

Consumer-Centered Data and Strategies to Advance Evidence-Based Advocacy in Child Health



Highlights from the Child and Adolescent Health Measurement Initiative Toolbox

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AAP Chapter Advocacy Summit
November 10, 2007
Williamsburg, VA





Presentation Goals

- 1) Link consumer-centered data and data collection and reporting strategies to priority AAP advocacy topics
- 2) Streamline access to these data and strategies
- 3) Share example frameworks and models

Highlights from the CAHMI Toolbox



- 1) About the CAHMI
- 2) Online Data Resource Center for Child and Adolescent Health to access national and state level data
- 3) Consumer-centered quality measurement framework and data collection and reporting tools



About the CAHMI

Who We Are:

The Child and Adolescent Health Measurement Initiative (CAHMI) is a national, not-for-profit initiative based out of Oregon Health and Science University in the Department of Pediatrics in Portland, OR. Originally housed at FACCT - Foundation for Accountability, the CAHMI was established in 1998.

Our Mission:

"To ensure that children, youth and families are at the center of quality measurement and improvement efforts in order to advance high quality consumer-centered health care."





How does the CAHMI achieve this mission?

- The CAHMI keeps the focus on consumer-centered health care.
 - Articulates and advances a consumer-centered quality framework
 - Participates in national committees & advisory boards.
 - Provides assistance in the development of consumer-centered strategies.
- The CAHMI builds the supply for consumer-centered measurement strategies.
 - Developing reliable, valid, and consumer-centered measures of health and health care quality.
 - Identifying and facilitating the filling of gaps in current measures.
 - Provides technical assistance and benchmarking databases for quality measures.



How does the CAHMI achieve this mission?

- The CAHMI builds the demand for consumer-centered measurement and improvement.
 - Advances strategies for putting data into action.
 - Designs, tests, and demonstrates the impact of consumer-centered tools in practice.
 - Creates and evaluates patient-centered strategies to improve health systems.



Key Topics Addressed by CAHMI Data and Measurement Tools

- **Coverage and Access**

- Insurance coverage, gaps in coverage and impact of uninsurance and type of coverage
- Adequacy of insurance
- Timely access to covered/needed care

- **Quality and Equity**

- Medical home for all children and children and youth with special health care needs
- Mental, emotional and behavioral health
- Health disparities for vulnerable populations (minorities, low income, by health status/CSHCN)



Key Topics Continued...

- **Prevention and Healthy Development**
 - Childhood obesity (BMI, Activities, TV watching, etc)
 - Early childhood development
 - Transition to adulthood

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The Data Resource Center for Child and Adolescent Health

www.childhealthdata.org





Why is Data Useful?

- 1. ADVOCACY:** Data strengthens your position that change is needed.
- 2. REPRESENTATION:** Data describes who you are and why your views are important.
- 3. JUSTIFICATION:** Data supports your assertion that specific changes or programs you advocate for are worthwhile.

Why is Data Useful?



Stories give a face and heart to needs.

Data expands your stories to inform policy debates and drive change.



Using data to enhance the human story

THE STORY:

Many children lack health insurance or have insurance that is inadequate. Let me tell you about Jenny.....

VS.

THE STORY WITH DATA:

- Like Jenny, many CSHCN lack adequate health insurance.
 - Nationally, **over 1 in 10** (11.6%) children with special health care needs (CSHCN) in America have no health insurance.
 - There is nearly a **four fold difference** in the rate of uninsured children across states in America.
 - 6.3% (HI) to 22.8 %(TX)

Using data to enhance the human story

- Of CSHCN that are insured:
 - Over **1 in 3** (33.8%) have insurance that does not adequately meet their needs.
 - This ranges from 1 in 4 [26% -MN] to two in five [41.7%-IL] across states.



This translates into nearly 77,825 school buses filled with CSHCN with inadequate health insurance –enough to span the entire length of California.

All of this data was obtained in less than one minute on the CAHMI Data Resource Center –www.childhealthdata.org



What is the DRC?

