Leveraging CAHMI’s Data Resource Center
State Systems Development Initiative Workshop

Title V Maternal & Child Health Federal-State Partnership Meeting
November 7, 2023

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What is the CAHMI?

Theory of Change

Our 26 years to promote early and lifelong health using family centered research, data and tools.
State Systems Development Initiative

The goals of the SSDI program are directly aligned with those of the CAHMI

1) **Strengthen capacity** to collect, analyze, and use reliable data for the Title V MCH Block Grant to assure **data-driven programming**;

2) **Strengthen access** to, and linkage of, key MCH datasets to inform MCH Block Grant programming and policy development, and assure and strengthen information exchange and data interoperability;

3) Enhance the development, integration, and tracking of **health equity and social determinants of health (SDoH) metrics** to inform Title V programming;

4) Develop and enhance **capacity for timely MCH data collection**, analysis, reporting, and visualization to inform rapid state program and policy action related to emergencies and emerging issues/threats
QUICK LINKS TO RESOURCES FOR TITLE V NEEDS ASSESSMENT

The resource links included in this document provide a high-level summary of resources to help you leverage the Data Resource Center (www.childhealthdata.org) and Related Child and Adolescent Health Measurement Initiative (CAHMI) resources to support each step of the needs assessment process.

**TA Priority**
Topics are organized by steps along the Title V Needs Assessment process and MCH resource category.

**RESOURCES**
Resources include videos, documents, research and reports, related models and tools and data and measurement resources.

**QUICK LINKS**
Links are provided throughout. Look out for hyperlinked text to access resources. Simple language is used.

November 2023

**Citation:** Child and Adolescent Health Measurement Initiative (2023). "Starting Point Quick Links – Title V Needs Assessment." Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).
Quick Glance Overview of CAHMI Resources for SSDI Consideration

Data Resource Center
- Interactive Data Query
- Hot Spotting Tables
- U.S. Maps
- Crosswalk of NSCH Survey Items
- Content Maps

Measurement in Action: Steps 2,3,4,5,6,9
- Information on wide array of validated measures
- MCH Measures Compendium-cross system indicators
- Measurement Research Network
- National Strategic Measurement Agenda

Engagement in Action: Steps 1,6,7
- Engagement in Action (EnAct!) Framework
- Cycle of Engagement Well Visit Planner Approach
- Shared Care Planning for CSHCN
Over half of all US children experience complex social and relational health risks – this is 2/3 of those with a mental health condition.

Social Health Risks:
Poverty, food insecurity, exposure to community violence, racism, etc.

Relational Health Risks:
Adverse childhood experiences (ACEs), low parental mental health, low parent emotional support, etc.

60% of children with relational health risks DID NOT have social health risks.

Source: Child and Adolescent Health Measurement Initiative Analysis of National Survey of Children’s Health

Bethell, C. 2023
WHOLE CHILD AND FAMILY INTEGRATED SYSTEMS TRANSFORMATION REQUIRED!
EXAMPLE: Prevalence of Mental, Emotional and/or Behavioral Health Problems
By Children’s Exposure to Social and Relational Health Risks

![Bar chart showing prevalence of mental health problems based on social and relational health risks.](chart.png)

Study Reveals Fourfold Range in Rates of Mental Health Problems Among U.S. Children Based on Relational and Social Risks

More recent national data, from 2020 to 2021, also highlights relationship-focused preventive factors linked to overall mental health outcomes.

### Study Details:


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Bethell, C. 2023
Intentional collaboration across system partners to support families and children based on their agenda is possible with the Well Visit Planner interoperable tool.
71 Topical Areas Across 9 MCH Programs By Measurement Domain

- **A: Access and Utilization**
  - N=12
  - 16.9%

- **B: Quality of Care: Screening, Referral, and Follow Up**
  - N=17
  - 23.6%

- **C: Quality of Care: Care Processes, Education, and Counseling**
  - N=11
  - 15.5%

- **D: Health and Intermediate Outcomes**
  - N=31
  - 43.6%

Bethell, C. 4.13.2023
13 Topical Areas Shared Across 3+ MCH Programs
(out of 71 topical areas and 309 measures)

A Prenatal and Postpartum care
A Receipt of Dental Care Services
A Well Child Visits
A Adolescent Well Visits
A Well Woman Visit
B Completed Depression Referrals
B Depression Screening
B Early Childhood Developmental Screening
B Tobacco, Alcohol or Other Drug Cessation Referrals/Treatments for Adults and/or Caregivers
C Weight Assessment, Counseling for Nutrition, Physical Activity
C Child and Adolescent Immunization status
D Emergency Department Visits and Injury Hospitalizations
D Low Birth Weight

5 agencies involved:
1. CHCs
2. MIECHV
3. HEDIS
4. Medicaid/CHIP
5. Title V

Note: In 2024 Medicaid/CHIP, MIECHV, Title V and CHCs/FQHCs will be required to report on Development Screening rates

Depression Screening and Prenatal/Postpartum Care are aligned across all five
The Engagement in Action (EnAct!) Framework for a Statewide Integrated Early Childhood Health System
Collaboratively designed with Mississippi Thrive! by the Child and Adolescent Health Measurement Initiative

**Framework Purpose:**
Positive Health Equity

The purpose of the EnAct! framework is to catalyze child health equity and improve child flourishing, school readiness, and family resilience.

**Key Elements of the Framework:**
1. **Everyone a Leader**
   - Personalized, Strengths-Based Health Promotion and Supports

2. **Outcomes and Equity-Based Quality Measurement and Improvement**
   - Universal developmental and comprehensive whole child and family screening and assessments

3. **Through any door**
   - Family engagement to activate trust and partner in care

4. **No Broken Link**
   - Coordinated, Warm Links to Quality Services and Interventions

**Action:** Establish a sustainable cross-system, multi-level state leadership capacity

- **Outcome #1:** A cross-sector body has the structure, capacity, and influence to sustain advance state program and policy strat to promote positive early childhood health
- **Outcome #2:** State leadership builds an infrastructure to coordinate strategies, resources, operations, and performance measures that promote early childhood development
- **Outcome #3:** Local community coordination bodies lead and link with state leadership to drive effective frontline systems change and improvements

**Source:** Child and Adolescent Health Measurement Initiative, Feb. 2023
The Cycle of Engagement Family Engaged IT Tool for Local Data: Real Time, Valid, Interoperable

“"If you want to effectively engage families, efficiently provide comprehensive care, and meet standards you need the Well Visit Planner.”"

