# The National Center for a System of Services for CYSHCN

Title V Virtual Café Utilizing NS-CH Data Related to Financing in Your Needs Assessment

### Friday May 3, 2024, 12-1pm CT/1-2pm ET

The National Center for a System of Services for CYSHCN is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$1,500,000 with no funding from nongovernmental sources. The information or content are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.



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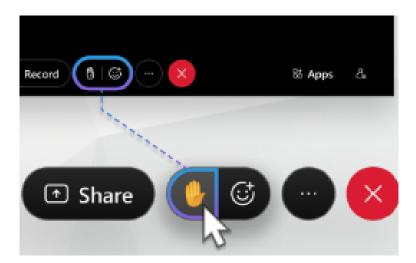


Connecting systems so CYSHCN & their families thrive

### HOUSEKEEPING

- The didactic presentation will be recorded; peer discussion will not be recorded
- All participants have been muted
- Utilize chat box to share comments, questions, or relevant resources
- Utilize hand raising feature during discussion portion
- Rename yourself to include your name and state/jurisdiction
- Direct chat AAP staff with technical issues









### Agenda

- 1. Review of the National Survey of Children's Health (NS-CH)
  - a. Financing-related concepts
- 2. Accessing the NS-CH data related to financing on www.childhealthdata.org
- 3. Accessing and Interpreting Financing-related Data from the NS-CH
- 4. Discussion and Q&A
- 5. Evaluation Survey

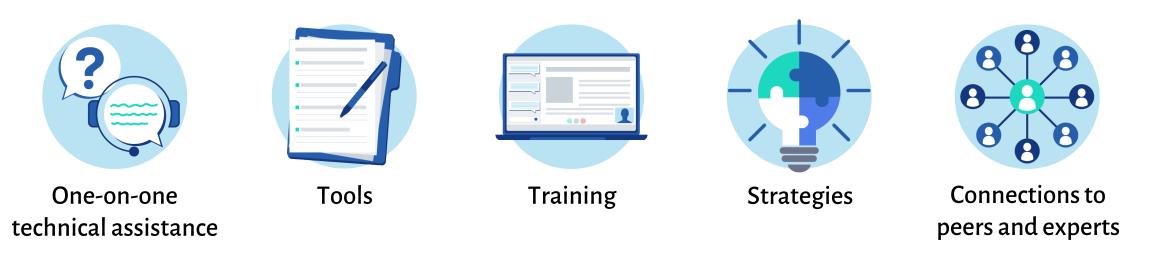


# **THE BLUEPRINT NATIONAL CENTER**



Connecting systems so CYSHCN & their families thrive

**Goal:** To advance and strengthen the system of services for CYSHCN and their families/caregivers at the community, state, and national levels by leading the field to promote health care and other supports that are integrated, family-centered, evidence-informed, and culturally responsive.





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# Integrating the Blueprint Into Your Needs Assessment | Part 2: **Utilizing NS-CH Data - Financing**

Presented by the Catalyst Center at Boston University Allyson Baughman

Meg Comeau

Bethlyn Houlihan Vergo



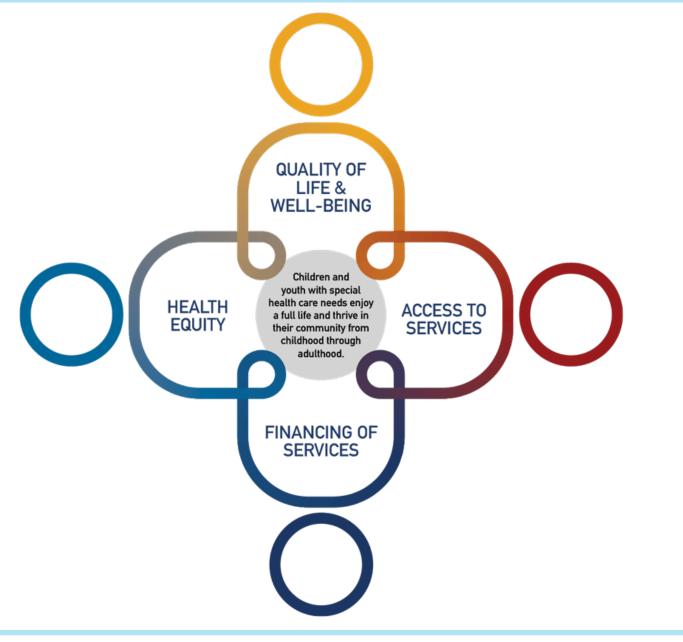
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## FINANCING AND FAMILIES RAISING CYSHCN