MCHB Sponsored Interactive Online Data Resource Center providing:

- 1. “Point and Click”, User-Friendly Access to Data**
 - National Survey of Children with Special Health Care Needs (NS-CSHCN)
 - National Survey of Children’s Health (NSCH)
- 2. Resources and Information about Data**
- 3. Education**
 - Obtain technical assistance for understanding, interpreting and using data, online workshops, and opportunities to partner with other stakeholders to discuss, interpret and act on data findings

In-depth CSHCN interview collects information nationally and across states for 2001 and 2005/06:



- Child health and functional status
- Child health insurance status and adequacy of coverage
- Access to health care — needed services & unmet needs
- Medical Home: comprehensive, coordinated, family centered care
- Impact of child's health on family
- MCHB core outcomes for CYSHCN
- Key indicators of CSHCN health & system performance

NEW DATA RELEASED NOVEMBER 28th 2007!!

● ● ● | **Survey yields over 100 indicators of child health & well-being at the national and state levels for 2003/0 and 2007/8:**

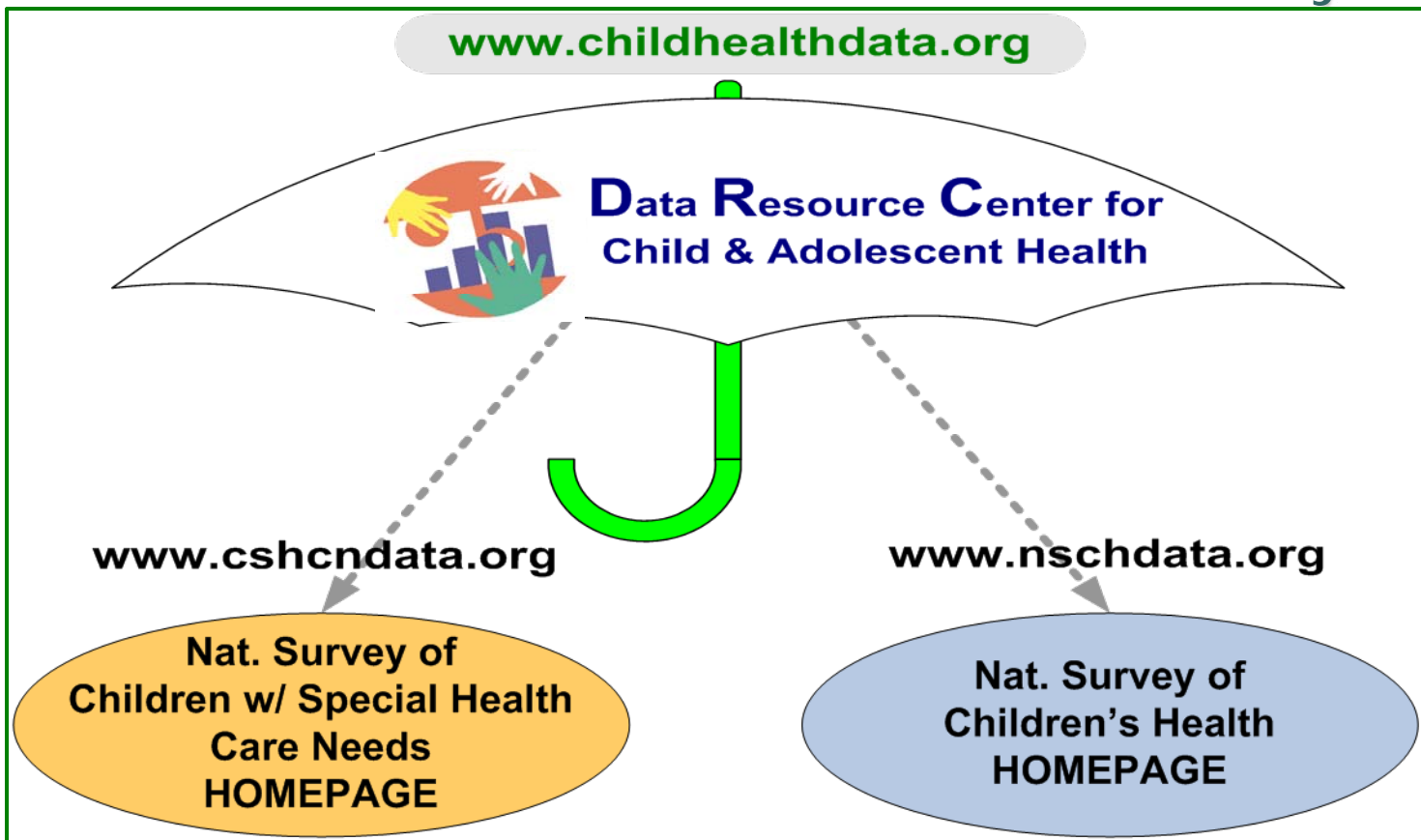


- Child's health status: **physical, emotional, dental**
- Child's health care – **including medical home**
- Child's school & activities
- Child's family & neighborhood -- **including maternal health status**
- Early childhood (ages 0-5)
- School-age (ages 6-17)

Data Resource Center Tour

WEBSITE - www.childhealthdata.org

serves as an umbrella site for national survey data





CAHMI's Consumer-Centered Quality Measurement Framework and Tools

- Three primary measurement tools yield over 45 integrated measures for numerous child subgroups. Focus On:
- Early Childhood Development
- Children and Youth with Special Health Care Needs
- Adolescent Preventive Care