- Pediatric Provider
"The WVP empowers families so we can support their goals and needs. It gives us the reassurance all screens are done and we meet family priorities. Saves time to connect, build trust and link to supports." (Pediatrician)

www.cycleofengagement.org
Clinical Summary of Well Visit Planner® Findings: 15 Month Well Visit

Date of Well Visit: No response  •  Date WVP Completed: 9/7/2022  •  Birth Month & Year: 4/2021

Key: ☑ family response indicated  ☐ family response indicated  ☐ family did not respond; no or low risk  ☑ some risk or concern  ☐ nonresponse could indicate risk

Screening and Assessments Summary and Topics to Address: Assess & Address

Child Development
Developmental Surveillance and Screening
- Developmental Screening SWYC milestone score: 10 (Results from 15 Month SWYC did not meet age expectations); score may or may not indicate a delay. Clinical review with family needed.
  - Very Much
    - Calls you "mama" or "dada" or similar name
  - Looks around when you say things like "Where’s your blankie?" or "Where’s your banana?"
  - Names at least 5 body parts - like nose, hand, or tummy
  - Names at least 5 familiar objects - like ball or milk
  - Somewhat
    - Copies sounds that you make
    - Walks across a room without help
  - Not Yet
    - Kicks a ball
    - Rumps
    - Walks up stairs with help
  - Missing
    - Follows directions - like "Come here" or "Give me the ball"
- Caregiver reports completing standardized developmental, behavioral screening; No
- Caregiver’s overall level of concern about child’s development, learning, behavior: A little
- Hearing concerns: Yes
- Speaking concerns: No
- Lazy or crossed eyes: No
- Bowel movements/urination concerns: No

Health Behaviors
- Smoking: Child exposed to smoking
- Flag for potential alcohol misuse
- Recreational/non-prescription drug use

Relational Health Risks
- Intimate partner violence risk:
  - Caregiver and partner work out arguments with some difficulty
  - Some tension in relationship with partner

Social Factors/Determinants
- Lives with both parents: Yes
- Economic Hardships: Somewhat
- Very often hard to cover costs of basic needs, like food or housing
- Impact of COVID-19: Not a lot
- Impact of Covid-19 on family’s well-being: Somewhat

Caregiver Emotional Health
- Depression risk: PHQ-2 Score: 3
  - Down, depressed, or hopeless several days over the past 2 weeks
  - Little interest or pleasure in doing things more than half the days over past 2 weeks
- Caregiver social support
  - Caregiver self care/hobbies: Has spent time in last 2 weeks doing things they enjoy
  - Caregiver coping: Not Very Well

About This Child
Name: Sara Initials (F: M: L): SM
Special Keyword: dog
WVP completed by: Mother
Gender: No response
Insurance coverage/type: No response
Interested in telemedicine visits: No
Concerns about telemedicine to address: Family’s privacy

General Health and Updates
Child’s Health and Health History
- Child has ongoing health problem requiring routine screenings (CCHSN screener)
- New medications
- Currently taking vitamins/herbal supplements:
  - Dentist: Currently no dentist
  - Fluoride: No fluoride in water source

Family History and Updates
- Recent family changes (e.g. move, job change, separation, divorce, death in the family): Move
- New medical problem in family
- Parent/grandparent had stroke or heart problem before age 55
- Parent has elevated blood cholesterol

Strengths to Celebrate! Connect & Celebrate
Caregiver social support: Caregiver has at least one person they trust and can go to with personal difficulties
Caregiver self care/hobbies: Caregiver has spent time in the last 2 weeks doing hobbies, self care, or spare-time activities they enjoy
One thing that is going well for the caregiver as a caregiver: My parents are very supportive and they love my child.

Additional caregiver/parent goals and/or concerns to address during the visit: Would like to discuss about my child’s development and expectations.

Other assessments added by provider:
- Autism spectrum disorder screen (M-CHAT RRF) Score unknown (incomplete)
- SAWLS ACE score: 3
  - PEARLS Toxic Stress Risk Factor score: 1
  - Child flourishing: At Risk
  - Family resilience: At risk
  - Parent-child connection: At Risk

See details on 2nd page

Let’s make progress: Next Steps

Well Being Themes
Nutrition Positive Experiences
Build Family Strengths & Resilience
Promote Positive Communication
Prioritize attachment & Social & Emotional Skills
National Data Resource Center for Child and Adolescent Health (DRC)

The DRC is a national center assisting in the design, development, documentation and public dissemination of user friendly information about, data findings on and datasets and codebooks for the National Survey of Children’s Health (NSCH).

childhealthdata.org

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National Survey of Children's Health Interactive Data Query

Video Tour of the Interactive Data Query

- 2018-2019 (two years combined)
- Nationwide

Note: For the most reliable estimates, use the two-year combined data (e.g., 2018-2019).

Learn About the NSCH

Explore the Data

Spread the Word

About Us

How to Use the DRC Website

The DRC advances the use of the National Survey of Children's Health, led by HRSA MCHB. Find more resources here:

- About the DRC
- DRC Video Overview
- DRC Frequently Asked Questions
- Data available in the online data query
- Request NSCH datasets
- Download NSCH codebooks

For Title V

The DRC focuses on data and resources for Title V programs and partners. For over 75 years, the HRSA Maternal and Child Health Bureau (MCHB) has funded the Title V program to ensure the health of the nation's mothers, women, children and youth.

- Link to Ways to Compare Data Across States on the DRC Website
- Link to HRSA MCHB Title V Information System
- Link to Get Help

www.childhealthdata.org
Child and Family Health Data for Title V Needs Assessment

Background
Title V Maternal and Child Health legislation requires states to prepare a statewide needs assessment every five years consistent with national health objectives and health status goals. The next five-year Needs Assessment will be submitted by July 15th 2015. Each state’s assessment will identify need for the following services and priority populations:
- Preventive and primary care services for pregnant women, mothers and infants up to age one;
- Preventive and primary care services for children; and
- Services for children with special health care needs (CSHCN).

Online resource for child health care quality data
The Data Resource Center for Child and Adolescent Health (CRC) website offers standardized national- and state-level child health data from the National Survey of Children’s Health (NSCH). The site’s interactive data query feature allows users to search and compare state, national, and regional results for an array of child health indicators including National Performance and Outcome Measures. In addition, users can stratify and compare findings for children by age, household income, race/ethnicity, family structure, special health care needs status, adverse childhood experiences, and more. CRC staff are also available to provide expert technical assistance.