- Families raising CYSHCN are more likely to live in poverty (Parish et al., 2006).
- CYSHCN are more likely to experience household food insecurity (70% v. 56%) than their peers (Sonik et al., 2020; Rose-Jacobs et al., 2016), and they experience greater reductions in health status when exposed to food insufficiency (Sonik et al., 2020).
- Families raising CYSHCN who do not receive Supplemental Security Income (SSI) report higher rates of housing instability (Rose-Jacobs et al., 2019).
- Having a child with an early-life disability is also associated with substantially higher levels of unsecured debt that remain high throughout the lifespan (Houle et al., 2017).
- Lost earnings due to forgone family employment are estimated at \$18,000 per year for each affected household (Foster et al., 2021).





# BLUEPRINT FOR CHANGE FRAMEWORK



### **Previous Virtual Cafés**

View details of our previously held virtual cafés, including the presentation slides and accompanying fact sheet on that topic, below.

Integrating the Blueprint Into Your Needs Assessment Part 1: Understanding How to Use NSCH Data

Virtual Café 1 (February 23, 2024)

Presentation Slides

Fact Sheet

### Ask the Experts: Medical Home NPM

Virtual Café 2 (March 8, 2024)

**Presentation Slides** 

Fact Sheet

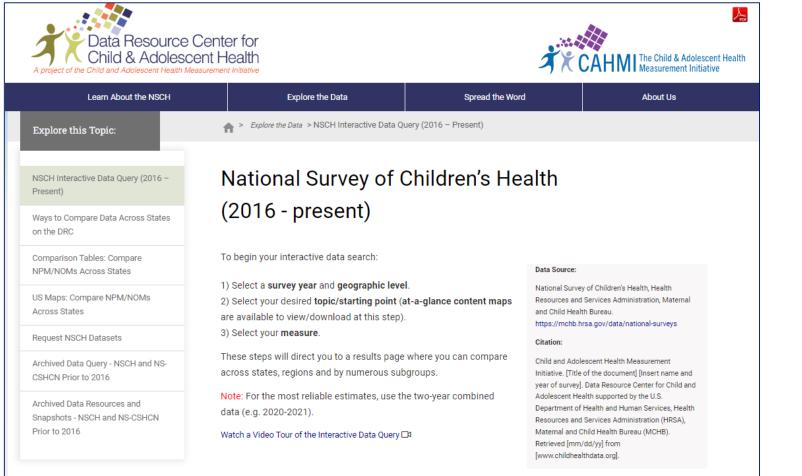


# **Key Facts about the NS-CH**

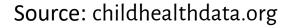
- National and state-level data on physical and emotional health of children 0-17 years old in the US
- Source of data on NOM/NPMs
- Parent-reported
- Annual since 2016
- Households invited to participate by mail
- Screener to determine if children are in the household
- Survey is administered online or on paper
- Survey is available in English and Spanish



### **DRC** WEBSITE – CHILDHEALTHDATA.ORG



### The DRC can be contacted at: info@cahmi.org





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## **NS-CH FINANCING-RELATED CONCEPTS**

- Uninsurance
- Adequate Insurance
  - Insurance benefits meet the child's need
  - Insurance coverage allows the child to see needed providers
  - Out-of-pocket costs are reasonable
- Family Financial Hardship



### **NS-CH-** FINANCING-RELATED CHILD AND FAMILY HEALTH MEASURES

- Health Insurance Status
- · Consistency of Insurance Coverage
- $\cdot$  Type of Insurance Coverage
- · Adequacy of Current Insurance
- Adequate and Continuous Insurance
- $\cdot\,$  Adequacy of Insurance Coverage for Mental Health Care, Age 3-17
- Out-of-pocket Costs for Medical Care and Health Care
- $\cdot$  Forgone Health Care Due to Cost
  - $\cdot$   $\,$  Problems Paying Medical Bills
- · Children Living in "Working Poor" Households
- Left a Job, Took a Leave of Absence, or Cut Back Hours Due to Child's Health
- · Avoided Changing Jobs to Maintain Insurance
- Received Food or Cash Assistance
- Family Health · New in 2022