CAHMI's Consumer Quality Information Framework

- **Focus of measurement:** Collect data on key aims for quality across **consumer relevant** quality domains
- **Data Collection Strategy:** Collect data in ways that create a **profile of performance** at the child level.
- **Scoring and Reporting:** Report data in ways that **tell a story** to engage partners to act on information provided.



CAHMI's Consumer Quality Information Framework*

- Consumer Relevant Quality Domains
 - **The Basics** (access, customer service, etc.)
 - **Healthy Development/Staying Healthy** (prevention)
 - **Getting Better** (acute care)
 - **Living with Illness** (CSHCN)
 - **Changing Needs** (e.g. major disability; end of life)
- Key Domains
 - **Results** of Good Care (effective, equitable, safe)
 - **Steps** to Good Care (effective processes, efficient)
 - **Experience** of Care (patient-centered, timely, equitable)

*Used in national quality reports and by AHRQ, NCQA and IOM. Developed by CAHMI staff while at FACCT.



Agency for Healthcare Research and Quality

Quality Research for Quality Healthcare

National Healthcare Quality Report Framework

Components of Health Care Quality

Health care needs

Effectiveness

Safety

Timeliness

Patient centeredness

Staying healthy

Getting better

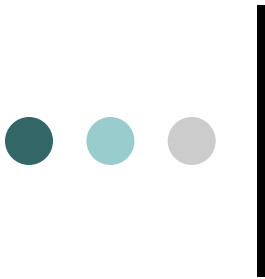
Living with illness
or disability

End of life care

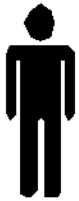
	Effectiveness	Safety	Timeliness	Patient centeredness
Staying healthy				
Getting better				
Living with illness or disability				
End of life care				

- Equity is a component of health care quality that applies to all cells in the matrix
- Resource generation is another component discussed in the National Healthcare Report
- The first NHQR is due to Congress in 2003.