<table>
<thead>
<tr>
<th>Title V Needs Assessment Process</th>
<th>How the Data Resource Center Can Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess Needs and Identify Priorities</td>
<td>Immediate access to over 350 state-specific indicators of child health and well-being for children overall and children with special health care needs (CSHCN) provides information to help frame and choose critical questions.</td>
</tr>
<tr>
<td>Examine Strengths and Capacity</td>
<td>“Point and click” menus allow users to explore disparities and gaps in access to care and services for various subgroups of children and CSHCN.</td>
</tr>
<tr>
<td>Select Priorities</td>
<td>User-generated tables and bar charts supply prevalence and count estimates to help guide selection of priority needs.</td>
</tr>
<tr>
<td>Set Performance Objectives</td>
<td>“All States” ranking maps and tables provide benchmark data to assist in identifying state-negotiated performance measure targets.</td>
</tr>
<tr>
<td>Develop an Action Plan</td>
<td>Information on national, within and across state variation using standardized indicators encourages dialogue and helps stimulate collaborative efforts within the MCHB, Department of Health, and other state organizations.</td>
</tr>
<tr>
<td>Monitor Progress</td>
<td>Centralized resource for population-based survey questions to use in collecting standardized child health data, helping to inform local and program-level evaluation efforts.</td>
</tr>
</tbody>
</table>
Go to [www.childhealthdata.org](http://www.childhealthdata.org) to interactively Explore and Access Information and Resources on the Majority of State Priorities for Improving MCH Outcomes and System Performance.

<table>
<thead>
<tr>
<th>Priority Need</th>
<th>Priority Topic</th>
<th>Frequency</th>
<th>Population Groups with State Level Information Available on the Data Resource Center (DRC) Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Care</td>
<td>Access to Quality Care</td>
<td>27</td>
<td>45.0%</td>
</tr>
<tr>
<td>Reducing Disparities</td>
<td>Health Equity</td>
<td>25</td>
<td>41.7%</td>
</tr>
<tr>
<td>Developmental Screening</td>
<td>Access to Quality Care</td>
<td>24</td>
<td>40.0%</td>
</tr>
<tr>
<td>Access to Preventive Care</td>
<td>Access to Quality Care</td>
<td>23</td>
<td>38.3%</td>
</tr>
<tr>
<td>Systems of Care for CYSHCN</td>
<td>Access to Quality Care</td>
<td>23</td>
<td>38.3%</td>
</tr>
<tr>
<td>Medical Home</td>
<td>Access to Quality Care</td>
<td>20</td>
<td>33.3%</td>
</tr>
<tr>
<td>Behavioral Health</td>
<td>Access to Quality Care</td>
<td>20</td>
<td>33.3%</td>
</tr>
<tr>
<td>Breastfeeding</td>
<td>Healthy Behaviors</td>
<td>19</td>
<td>31.7%</td>
</tr>
<tr>
<td>Oral Health Services</td>
<td>Access to Quality Care</td>
<td>17</td>
<td>28.3%</td>
</tr>
<tr>
<td>Reducing Disparities</td>
<td>Social Determinants of Health</td>
<td>16</td>
<td>26.7%</td>
</tr>
<tr>
<td>Protective Factors</td>
<td>Access to Quality Care</td>
<td>15</td>
<td>25.0%</td>
</tr>
<tr>
<td>Reducing Disparities</td>
<td>Access to Quality Care</td>
<td>15</td>
<td>25.0%</td>
</tr>
<tr>
<td>Tobacco</td>
<td>Healthy Behaviors</td>
<td>14</td>
<td>23.3%</td>
</tr>
<tr>
<td>Social Emotional Health</td>
<td>Access to Quality Care</td>
<td>13</td>
<td>21.7%</td>
</tr>
<tr>
<td>Obesity</td>
<td>Health Status</td>
<td>13</td>
<td>21.7%</td>
</tr>
<tr>
<td>Low Birth Weight/Very Low Birth Weight/Prematurity</td>
<td>Health Status</td>
<td>13</td>
<td>21.7%</td>
</tr>
<tr>
<td>Economic Stability</td>
<td>Social Determinants of Health</td>
<td>12</td>
<td>20.0%</td>
</tr>
<tr>
<td>Specialized Care</td>
<td>Access to Quality Care</td>
<td>11</td>
<td>18.3%</td>
</tr>
<tr>
<td>Protective Factors</td>
<td>Healthy Behaviors</td>
<td>11</td>
<td>18.3%</td>
</tr>
<tr>
<td>Care Coordination</td>
<td>Access to Quality Care</td>
<td>9</td>
<td>15.0%</td>
</tr>
<tr>
<td>Health Insurance Coverage</td>
<td>Access to Quality Care</td>
<td>9</td>
<td>15.0%</td>
</tr>
<tr>
<td>Bullying/Harassment</td>
<td>Healthy Behaviors</td>
<td>0</td>
<td>15.0%</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>Healthy Behaviors</td>
<td>8</td>
<td>13.3%</td>
</tr>
</tbody>
</table>

1 Alvaran (2021), State Priorities and Performance Measures Trends Between 2015 and 2020. “Priority needs identified in the FY2021-FY2023 needs assessment cycle are referred to as “2020 priority needs”.”
Go to [www.childhealthdata.org](http://www.childhealthdata.org) to interactively Explore and Access Information and Resources on 18 NOMs and NPMs based on NSCH data.

Updated NOMs and NPMs coming soon!
Four Key DRC Online Website Features

https://www.childhealthdata.org/
Currently Available NOMs and NPMs Derived from NSCH

Title V Maternal and Child Health Services Block Grant Measures
Available from the 2020-2021 National Survey of Children’s Health (two years combined)

National Performance Measures
(NPM)

National Outcome Measures
(NOM)

NPM-6 Developmental screening, 9-35 months
NPM-8.2 Physical activity, 12-17 years
NPM-9 Bullied, 12-17 years
NMP-10 Preventive medical visit, 12-17 years
NPM-11 Medical home, children with special health care needs
NPM-12 Transition to adult health care, children with special health care needs, 12-17 years
NPM-13.2 Preventive dental visit, 1-17 years
NPM-14.3 Someone living in the household smokes
NPM-15 Adequate and continuous insurance

NOM-14 Tooth decay/carries, 1-17 years
NOM-17.1 Children with special health care needs
NOM-17.2 Systems of care, children with special health care needs
NOM-17.3 Autism/ASD, 3-17 years
NOM-17.4 ADD/ADHD, 3-17 years
NOM-18 Mental health treatment or counseling, 3-17 years with a mental/behavioral condition
NOM-19 Overall health status
NOM-20 Obesity, 10-17 years
NOM-25 Forgone health care

Note: The definition of all measures can be found in the 2020-2021 NSCH codebook and through the information icon on the data query at childhealthfutures.org.
For more information about NPMs and NOMs visit the HHS ACHC website:
http://mchb.hrsa.gov

Citation: Child and Adolescent Health Measurement Initiative (2022). “Title V Maternal and Child Health Services Block Grant Measures Content Map, 2020-2021 National Survey of Children’s Health (two years combined).” Data Resource Center for Child and Adolescent Health, supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved (mm/dd/yy) from [www.childhealthfutures.org].