Health

Insurance Coverage

Health Care

Access and

Quality

and Activities

- Child receives Supplemental Security Income
- Housing Instability
- $\cdot$  Caregiver stress about being evicted or removed from house

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## **NS-CH UNINSURANCE VARIABLES**

Indicator	Question
Indicator 3.1 Current health insurance status	Is this child currently covered by health insurance or health coverage plans?
Indicator 3.2 Consistency of insurance coverage	Did this child have consistent health insurance coverage during the past 12 months?



## **NS-CH ADEQUATE INSURANCE VARIABLES**

Indicator	Question
Indicator 3.4 Adequacy of current insurance	Is this child's current insurance coverage usually/always adequate to mee their needs?
Health insurance benefits met child's needs	How often does this child's health insurance offer benefits or cover services that meet this child's needs?
Coverage allowed child to see needed providers	How often does this child's health insurance all them to see the health care providers they need?
Reasonable out-of-pocket health care costs	How often are out-of-pocket costs for this child's health care reasonable?
Indicator 3.4a Adequate and continuous insurance	Is this child adequately and continuously insured; that is, is their current insurance adequate and were they insured for the entire past 12 months?
Indicator 3.5 Adequacy of insurance coverage for mental health care, age 3-17	Thinking specifically about this child's mental or behavioral health needs, how often does this child's health insurance offer benefits or cover services that meet these needs, age 3- 17 years?

## **NS-CH ADEQUATE INSURANCE VARIABLES (CONT.)**

Indicator	Question
Indicator 3.6: Out-of-pocket cost for medical and health care	Including co-pays and amounts reimbursed from Health Savings Accounts (HSA) and Flexible Spending Accounts (FSA), how much money did you pay for this child's medical, health, dental, and vision care DURING THE PAST 12 MONTHS? <i>Do not</i> <i>include health insurance premiums or costs that were or will be</i> <i>reimbursed by insurance or another source.</i>
Forgone health care due to cost	Did the following reason contribute to this child not receiving needed health services: there were issues related to cost?
Indicator 4.19: Problem paying medical bills	During the past 12 months, did your family have problems paying for any of this child's medical or health care bills?



### **NS-CH FAMILY FINANCIAL HARDSHIPS VARIABLES**

Indicator	Question	
Indicator 4.19: Problem paying medical bills	During the past 12 months, did your family have problems paying for any of this child's medical or health care bills?	
Indicator 6.5a: Children living in "working poor" households	Does this child live in a "working poor" household: that is, a household with incomes less than 100% of the federal poverty level with at least one caregiver employed full- or part-time?	
Indicator 6.17: Job change due to problems with childcare, age 0-5 years	During the past 12 months, did you or anyone in the family have to quit a job, not take a job, or greatly change your job because of problems with childcare for this child, age 0-5 years?	
Indicator 6.18: Left a job, took a leave for absence or cut back hours due to child's health	During the past 12 months, have you or other family members left a job, taken a leave of absence, or cut down on the hours you work because of this child's health or health conditions?	
Indicator 6.19: Avoided changing jobs to maintain insurance	During the past 12 months, have you or other family members avoided changing jobs because of concerns about maintaining health insurance for this child?	

### **NS-CH FAMILY FINANCIAL HARDSHIPS VARIABLES (CONT.)**

Indicator	Question
Indicator 6.27: Received food or cash assistance	Does this child live in a household that received food or cash assistance at any time during the past 12 months, even for one month?
Cash assistance from government	At any time during the past 12 months, even for one month, did anyone in your family receive cash assistance from a government welfare program?
Food Stamps	At any time during the past 12 months, even for one month, did anyone in your family receive Food Stamps or Supplemental Nutrition Assistance Program benefits (SNAP)?
Free or reduced cost meals	At any time during the past 12 months, even for one month, did anyone in your family receive free or reduced-cost breakfasts or lunches at school?
WIC benefits	At any time during the past 12 months, even for one month, did anyone in your family receive benefits from the Woman, Infants, and Children (WIC) Program?