Health Care Providers



Right people



Parents/Guardians of
Young Children

Successful use of quality care information

Right way



- Multi-media approach that presents the information in multiple ways

Right time



-- Before or during well-child visit
-- Information provided more than one-time



Right information



- General and framing information
- Quality of care findings coupled with specific information about individual aspects of care
- Tips and notes about specific actions that can be taken to improve care



All CAHMI's Consumer-Centered Tools are in the public domain-WWW.CAHMI.ORG

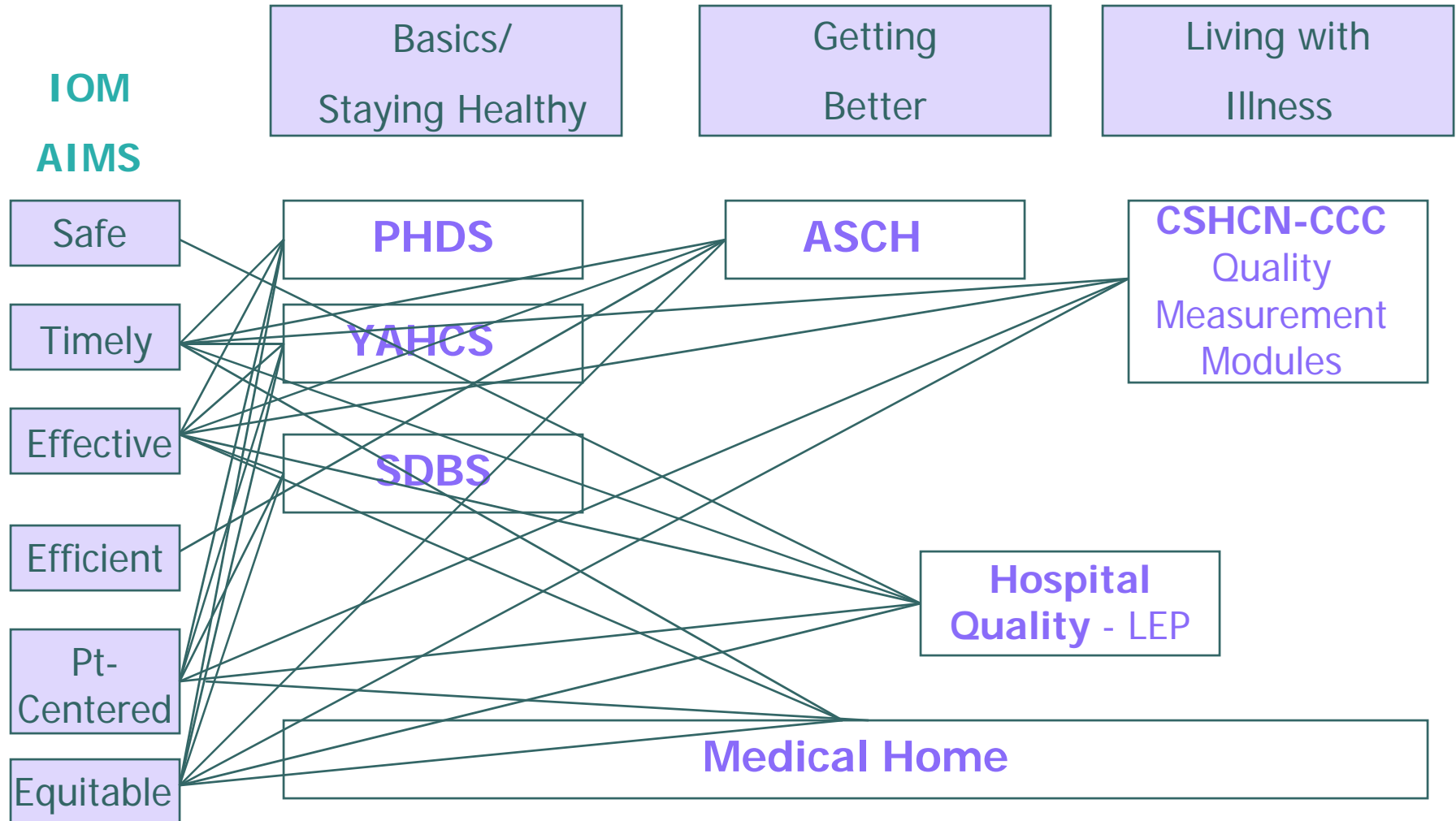
- **Promoting Healthy Development Survey (PHDS)** * State, Health Plan, and Provider/Office Level Applications
- **Standardized Developmental and Behavioral Screening Measure (SDBS)**
- **Young Adult Health Care Survey (YAHCS)***
- **CSHCN Screener*** (integrated into numerous national surveys). Adolescent & Adult versions also available.
- **CSHCN Quality Module/CAHPS CCC***: includes alternative sampling and/or scoring models to obtain information on all measures for CSHCN as well as Medical Home and other measures
- **Medical Home Measurement Module**
- **Standardized Ambulatory Care Sensitive Condition Hospitalization measure (ASCH)** (negative indicator of overall primary care access and quality)
- **Hospital Quality for LEP Children** (toolkit and paper; survey in filed testing phase)