+ Over 300 Child and Family Health Measures
Title V National Performance Measure (NPM) and National Outcome Measure (NOM) Changes in the National Survey of Children’s Health (NSCH)

This document summarizes changes in the Title V National Performance and Outcome measures across survey years. The 2016 NSCH data serves as a baseline. Data collected prior to 2016 cannot be compared due to significant changes in the survey design and operation, including the shift from telephonic interviews to a self-administered address-based survey completed by web or paper and pencil. View a crosswalk of survey items from 2016 through 2022 for additional information on item-level changes.

Keys:
- Measure is comparable across survey years
- Measure is not comparable across survey years

<table>
<thead>
<tr>
<th>Measure</th>
<th>Comparable across survey years?</th>
<th>Summary of key changes in measure since 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPM 6: Percent of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year</td>
<td>2016 2017 2018 2019 2020 2021 2022</td>
<td>No changes</td>
</tr>
<tr>
<td>NPM 8.1: Percent of children, ages 6 through 11, who are physically active at least 60 minutes per day NPM 8.2: Percent of adolescents, ages 12 through 17, who are physically active at least 60 minutes per day</td>
<td>2016 2017 2018 2019 2020 2021 2022</td>
<td>No changes</td>
</tr>
<tr>
<td>NPM 9: Percent of adolescents, ages 12 through 17, who are bullied or who bully others</td>
<td>2016 2017 2018 2019 2020 2021 2022</td>
<td>Major content change in 2018; data from 2018 and beyond cannot be compared to 2016 or 2017. In 2018, the survey questions and timeframe changed to ask about frequency of occurrence during the past 12 months of how often did the child “bully others, pick on them, or exclude them” and the child “was bullied, picked on, or excluded by other children”. Response options were revised</td>
</tr>
</tbody>
</table>

Accessing on the spot details on measurement specifications

National Performance Measure 11: Percent of children with special health care needs, ages 0 through 17, who have a medical home

<table>
<thead>
<tr>
<th>Care meets medical home criteria</th>
<th>Care does not meet medical home criteria</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>42.0</td>
<td>58.0</td>
</tr>
<tr>
<td>C.I.</td>
<td>40.5 - 43.4</td>
<td>56.6 - 59.5</td>
</tr>
<tr>
<td>Sample Count</td>
<td>9,832</td>
<td>11,349</td>
</tr>
<tr>
<td>Pop. Est.</td>
<td>5,940,544</td>
<td>8,218,253</td>
</tr>
</tbody>
</table>

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop. Est.) are weighted to represent child population in U.S.

Survey Items: Survey instrument item number for children 0-5 years: C1, C6, C9, D1-D4, D7-D12; for children 6-11 years: C1, C6, C9, D1-D4, D7-D12; for children 12-17 years: C1, C6, C9, D1-D4, D7-D12

Denominator: Children with special health care needs ages 0-17 years

Numerator: Care meets medical home criteria; Care does not meet medical home criteria

Revisions and Changes: Though there were changes to a few items which are used to score this measure since 2016, the overall concept of medical home and how it is measured in the survey did not change. For more information about the changes, click here.

Additional Notes: The American Academy of Pediatrics specifies seven qualities essential to medical home care: accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective careIdeally, medical home care is delivered within the context of a trusting and collaborative relationship between the child, family and a competent health professional who is familiar with the child and family and the child's health history. The presence of a medical home was measured by a composite measure based on five components constructed from a total of 16 survey items. These components are:
- Personal doctor or nurse (Indicator 4.12: PedCare 2021)
- Usual source for sick care (Indicator 4.13: UsualSickCare 2021)
- Family-centered care (Indicator 4.12: FamCentCare 2021)
- Family getting needed referrals (Indicator 4.13: ReferralRpr 2021)
- Effective Care Coordination when needed (Indicator 4.12: CareCoord 2021)

One was added to the denominator when calculating prevalence estimates and weighted population counts displayed in the Interactive Data Query results table. In the majority of cases, the proportion of missing values is less than 2%. Exceptions are noted in the form of a Data Alert at the bottom of a results table. The exclusion of these values does not change the prevalence estimates (%) and only marginally affects the weighted population counts (Pop. Est.) To learn about the impact of the missing values on the population count estimates, click here.

History and Development:

The Title V Maternal and Child Health Block Grant Program is a federal-state partnership to improve the health and well-being of mothers, children (including children with special health care needs) and their families in all 50 states and jurisdictions. The Title V Maternal and Child Health Block Grant Program provides states with the flexible resources they need to carry out the program’s mission to improve the health and well-being of mothers and children. The Title V Maternal and Child Health Block Grant Program’s mission is to provide and promote health-promoting, health-protecting, and health-restoring services to improve the health and well-being of pregnant and parenting women, infants, and children.

About NPM 11:
The National Survey of Children's Health (NSCH), funded and directed by the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), is designed to provide national and state-level information on the health and well-being of children ages 0-17 years in the United States. The U.S. Census Bureau administers the survey, oversees the sampling, and produces a final set of survey results. HRSA’s Maternal and Child Health Bureau (MCHB) develops survey content in collaboration with the U.S. Census Bureau and a Technical Expert Panel. The Technical Expert Panel consists of experts in survey methodology and children’s health and data stakeholders. HRSA and the MCHB have reviewed the information in this report and the combined content from both the NSCH and the National Survey of Children with Special Health Care Needs (NS-CSHCN). Further information on that can be found in “The Design and Implementation of the 2016 National Survey of Children’s Health.”
Guidelines to Optimize Data for Local Areas Using Synthetic Estimate

So, let's calculate a synthetic estimate!
We'll estimate the percentage of children in Marin County with a medical home.