### NS-CH FAMILY FINANCIAL HARDSHIPS VARIABLES – 2022 ONLY

Indicator	Question	
Indicator 6.28: Child receives Supplemental Security Income	Does this child receive SSI, that is, Supplemental Security Income?	
Indicator 6.28a: Child receives Supplemental Security Income for a disability	Does this child receive Supplemental Security Income (SSI) for a disability they have?	
Indicator 6.29: Housing Instability	Did this child's family experience housing instability in the past year?	
Not able to pay mortgage or rent	During the past 12 months, was there a time when you were not able to pay the mortgage or rent on time?	
Child ever experienced homelessness	Since this child was born, have they ever been homeless or lived in a shelter? Include living in a shelter, motel, temporary or transitional living situation, scattered site housing, or having no steady place to sleep at night.	
Number of places child has lived	During the past 12 months, how many places has this child lived?	
Indicator 6.30: Caregiver stress about being evicted or removed from house	During the past 12 months, how often were you worried or stressed about being evicted, foreclosed on, or having your house condemned?	



Physical, Oral Health and Functional Status

Individual oral health problems, age 1-17 years

Prevalence and severity of current or lifelong health

conditions

Blood disorders (such as sickle cell disease, thalassemia,

Cerebral palsy (severity data not collected in 2022)

Down syndrome (severity data not collected)

Frequent or severe headaches, 3-17 years

Behavioral and conduct problem, 3-17 years

Speech or other language disorder, 3-17 years

Hearing problem (severity data not collected)

Vision problem (severity data not collected)

Autism/Autism Spectrum Disorder (ASD), 3-17 years

Prevalence of additional health conditions

(not included in indicator 1.9 condition count)

Prevalence of specific functional difficulties

Difficulty with repeated or chronic physical pain, including

Difficulty coordinating or moving around, 0-5 years

Serious difficulty concentrating, remembering, or making

Serious difficulty walking or climbing stairs, 6-17 years

Difficulty dressing or bathing, 6-17 years

Difficulty doing errands alone, 12-17 years

Difficulty with breathing or other respiratory problems

Allergies including food, drug, insect, seasonal or other

Toothaches

Asthma

or hemophilia)

Cystic fibrosis

Heart condition

Bleeding gums

Decayed teeth or cavities

Epilepsy or seizure disorder

Genetic or inherited condition

Tourette Syndrome, 3-17 years

Development delay, 3-17 years

Intellectual disability, 3-17 years

Learning disability, 3-17 years

Concussion or brain injury

Congenital heart condition

Difficulty with eating or swallowing

Difficulty with digesting food

decisions, 6-17 years

Hearing problems

Vision problems

Difficulty using hands, 0-5 years

headaches

Anxiety problems, 3-17 years

Depression, 3-17 years

ADD/ADHD, 3-17 years

#### Child and Family Health Measures – Survey Items Displayed in the Data Query

2021-2022 National Survey of Children's Health

#### Health Insurance Coverage

#### Individual items for insurance adequacy

Health insurance benefits met child's needs Coverage allowed child to see needed provider Reasonable out-of-pocket health care expenses

#### Health Care Access and Quality

 Dental check-up Dental Dental cleaning
Instruction on oral health care

Dental X-rays Eluoride treatment

Dental sealant

#### Types of care received from an eve doctor

- Received eve examination
- Received prescription for eyeglasses or contact lenses Received a diagnosis of a vision disorder other than nearsighted, farsighted, or astigmatism

#### Recommendation for a vision test

Recommended for an eve examination or additional vision services

#### Individual components of family-centered care

- Doctors spent enough time with the child
- Doctors listened carefully
- Doctors showed sensitivity to family values and customs
- Doctors provided information specific to parents' concerns

#### Doctors helped parents to feel like partners in care

#### Individual components of care coordination

Family gets help with coordinating child's health care among those who needed Needed extra help to coordinate health care Got needed extra help with care coordination Satisfaction with communication among child's doctor and other health care providers Health care provider communicated with child's school, childcare provider, or special education program Satisfaction with communication among child's doctors and school, childcare provider, or special education program

#### Individual components of shared decision making

 Doctors discussed range of health care/treatment options Doctors made it easy for parents to raise concerns or disagree with recommendations Doctors worked with parents to decide together health care/treatment options

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Citation: Child and Adolescent Health Measurement Initiative (2023). "Child and Family Health Measures Content Map - Survey Items Displayed in the Data Query, 2021-2022 National Survey of Children's Health". 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.childhealthdata.org].