All tools are non-proprietary. Papers, reports, and/or toolkits are available.

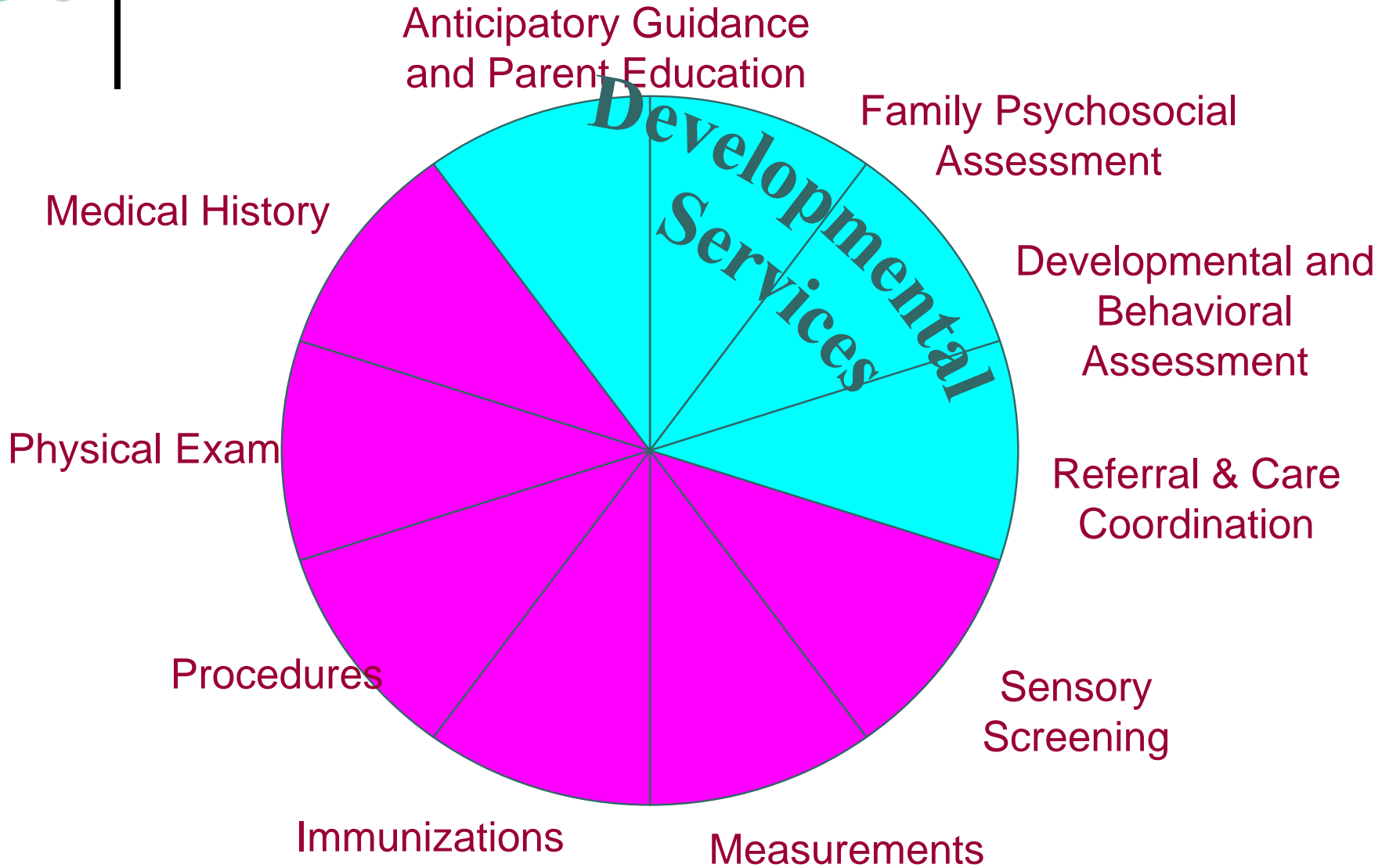
* Endorsed by the National Quality Forum for voluntary use.

