ANY medical, behavioral or other health condition?
 43.1% 56.9%
 Yes → Go to Question 34b No → Go to Question 35

34b. Is this a condition that has lasted or is expected to last for at least 12 months?
 52.3% 47.7%
 Yes No

35. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
 2.8% 97.2%
 Yes → Go to Question 35a No → Go to Question 36

35a. Has this problem lasted or is it expected to last for at least 12 months?
 33% 67%
 Yes → Go to Question 35 No → Go to Question 36

These next questions are about you. They are being asked for grouping purposes only.

36. Is the child named in this survey your first child?
 40.3% (N=1373) 57.3% (N=1952) 2.4% (N=81)
 Yes No The question does not apply to me

37. How many children under the age of 18 are living in your household (including the child named in this survey)?
 31.2% (N=1048) 35% (N=1173) 19.4% (N=652) 8.2% (N=276) 6.1% (N=205)
 1 2 3 4 5 or more

38. Are you male or female?
 4.6% (N=155) 95.4% (N=3247)
 Male Female

39. What is your age right now?

2.3% (N=79)	29.1% (N=1015)	48.6% (N=1698)	17.9% (N=624)	1.7% (N=60)	0.3% (N=12)	0.1% (N=3)	0.0% (N=0) 75 or older
Under 18	18 to 24	25-34	35-44	45-54	55-64	65-74	

40. How are you related to the child named in this survey?

93.3% (N=3229)	3.8% (N=132)	0.5% (N=17)	0.2% (N=7)	1.5% (N=53)	0.6% (N=22)	0.1% (N=2)
Mother	Father	Aunt or uncle	Older brother or sister	Grandmother or Grandfather	Guardian	Other relative

41. What is the highest grade or level of school that you have completed?

6.7% (N=234)	13.5% (N=469)	32.2% (N=1118)	38.7% (N=1345) Some college or 2-year degree	6.4% (N=222)	2.5% (N=88) More than a 4-year college degree
8 th grade or less	Some high school, but did not graduate	High School graduate or GED		4 year college graduate	

42. How do you describe yourself? Select all that apply.

66.7% (N=2325)	4.0% (N=138)	3.4% (N=118)	3.5% (N=122)	19.6% (N=682)	0.9% (N=31)	2.0% (N=69)
White	Black or African American	Asian	American Indian or Alaskan Native	Hispanic or Latino	Native Hawaiian or Other Pacific Islander	Other

43. What is your current marital status?

20.8% (N=714)	56.6% (N=1943)	11.7% (N=400)	0.5% (N=17)	6.6% (N=226)	3.8% (N=130)
I have never been married	Married	Living with significant other	Widowed	Divorced	Separated

YOU'RE DONE!!
Thank you for completing the survey.
You have helped to make a difference

Please return the completed survey
in the envelope provided.