This Content Map presents the list of survey items displayed in the 2021-2022 NSCH Interactive Data Query. The Indicator level Content Maps for the "Child and Family Health Measures" and the "National Performance and Outcome Measures" are available on the DRC website.

Vandalism such as broken windows or graffiti



11 survey items, 1-5 years

 Bounce back quickly when things don't go their way Affectionate and tender with parent Show interest and curiosity in learning new things

#### 6-17 years

 Show interest and <u>curit</u> Stay calm and an control when faced with a challen Work to mish the task they start

- Not covered by health insurance due to change in employment
- status
- Dropped health insurance coverage because it was unaffordable
- Dropped health insurance coverage because choice of health care
- Not covered by insurance due to problems with application or renewal process Problems with application or renewal process

Time spent outdoors on most weekdays

Sugary drink consumption

Vegetable consumption

Fruit consumption

or behavioral conditions criteria

Types of special health care needs

Complexity of special health care needs

Number of CSHCN Screener criteria CSHCN met

special health care needs

#### Individual flourishing items for young children,

Smile and laugh

#### Individual flourishing items for children and adolescents, age

#### Health Insurance Coverage

- Reasons not covered by insurance entire year

  - Not covered by health insurance because of cancellation due to overdue premium
  - Dropped health insurance coverage because benefits were inadequate
  - provider was inadequate

Time spent outdoors, age 3-5 years Time spent outdoors on an average weekend day Emotional and Mental Health

Physical, Oral Health and Functional Status

Types of special health care needs

Qualifying on CSHCN Screener prescription medication criteria

Qualifying on CSHCN Screener for elevated use of service criteria

Qualifying on the CSHCN Screener ongoing emotional, development

Ongoing emotional, developmental, or behavioral needs and other

Healthy eating

(consumption of sugary drinks, vegetables, fruit), 1-5 years

Qualifying on the CSHCN Screener functional limitations criteria

Qualifying on the CSHCN Screener specialized therapy criteria

#### age 6 months-5 years

# **DISCUSSION QUESTIONS**

- What aspects of financing have you considered including in your state Title V Needs Assessment?
- 2. How can you effectively incorporate input from people with lived experience into financing-related aspects of your Needs Assessment?
- 3. What financing-related variables from the NS-CH do you regularly review?
- **4**. How you are using/planning to use NS-CH data to identify financing-related gaps and opportunities for CYSHCN?
- 5. How can the National Center help you with utilizing data from the NS-CH?



### **ANY OTHER QUESTIONS?**



# **CONTACT US!**

- Blueprint4CYSHCN@aap.org
- National Center for a System of Services for CYSHCN Web site
- Subscribe to the National Center for a system of services for CYSHCN listserv to get access to valuable resources, event notifications, and so much more!



### **VIRTUAL CAFÉ EVALUATION SURVEY**





## **NS-CH REVIEW**

- The National Survey of Children's Health (NS-CH) MCHB-funded and supported data source for state Title V programs and allies
- National and state-level data on the physical and emotional health of children 0-17 years old in the US
- Broad array of indicators, including access to and use of health care, family interactions, parental health, school and after-school experiences, and neighborhood characteristics
- Provides data to see progress on 19 NOM/NPM and each state's Title V needs assessment



## **NS-CHOVERVIEW – FREQUENCY**

- Since 2016, the NS-CH has been an annual survey.
- The survey supports national estimates every year and state-level estimates by combining 2 or 3 years of data.
- Before 2016, the survey was conducted every 4 years.
- For the 2022 survey, data were collected from July 2022 to January 2023.