National Frameworks and Aspects of Care: CAHMI Tools

CONSUMER INFORMATION FRAMEWORK



EXAMPLE: Measuring the Quality of "Well" Child Care Services



Your Child's Health Care



19. How many days in the *last week* have you felt depressed?

0 Days	1 Day	2 Days	3 Days	4 Days	5 Days	6 Days	All 7 Days
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8

20. In the *last 12 months*, have you had two weeks or more during which you felt sad, blue, depressed or lost pleasure in things you usually cared about or enjoyed?

Yes	No
<input type="checkbox"/> 1	<input type="checkbox"/> 2

21. How much trouble have you had paying for...

	A Lot of Trouble	Some Trouble	No Trouble
a) Child's health and medical expenses	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b) Supplies like formula, food, diapers, clothes and shoes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c) Healthcare for yourself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Thank you for completing the survey.

Please return the survey to us in the postage paid envelope provided.

You have helped make a difference.

You're Done!

CONFIDENTIAL I.D. CODE

DATA SET #5013



Your Child's Health Care

- ♥ This survey is about discussions you may have had with your child's doctors or other health providers in the *last 12 months*.
- ♥ By completing this survey, you are indicating that you have given your consent to participate.
- ♥ This survey is confidential. Do *not* write your name or your child's name on this survey.
- ♥ If you choose to not answer the survey, the decision will have no effect on the health care you or your child receive or on your health care benefits.
- ♥ If you begin to answer the questions and then change your mind, you may stop at any time. Also, if there are particular questions that you don't want to answer, you may skip them. If you choose to skip or not answer any questions it will have no effect on the health care you or your child receive or on your health care benefits.

INSTRUCTIONS:

1. Please use a BLUE or BLACK ink pen to complete this survey.
2. Answer all the questions by checking the box below your answer—like this:

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>



Example from the Promoting Healthy Development Survey

• Six quality of care measures evaluated

- **Measures 1-3: Anticipatory guidance and parental education** measures using a “needs met” scoring approach.
 - Physical care of child
 - Injury Prevention
 - Child development and behavior
- **Measure 4-5: Developmental surveillance and screening;** whether provider asked parents about any concerns they may have about their child’s development and/or behavior
- **Measure 6-7: Assessment of the Family:** Whether provider asked about one of five core topics on family and parent emotional and mental well-being and smoking, alcohol and drug abuse in the home
- **Measure 8: Family Centered Care:** Whether provider interacts with the parent and child in a respectful manner, engages the parent as a partner in care and listens to and addresses parent concerns.

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“Swamping” the System: Same PHDS Metrics Applied at All Levels of Change



National, State, geographic region, county



**Health plan, type of health care provider
(Pediatrician, Family Medicine)**



**Medical group, office, individual
health care provider**



**Patient:
Parent & Child**

Your Child's Health Care

Promoting Healthy Development Survey

Promoting Healthy Development Survey



Welcome!

This site is where parents can fill out the Promoting Healthy Development Survey.

The survey is about health care for young children (0-3 years).

Your child's health care provider may have asked you to fill out this survey or you may have read about this website and want take the survey to learn about the health care your child receives and how it can be improved.

The survey findings are used to help health care providers improve the care they provide to young children.

Parents get something from filling out this survey too! A **personalized report** will be created for you based on your responses. This report will guide you in **partnering** with your child's health care provider to improve your child's health care.