**STEP 1:** Determine the prevalence of your variable by selected demographic category at the state level. You can choose any variable for which you have state-level data. www.childhealthdata.org provides data on numerous measures of child health and well-being and allows stratification by various subgroups. We used data from the 2007 NSCH to find the prevalence of having a medical home in California stratified by race/ethnicity.

**STEP 2:** Determine the number of children in your county who fall into each category of the demographic characteristic you are using. You can use any demographic variable for which you have county and state-level information.

<table>
<thead>
<tr>
<th>Race/Ethnicity Category</th>
<th>Distribution in Marin County</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latino/Hispanic</td>
<td>16,241</td>
</tr>
<tr>
<td>White</td>
<td>31,583</td>
</tr>
<tr>
<td>Black</td>
<td>1,269</td>
</tr>
<tr>
<td>Multiracial</td>
<td>2,570</td>
</tr>
<tr>
<td>Other</td>
<td>1,988</td>
</tr>
<tr>
<td>Total</td>
<td>53,631</td>
</tr>
</tbody>
</table>

We got the 2007 race distribution in Marin County directly from KidsData.org (California only).

Note that we combined the Native American and Asian/Pacific Islander groups from the KidsData website into an “other” category to match categories in the 2007 NSCH. It is important to make sure the groupings in your two data sources match! You can also access county-level information from places such as: www.KidsCount.org, www.census.gov and your state department of finance.

**STEP 3:** Calculate the estimate. First, determine the estimated number of children who meet the indicator of interest within each demographic group for your selected county. In this example, it is the number of children with a medical home by race in Marin County (3rd column in the table below).

Then, determine the prevalence of your variable of interest in your county by dividing the total number of children in the county who meet that variable by the total number of children in the county. Here, we divide the total number of children estimated to have a medical home in Marin County by the total number of children living in Marin County in...
How do I access data on the DRC?

Interactive Data Query

National Survey of Children’s Health
(2016 - present)

To begin your interactive data search:
1) Select a survey year and geographic level.
2) Select your desired topic/starting point (at-a-glance content maps are available to view/download at this step).
3) Select your measure.

These steps will direct you to a results page where you can compare across states, regions, and by numerous subgroups.

Note: For the most reliable estimates, use the two-year combined data (e.g. 2020-2021).

Watch a Video Tour of the Interactive Data Query

1. Select a Survey Year and Geographic Area
   - 2020-2021 (two years combined)
   - Nationwide

2. Select a Starting Point/Topic
   - [Content Map]
The DRC’s Interactive Data Query

3. Select a Survey Question (click the i for more information on the question)

- NPM 6: Developmental screening, age 9-35 months
- NPM 8.1: Physical activity, age 6-11 years
- NPM 8.2: Physical activity, age 12-17 years
- NPM 9: Bullied others, age 12-17 years
- NPM 9: Bullied, age 12-17 years
- NPM 10: Preventive medical visit, age 12-17 years
- **NPM 11: Medical home, children with special health care needs (CSHCN)**
- NPM 11: Medical home, children without special health care needs (Non-CSHCN)
- NPM 12: Transition to adult health care, CSHCN age 12-17 years
- NPM 12: Transition to adult health care, Non-CSHCN age 12-17 years
- NPM 13.2: Preventive dental visit, age 1-17 years
- NPM 14.2: Someone living in the household smokes
- NPM 15: Adequate and continuous insurance

CAHMI
### Current Search Criteria

**Survey:** 2020-2021 National Survey of Children's Health  
**Starting Point:** Title V Maternal and Child Health Services  
**Block Grant Measures:**

- State/Region: Nationwide (quick edit)  
- Topic: National Performance Measures  
- Question: NPM 11: Medical home, children with special health care needs (CSHCN)

**Sub Group:** Race/ethnicity of child – 7 categories

### National Performance Measure 11: Percent of children with special health care needs, ages 0 through 17, who have a medical home

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Care meets medical home criteria</th>
<th>Care does not meet medical home criteria</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hispanic</strong></td>
<td>% 35.6</td>
<td>64.4</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>C.I. 31.6 - 39.8</td>
<td>50.2 - 68.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sample Count: 1,014</td>
<td>1,670</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pop. Est: 1,159,000</td>
<td>2,095,605</td>
<td></td>
</tr>
<tr>
<td><strong>White, non-Hispanic</strong></td>
<td>46.3</td>
<td>53.7</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>C.I. 44.8 - 47.8</td>
<td>52.2 - 55.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sample Count: 7,055</td>
<td>7,278</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pop. Est: 3,397,210</td>
<td>3,946,187</td>
<td></td>
</tr>
<tr>
<td><strong>Black, non-Hispanic</strong></td>
<td>38.6</td>
<td>63.2</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>C.I. 33.1 - 40.6</td>
<td>59.4 - 66.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sample Count: 639</td>
<td>977</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pop. Est: 829,038</td>
<td>1,424,009</td>
<td></td>
</tr>
<tr>
<td><strong>Asian, non-Hispanic</strong></td>
<td>43.2</td>
<td>56.8</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>C.I. 34.9 - 51.9</td>
<td>48.1 - 65.1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sample Count: 675</td>
<td>675</td>
<td></td>
</tr>
</tbody>
</table>

### View Findings by Subgroups

- Age in 3 groups
- Sex of child
- Race/ethnicity of child
- Race/ethnicity of child – 7 categories
- Parental nativity
- Primary language in household
- Primary household language for Hispanic children
- Family structure
- Household income level
- Household income level (SCHIP)
- Highest education of adult in household
- Military status of adult(s) in household
- Family resilience
- Adverse Childhood Experiences
- Special health care needs status
- Complexity of health care needs
- Emotional, behavioral, or developmental issues for which treatment or counseling is needed
- Family resilience
- Medical home
- Current insurance status
- Adequate and consistency of health insurance
- Consistency of health insurance coverage
- Type of health insurance
- Well-functioning system of care
Compare Data Across States

Ways to Compare Data Across States on the DRC

There are three primary ways to compare data across states using the DRC website. Your options include:

1. View findings on single indicators (and by subgroup) for all states using our Across-States Interactive Data Query (see below for steps).
2. Compare states on all NSCH derived Title V National Outcome and Performance Measures using our Across-State Comparison Tables.
3. View US maps shaded to indicate how each state’s finding differs from the nation on Title V National Outcome and Performance Measures using our Across-State Comparison US Maps.