## **NS-CHOVERVIEW – SURVEY PARTICIPANTS**

- In 2022, a sample of approximately 360,000 addresses was selected from the Census Master Address File
- Households were randomly contacted by mail to identify those with one or more children under 18 years old.
- Number of surveys completed in 2022:
  - Approximately 125,000 households were screened for age-eligible children in sampled addresses
  - 67,269 children reported on completed screeners
  - 54,103 child-level topical questionnaires completed (state ranges from 688 to 4,724)
  - 13,016 of topical questionnaires completed on CSHCN
- Survey data were weighted to represent the population of non-institutionalized children ages 0-17 who live in housing units nationally and in each state.



### **NS-CHOVERVIEW – DATA COLLECTION**

- Households received a mailed invitation asking an adult in the household who is familiar with the child's health and health care (usually a parent) to complete a short screener questionnaire (via web or paper).
- If a child (or children) was reported to live in the household, participants who chose to respond online were immediately directed to a more detailed, age-specific topical questionnaire for one randomly selected child
- Participants also had an option to complete a paper version of the screener and topical questionnaire.
- Telephone questionnaire assistance was available to complete the survey over the phone.
- The NS-CH screener and topical questionnaires were available in both English and in Spanish.



## **NS-CHOVERVIEW - SCREENER**

- A screener instrument identifies households with children.
- The screener questionnaire included a series of health questions (next slide) used to determine whether each eligible child could be classified as having a special health care need. One eligible child from each completed screener questionnaire was subsampled.
- When subsampling CSHCN were oversampled (at 80%)
- The Screener data file must be used to estimate the proportion of households with CSHCN and the prevalence estimates at the state and national levels.



In order for a child to meet CSHCN Screener criteria for having a special health care need, all three parts of at least one screener question (or in the case of question 5, the two parts) must be answered "YES"

<ul> <li>Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?</li> <li>Yes No</li> <li>If yes, is this child's need for prescription medicine because of ANY medical, behavioral, or other health condition?</li> <li>Yes No</li> <li>Yes No</li> <li>If yes, is this a condition that has lasted or is expected to last 12 months or longer?</li> <li>Yes No</li> </ul>	<ul> <li>9 Is this child limited or prevented in any way in their ability to do the things most children of the same age can do?</li> <li>Yes</li> <li>No</li> <li>→ If yes, is this child's limitation in abilities because of ANY medical, behavioral, or other health condition?</li> <li>Yes</li> <li>No</li> <li>→ If yes, is this a condition that has lasted or is expected to last 12 months or longer?</li> <li>Yes</li> <li>No</li> </ul>	<ul> <li>Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?</li> <li>Yes</li> <li>No</li> </ul>
<ul> <li>Boes this child need or use more medical care, mental health, or educational services than is usual for most children of the same age?</li> <li>Yes No</li> <li>→ If yes, is this child's need for medical care, mental health, or educational services because of ANY medical, behavioral, or other health condition?</li> <li>Yes No</li> <li>→ If yes, is this a condition that has lasted or is expected to last 12 months or longer?</li> </ul>	<ul> <li>Does this child need or get special therapy, such as physical, occupational, or speech therapy?</li> <li>Yes</li> <li>No</li> <li>If yes, is this because of ANY medical, behavioral, or other health condition?</li> <li>Yes</li> <li>No</li> <li>If yes, is this a condition that has lasted or is expected to last 12 months or longer?</li> <li>Yes</li> <li>No</li> </ul>	<ul> <li>If yes, has their emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?</li> <li>Yes</li> <li>No</li> </ul>

Source: https://www.census.gov/content/dam/Census/programs-surveys/NS-CH/tech-documentation/questionnaires/2022/NS-CH-S1.pdf



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# **DRC WEBSITE**

- The Data Resource Center takes the results from the NS-CH and makes them easily accessible to parents, researchers, community health providers and anyone interested in maternal and child health
- Data on this site are for the nation and each of the 50 states plus the District of Columbia.
- On the site, state and national data on subgroups can also be accessed.
  - Subgroups available include age, sex, race/ethnicity, income, language, family structure, special health care needs status, complexity of health care needs, adverse childhood experiences, and more