Get Started!

Click Here to Take the Survey

Do you have questions before you want to continue?

- ▶ [Who developed and maintains this website?](#)
- ▶ [What is the Promoting Healthy Development Survey?](#)
- ▶ [Who developed the survey?](#)
- ▶ [How is the information gathered on this website used? \(Privacy Statement\)](#)



Are you returning to complete your survey?

Enter your survey
ID code here:

Submit

Your Child's Health Care

Promoting Healthy Development Survey

GENERAL INFORMATION ABOUT YOUR CHILD'S HEALTH CARE

1. In the last 12 months, how many times did your child go to an emergency room?

- 0 times 1 time 2-3 times 4-5 times 6-10 times 10 or more times

2. In the last 12 months, (not counting the times your child went to an emergency room) how many times did your child go to a doctor's office or clinic?

- 0 times 1 time 2-3 times 4-5 times 6-10 times 10 or more times

3. In the last 12 months, how many times was your child a patient in a hospital overnight or longer?

- 0 times 1 time 2-3 times 4-5 times 6-10 times 10 or more times

4. In the last 12 months, has your child needed care right away for an illness or injury?

- Yes → **Go to Question 4a** No → **Go to Question 5**

4a. When your child needed care right away for an illness or injury, **how often** did your child get this care as soon as you wanted?

- Never Sometimes Usually Always

5. 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 service?

- Yes → **Go to Question 5a** No → **Finished with this section**

5a. 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?

- Yes No My child did not get care from different providers or use more than one service

0% Complete



Your Customized Feedback Report

Helping You Know What to Expect and Be a Partner with Your Child's Health Care Providers

Thank you for answering the survey. Use this feedback report to remember questions you should ask during your child's next visit. By partnering with your child's health care providers, you can make sure your child gets the care that is recommended to ensure their well-being and healthy development.

[Print](#) [Close](#)

Well-child visits are a great opportunity to get information and guidance about your child

Your Child's Physical Needs

Based on your survey responses, you had your needs met on 2 of the recommended topics about your child's physical needs.

Listed below are the topics you wanted more information.

Be a Partner- Ask Your Child's Health Care Providers About:

- Bedtime routines and good sleep habits
- Issues related to preschool
- Whether and how much your child watches Television or videos

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.



Your Child's Development and Behavior

Based on your survey responses, you had your needs met on 3 of the recommended topics related to development and behavior. Listed below are the topics you wanted more information.

Be a Partner- Ask Your Child's Health Care Providers About:

- Reading with your child
- Things your child may start to do for himself/herself such as washing and dressing
- Toilet training
- Ways to guide and discipline your child



Example Parent-Centered Intervention to Improve Quality

Enhanced “Encounter” (informed parents & providers / proactive participants)

Time frame A:

During week prior to well child visit:



- 1) Parents go to website for **pre-visit interactive session** designed to give individualized, tailored information based on parents' answers to:

- Current concerns about child
- Anticipatory guidance and parental education needs
- Brief assessment of child's development
- Assessment of family risk factors

Parents can link to & print out **tailored educational materials** that respond to priorities and interests identified during session

- 2) After completing pre-visit interactive session, parents print out a customized copy of **“What to Discuss at your Child's Visit: a Personalized Guide”** – and results of the child and family assessment to review and bring to well child visit.

- 3) Pediatric clinicians use **link in the EMR to review interactive session results** for developmental screening, family risk assessment, and priority educational needs prior to well child visit.