Steps for Using the DRC Across-State Interactive Data Query:
1. Go to the NSCH Interactive Data Query.
2. Select “All States” in the drop-down menu where you select the state or region you wish to see results for.
3. Select your indicator of interest.
4. Select any subgroups you wish to view the indicator by.
5. View findings for all states and sort by the response option you are interested in by clicking on the response option at the top of the data table.
6. If you selected a subgroup, select the specific indicator response option you wish to view across-state findings for by your subgroup.
7. If you want to return to the interactive query just for your state (or with one other geographic area), just click on the state and it will return you to the state by state (and two areas at a time) data query option.

Steps for Using the Across-State Comparison Tables:
1. Go to the Across-State Comparison Tables.
2. Select to view National Outcome or Performance Measures.
3. The color-coding in the table represents a state’s comparison with national estimates.
4. To sort a measure by state prevalence, click the arrows at the top of the column.
5. To see the full measure description, hover over the measure title.
6. To compare national and state level data and access subgroup level data in the data query, click on any prevalence estimate in the table.

Steps for Using the Across-State Comparison US Maps:
1. Go to the DRC Across-State Comparison US Maps.
2. Select the National Outcome or Performance Measure you wish to view.
3. The color-coding in the map represents a state’s comparison with national estimates.
4. To compare national and state level data, click on any state.
View Findings By States or Regions or Across All States or Regions At the Same Time

### Current Search Criteria
- **Survey:** 2020-2021 National Survey of Children's Health
- **Starting Point:** Title V Maternal and Child Health Services Block Grant Measures
- **State/Region:** Nationwide vs. Maryland (quick edit)

**Topic:** National Performance Measures
**Question:** NPM 11: Medical home, children with special health care needs (CSHCN)

#### National Performance Measure 11: Percent of children with special health care needs, ages 0 through 17, who have a medical home

<table>
<thead>
<tr>
<th>State</th>
<th>Care meets medical home criteria %</th>
<th>Care does not meet medical home criteria %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>42.0</td>
<td>58.0</td>
<td>100.0</td>
</tr>
<tr>
<td>C.I.</td>
<td>40.5 - 43.4</td>
<td>56.5 - 59.5</td>
<td></td>
</tr>
<tr>
<td>Sample Count</td>
<td>9,852</td>
<td>11,349</td>
<td></td>
</tr>
<tr>
<td>Pop Est.</td>
<td>5,940,544</td>
<td>8,218,253</td>
<td></td>
</tr>
<tr>
<td>Maryland</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>49.5</td>
<td>50.5</td>
<td>100.0</td>
</tr>
<tr>
<td>C.I.</td>
<td>42.6 - 56.5</td>
<td>43.5 - 57.4</td>
<td></td>
</tr>
<tr>
<td>Sample Count</td>
<td>177</td>
<td>184</td>
<td></td>
</tr>
<tr>
<td>Pop Est.</td>
<td>131,816</td>
<td>134,279</td>
<td></td>
</tr>
</tbody>
</table>

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop Est.) are weighted to represent child population in US.
### Title V National Performance Measures (NPMs)

Across State Comparison Table, 2020-2021 NSCH

<table>
<thead>
<tr>
<th>State</th>
<th>NPM10</th>
<th>NPM11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>69.7</td>
<td>42.0</td>
</tr>
<tr>
<td>Alabama</td>
<td>72.0</td>
<td>46.5</td>
</tr>
<tr>
<td>Alaska</td>
<td>61.5</td>
<td>45.0</td>
</tr>
<tr>
<td>Arizona</td>
<td>64.8</td>
<td>46.0</td>
</tr>
<tr>
<td>Arkansas</td>
<td>61.8</td>
<td>44.0</td>
</tr>
<tr>
<td>California</td>
<td>67.7</td>
<td>50.4</td>
</tr>
<tr>
<td>Colorado</td>
<td>70.0</td>
<td>51.5</td>
</tr>
<tr>
<td>Connecticut</td>
<td>75.8</td>
<td>52.0</td>
</tr>
<tr>
<td>Delaware</td>
<td>77.1</td>
<td>53.5</td>
</tr>
<tr>
<td>District of Columbia</td>
<td>71.4</td>
<td>49.0</td>
</tr>
<tr>
<td>Florida</td>
<td>72.5</td>
<td>46.5</td>
</tr>
<tr>
<td>Georgia</td>
<td>71.6</td>
<td>47.0</td>
</tr>
</tbody>
</table>

**Color Key of State Level Data When Compared to National Level Data**

- State had Significantly Lower Performance
- State had Lower Performance, but not statistically significant
- State had Higher Performance, but not statistically significant
- State had Significantly Higher Performance

### Across-State Comparison Tables

Compare states on NSCH derived NOMs and NPMs.
Click on measure and state to access the interactive query and continue exploring!
Compare States Using Single-Measure Maps
DRC “Ready to Use” Datasets

DRC data set includes:

- All variables released in the Census public use file
- All DRC indicators and items shown on the DRC website:
  - coded/constructed Child and Family Health Indicators and demographics
- All constructed NPMs and NOMs

Available Formats:
SAS, SPSS, Stata (some years) and CSV

Labels and Formats:
Variable, value labels and missing values are clearly labeled

A codebook, other survey documents, online resources will also accompany the datasets.

http://childhealthdata.org/help/dataset
Transformational Change and the Creative and Effective Use of Data

- Shared Vision
- Build Trust
- Committed Leadership
- Incremental Success
- Joint Ownership - Establish Credibility

Avoid the 3C’s: Control, Credit, Competition,

Data to Action = Opportunity into Results

Spin the Wheel...

From J Richmond
Spotlight on Using the DRC to Drive Health Equity

Example 1 - Subgroup Comparison: Prevalence of children who experienced two or more adverse childhood experiences by their race/ethnicity

How to Use DRC to Address Health Equity (cont.)

This Reports:
Differences in prevalence of children who experienced two or more adverse childhood experiences by their race/ethnicity

Example Question: Are non-white children more likely to experience this outcome?

Subgroup Comparison
On A Topical Indicator

Race/Ethnicity is the Subgroup
The main measure

| Indicator 6.13: Has this child experienced one or more adverse childhood experiences |
|-----------------------------------|-----------------|-----------------|-----------------|-----------------|
|                                  | No adverse      | One adverse      | Two or more     | Total- |
|                                  | childhood       | childhood        | adverse          | experiences |
|                                  | experiences     | experiences      | childhood        | experiences   |
|                                  |                  |                  | experiences      | experiences   |
| Hispanic                         |                  |                  |                  |               |
| %                                |                  |                  |                  |               |
| C.I.                             |                  |                  |                  |               |
| Sample Count                     |                  |                  |                  |               |
| Pop. Est.                        |                  |                  |                  |               |
| White, non-Hispanic              |                  |                  |                  |               |
| %                                |                  |                  |                  |               |
| C.I.                             |                  |                  |                  |               |
| Sample Count                     |                  |                  |                  |               |
| Pop. Est.                        |                  |                  |                  |               |
| Black, non-Hispanic              |                  |                  |                  |               |
| %                                |                  |                  |                  |               |
| C.I.                             |                  |                  |                  |               |
| Sample Count                     |                  |                  |                  |               |
| Pop. Est.                        |                  |                  |                  |               |
Example 2 - Distribution of children with a specific issue/topic, by race: Proportion of all children who experience Adverse Childhood Experiences that are Hispanic, White-NH, Black-NH, or other race/ethnicities.

Examples:
The distribution of children with ACEs across different race/ethnicity groups.

Question Answered Is there a disproportionate number of non-white children experiencing this health risk?
Thank you!

Contact Us
Email us at: info@cahmi.org
Visit “Ask a Question” page on the DRC
How to Use DRC to Address Health Equity

Subgroup Comparison in Your State

Compare your state with the national average

<table>
<thead>
<tr>
<th>Select a Response Category:</th>
<th>Two or more adverse childhood experiences</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Hispanic</th>
<th>White, non-Hispanic</th>
<th>Black, non-Hispanic</th>
<th>Other, non-Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationwide</strong></td>
<td>%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>18.8</td>
<td>14.9</td>
<td>24.3</td>
<td>15.5</td>
</tr>
<tr>
<td></td>
<td>C.I.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>17.3 - 20.4</td>
<td>14.4 - 15.5</td>
<td>22.3 - 26.1</td>
<td>14.3 - 16.9</td>
</tr>
<tr>
<td></td>
<td>Sample Count</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2,449</td>
<td>9,061</td>
<td>1,452</td>
<td>2,056</td>
</tr>
<tr>
<td></td>
<td>Pop. Est.</td>
<td>3,423,137</td>
<td>5,327,064</td>
<td>2,232,012</td>
</tr>
<tr>
<td><strong>Maryland</strong></td>
<td>%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13.4</td>
<td>12.0</td>
<td>18.2</td>
<td>14.5</td>
</tr>
<tr>
<td></td>
<td>C.I.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7.7 - 22.3</td>
<td>9.2 - 15.5</td>
<td>13.3 - 24.4</td>
<td>9.3 - 22.0</td>
</tr>
<tr>
<td></td>
<td>Sample Count</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>79</td>
<td>55</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Pop. Est.</td>
<td>29,283</td>
<td>62,221</td>
<td>71,508</td>
</tr>
</tbody>
</table>
This Reports:

Does the prevalence of 2+ ACEs across race/ethnicity groups vary across states?

Example Question: Are there states with lower inequities in ACEs than others?
Example 2 - Distribution of children with a specific issue/topic, by race: Proportion of all children who experience Adverse Childhood Experiences that are Hispanic, White-NH, Black-NH, or other race/ethnicities.

Note: This is different from variations in prevalence as shown in Example 1. To view distribution by race for a specific health issue or topic, select “Race and ethnicity distribution of the child population” as the main measure, and select the health issue/topic of interest as the subgroup.
The DRC anticipates and provides quick links to resources for common questions from:

- State and national partners (Title V, CDC, HRSA)
- Community and local partners (non-profit, local community organizations)
- Participants and public (students, researchers, media, families, etc.)
- MCH systems professionals (health care, education, social services, wide range)

- Visit our Ask a Question page with FAQs and links to address common TA questions and responses. If you’re question cannot be answered, feel free to email us at info@cahmi.org. We try to respond within 48 hours.

### Examples of technical assistance area:
- Data Research and Evaluation
- CSHCN/Medical Home
- CSHCN/Developmental Disabilities
- Adequate Health Insurance Coverage
- CSHCN Family Engagement

### Examples of assistance provided:
- General NSCH and DRC website
- Understanding NSCH Data
- NSCH Data Analysis
- Specific Measures or Variables in the NSCH
- DRC and NSCH Citation Information
QUICK LINKS TO RESOURCES FOR TITLE V NEEDS ASSESSMENT

The resource links included in this document provide a high-level summary of resources to help you leverage the Data Resource Center (www.childhealthdata.org) and Related Child and Adolescent Health Measurement Initiative (CAHMI) resources to support each step of the needs assessment process.

TA Priority
Topics are organized by steps along the Title V Needs Assessment process and MCH resource category.

RESOURCES
Resources include videos, documents, research and reports, related models and tools and data and measurement resources

QUICK LINKS
Links are provided throughout. Look out for hyperlinked text to access resources. Simple language is used
Family Engaged, Whole Child, Integrated Early Childhood Health Systems
The Engagement in Action (EnAct!) Framework for a Statewide Integrated Early Childhood Health System
Collaboratively designed with Mississippi Thrive! by the Child and Adolescent Health Measurement Initiative

Framework Purpose: Positive Health Equity
The purpose of the EnAct! framework is to catalyze child health equity and improve child flourishing, school readiness and family resilience.

Key Elements of the Framework
1. everyone a leader
2. through any door to activate trust and... (Further details not visible)
3. personalized, strengths-based health promotion and supports (Further details not visible)

Outcomes and Equity-Based Quality Measurement and Improvement

Universal development and comprehensive whole child and family screening and assessments

"Through any door" family engagement to activate trust and partner in care

Personalized, Strengths-Based Health Promotion and Supports

Coordinated, Warm Links to Quality Services and Interventions

Source: Child and Adolescent Health Measurement Initiative, Feb. 2023

Action: Establish a sustainable, cross-system, multi-level state leadership capacity
- Outcome #1: A cross-sector body has the structure, capacity and influence to sustain advance state program and policy strategic promote positive early childhood health
- Outcome #2: State leadership builds an state agency infrastructure to coordinate strategies, resources, operations and performance measures that promote early childhood development
- Outcome #3: Local community coordination bodies lead and link with state leadership to drive effective frontline systems change and improvements

NO BROKEN LINK

IN EVERY ENCOUNTER

Work for the Thing!