Time frame B:

During well child visit:



- 4) Parent and pediatric clinician use **results from pre-visit interactive session** to prioritize and individualize content of well child visit



Advocacy Success Stories



Legislative Roles to Support Child Health Care Quality

1. Establish and regulate policies and allocate and monitor resources the support quality health care for children and adolescents
2. Assure that reimbursement policies support provision of good quality services
3. Assure that the provision and quality of services is monitored
4. Foster effective referrals and care coordination across health, public health, education, and human services



National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data... Your story

- [DRC Home](#)
- [Link to Us](#)
- [Glossary](#)
- [Search](#)
- [Contact Us](#)

- [CSHCN Survey Home](#)
- [Start Data Query](#)
- [State Profiles](#)
- [Quick Guides](#)
- [Resources for Data Users](#)
- [Especially for Families](#)
- [State Data Sets](#)

- [ONLINE TOUR](#)
- [ASK A QUESTION](#)
- [ANSWER OUR REPTIFF USER POLL](#)
- [TELL A FRIEND](#)
- [YOUR BRIEFCASE](#)



Data in Action

Compelling stories and examples of ways others are using data from the Data Resource Center to make a difference!

Massachusetts Mom Storms the State House

Carrie Howland included data from the Data Resource Center in a presentation at the National Respite Coalition event in Washington DC, in support of the National Lifespan Respite Care Act.

Alaska's Covering Kids Coalition Meeting

Presented by Barbara Hale
October 4, 2005

Massachusetts Office of Medicaid: Helping Families of Children with Special Health Care Needs Get Back to Work. A Cost Neutral Approach to Family Empowerment

2006

Save the CDRC

Dr. Brian Rogers used state-by-state comparisons from the National Survey of Children with Special Health Care Needs in is preparation for a legislative hearing on proposed budget cuts to the Child Development and Rehabilitation Center (CDRC).

Family Voices Leader in North Dakota

Donene Feist, a parent activist, understands the power of data to support and strengthen the stories parents and caregivers have to tell about the challenges of caring for children with special needs.

Racial/Ethnic Disparities in Adolescent and Young Adult Health

The Center for Applied Research and Technical Assistance (CARTA) used data from the DRC in a report on racial/ethnic disparities in adolescent and young adult health.

Substance abuse treatment duration for Medicaid versus commercial clients in an HMO

Presented by Frances Lynch
February 14th, 2006

Children's Health, The Nation's Wealth: Assessing and Improving Child Health

The National Academies of Science used data from the National Survey of Children's Health in a report that offers a new framework for the health measurement of children.

National Survey of Children with Special Health Care Needs

Chartbooks, Presentations, and Publications related to the National Survey of Children with Special Health Care Needs



Thank You

General Questions or Inquiries

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Preventive Services
for Young ChildrenStandardized
Developmental ScreeningPreventive
Services for TeensChildren with Special
Health Care NeedsData Resource
CenterOther CAHMI
Projects & ToolsExamples from
the Field

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Welcome...



Please excuse the dust while we improve our website. All features may not be available at this time. For assistance, contact the [CAHMI](#)

The Child and Adolescent Health Measurement Initiative

Our mission is to ensure that children, youth and families are at the center of quality measurement and improvement efforts in order to advance a high quality consumer-centered health care system.

The CAHMI has developed a number of quality measurement tools and strategies that assess the quality of care provided to children and young adults. To learn more about the CAHMI consumer-centered quality measurement strategies, click on the topic areas below.

CAHMI Quality Measurement Tools: By Topic Area

Click the Icon to show/hide Topics & Sub Topics

-  [Preventive Services for Young Children](#)
-  [Standardized Developmental Screening](#)
-  [Preventive Services for Teens](#)
-  [Children with Special Health Care Needs](#)
-  [Data Resource Center](#)



Spotlight On:

The NQF Endorses CAHMI Child and Youth Quality Measures

The steering committee of the [National Quality Forum \(NQF\)](#) endorsed three CAHMI measures as valid, reliable tools to assess the patient experience with recommended care. The [PHDS](#), the [YAHCS](#) and the [CAHPS-CCC](#) were endorsed as part of the in National Voluntary Consensus Standards for Ambulatory Care: Patient Experience of Care. [Click here for more information.](#)

Examples from the Field:

Applications of the CAHMI Tools

Coming soon will be examples of how the CAHMI tools have been used...

- In [National Surveys](#)
- By [Medicaid](#)
- By [Health Plans](#)
- By [Providers](#)
- By [Consumers](#)