All early childhood professionals and organizations collaborate to address social determinants of health needs, and ensure the enabling and sustaining policies and strategies critical for health plans, early childhood professionals are financed to enable and improvement...
Through Any Door Family and Engagement And Supports

Illustration of the Engagement In Action Framework’s Through Any Door Approach
Towards a Family Engaged, Community Based, Integrated Early Childhood Health System

Through Any Door Family Access Points

FAMILY

Community Based Access Points

Early care and education, home visiting, community resource brokers, faith based, etc.

Everyone leads, through every door, in every encounter
to inquire and engage families to provide and/or link to quality whole child and family preventive and developmental services and partner to coordinate supports across systems

Healthcare Access Points

Pediatrics, Family Practice, Perinatal Care, etc.

Use the family driven Well Visit Planner (or similar) to engage families
and share standardized data reports using the interoperable data platform to promote comprehensive, personalized, coordinated services.

Source: Child and Adolescent Health Measurement Initiative, Feb. 2023
"If you want to effectively engage families, efficiently provide comprehensive care, and meet standards you need the Well Visit Planner."

- Pediatric Provider
**Mathematica** Independent Evaluation Across End User Groups

**Equity-focused benefits**
- Brings screening to 100%. Equalizes family knowledge. Aligns health literacy. In Spanish. Families given ways to express concerns about racism. Addresses challenges driven by structural racism.
- Provides families with information about what to expect from a provider and gives tools to communicate during the visit.

**Equity-focused strategies**
- Use aggregate data reports for advocacy, to celebrate strengths, identify priorities, needs, quality.
- Partner with family-serving organizations.
- Let family specialist support families to use WVP.
- Identify and share resources to address family needs that are uncovered through the WVP.

---

Amplify community voices

Advance health equity

Address structural racism
A QUICK OVERVIEW OF THE WELL VISIT PLANNER
Big-4 Approach to Needs Assessment From Our Morning Plenary—Amy Zapata (Louisiana)

What are the external trends and pressures?

Data
- What’s going up? Down?
- What has had no attention?

“Wisdom”
- How do we know what is important?
- Who have we asked?
- Who haven’t we asked?

What changes are happening or coming?
- Health system
- Legislative

Resources/assets
- Maternal health blueprint
- Sickle cell strategic plan
- CYSHCN roadmap
- Medicaid innovations
Optimizing Health and Health Care Systems for Children with Special Health Care Needs Using the Life Course Perspective

Christina D. Bethell, Paul W. Newacheck, Amy Fine, Bonnie B. Strickland, Richard C. Antonelli, Cambria L. Wilhelm, Lynda E. Honberg & Nora Wells

Maternal and Child Health Journal 18, 467–477 (2014) | Cite this article

Taking Stock of the CSHCN Screener: A Review of Common Questions and Current Reflections

Christina D. Bethell, PhD, MBA, MPH1 [Director, Professor], Stephen J. Blumberg, PhD2 [Associate Director for Science], Ruth E. K. Stein, MD3 [Professor], Bonnie Strickland, PhD4 [Director], Julie Robertson, MPH, MSW5 [Former Research Associate], and Paul W. Newacheck, DrPH1 [Professor]

1Child and Adolescent Health Measurement Initiative, Department of Population, Family and Reproductive Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD
2National Center for Health Statistics, Hyattsville, MD
3Albert Einstein College of Medicine
4Maternal and Child Health Bureau, Rockville, MD
5Philip R. Lee Institute for Health

Abstract
Since 2000, the Children with Special Health Care Needs (CSHCN) Screener has been used to identify the number and characteristics of children with special health care needs. The Screener has been widely used nationally, and it is estimated that over 1.8 million children are identified each year. However, the Screener has not yet been validated to measure the definition of medical home for children with special health care needs. This paper reviews the Screener and discusses its potential use in measuring the definition of medical home for children with special health care needs.

Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs

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Affiliations + expand
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Abstract
Objective: National health goals include ensuring that all children have a medical home. Historically, medical home has been determined by the presence of a usual or primary source of care, such as a
Prevalence of Children With Special Health Care Needs, Mental Health Problems and Mothers in Very Good/Excellent Health by Adverse Childhood Experiences Levels

- **No ACEs**
  - Children With Special Health Care Needs: 14.0%
  - Experienced One or More Risks on the Integrated Child Risk Index: 4.5%
  - Children With Mothers in Excellent/Very Good Health: 76.2%

- **1 ACE**
  - Children With Special Health Care Needs: 23.6%
  - Experienced One or More Risks on the Integrated Child Risk Index: 12.3%
  - Children With Mothers in Excellent/Very Good Health: 54.8%

- **2 ACEs**
  - Children With Special Health Care Needs: 34.2%
  - Experienced One or More Risks on the Integrated Child Risk Index: 22.0%
  - Children With Mothers in Excellent/Very Good Health: 48.3%
Results:
Prevalence of **school engagement** among US children age 6-17 years, by Child Flourishing Index (CFI) individual items

- **Stays calm and in control when faced with a challenge**
  - Somewhat true or not true: 28.7%
  - Definitely True: 51.4%
  - Reference: 75.0%
  - Adjusted odds ratio (AOR): 3.98

- **Works to finish the tasks he/she starts**
  - Somewhat true or not true: 34.9%
  - Definitely True: 82.8%
  - Reference: 84.9%
  - Adjusted odds ratio (AOR): 9.02

- **Shows interest and curiosity in learning new things**
  - Somewhat true or not true: 51.4%
  - Definitely True: 28.7%
  - Reference: 75.0%
  - Adjusted odds ratio (AOR): 5.98

Adjusted odds ratios (AOR) are adjusted for age, sex, race/ethnicity, income, CSHCN status and ACEs. *AOR is statistically significant.*
“Through Any Door” moment by moment positive childhood experiences are highly protective, even amid high adversity.

We Are the Medicine—Building Our Caring Capacity is Imperative ....everyone is a leader!

1. “Through Any Door”
2. “In Every Encounter”
3. “No Broken Link”

Simple rules for a complex system!
Relational health refers to the experience of and capacity to develop and sustain safe, stable, nurturing relationships (SSNRs), which in turn prevent the extreme or prolonged activation of the body’s stress response systems.

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<td><strong>Toxic stress defines the problem.</strong></td>
<td><strong>Relational health defines the solution.</strong></td>
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<td>Toxic stress explains how many of our society’s most intractable problems (disparities in health, education and economic stability) are rooted in our shared biology but divergent experiences and opportunities.</td>
<td>Relational health explains how the individual, family and community capacities that support the development and maintenance of safe, stable and nurturing relationships also buffer adversity and build resilience across the life-course.</td>
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