



Data Resource Center on Child and Adolescent Health

Maximizing the use of the new national surveys on
child and adolescent health and health care

Every State and Family Child Health Leader Deserves a Data Home

MCHB Webcast
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Data Resource Center for Child and Adolescent Health
From Information to Action

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Children & Youth with Special Health Care Needs (CYSHCN)

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- ▶ Resources for Data Users
- ▶ Issue Briefs
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Children & Youth with Special Health Care Needs

Welcome to the Children and Youth with Special Health Care Needs (CYSHCN) homepage of the Data Resource Center for Child and Adolescent Health.

You will find tips and tools for using data to help guide improvements in community-based systems of care for CYSHCN - including an easy to use, interactive data query feature that allows users to view and compare state, regional and nationwide findings from the **National Survey of Children with Special Health Care Needs**, Educational materials about the survey as well as state profiles on key performance indicators for CYSHCN from the National Survey of Children with Special Health Care Needs are also available.

Other resources to help state and family data users include:

Join a Discussion

Ask a Question

Make a Suggestion

Your Voice Counts!
Answer our poll




What is the Data Resource Center?

- A website that delivers hands-on, user-friendly access to national, state and regional data from the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the 2003 National Survey of Children's Health (NS-CH)
- A technical assistance resource:
 - email and telephone assistance
 - "hot topic" e-updates
 - in-person, telephone and online workshops
 - Online educational materials, examples of data use by states and links to related websites

What are the Goals for the Data Resource Center?

- Provide centralized and user-friendly access to standardized national survey findings
- Build common knowledge, capacity and passion for using data to stimulate and inform system change locally and nationally

Who are we?

- The Child and Adolescent Health Measurement Initiative staff
- Family Voices staff and family leaders advisory group
- Technical Advisory Committee

Who else do you need to know about?

- The Data Resource Center is one of several efforts coordinated under the rubric of the Champions for Progress Center at UT State University
- You! State and Family advisory committees provide ongoing and essential input and guidance!
- Our sponsor! The Division of CSHCN, Maternal and Child Health Bureau, Health Resources and Services Administration

What you can do?

- **Access information** about children, youth and their families
- **Search and compare** national, state, and regional survey results
- **Learn** to use data more effectively
- **Discover** how other state and family leaders are using these findings
- **Get expert help** – by e-mailing us your questions, plus get links to other data sets and resources

Pilot Study

- **Six months timeline** (Oct 2002 – April 2003)
- **Funded by MCHB**
- **Collaboration btw. CAHMI & Family Voices**
- **Goals:**
 - Develop the conceptual model for a relevant, easy-to-use Web-based data resource center for states and family audiences
 - Design a prototype interactive data query interface that allows users access to data from the National Survey of CSHCN and similar surveys
 - Specify technical requirements for proposed online database and associated costs to build & maintain Web-site

What do state and family leaders say they need to use data from the national surveys effectively?

- **Easy access to the data**—data already merged, cleaned, preconstruction of complex variables and weighting for complex sampling
- **Specific knowledge of the survey** questions asked and construction of indicator variables
- **Technical help** in interpreting and using the data
- **Opportunities to learn** from and share with other state and family leaders using data
- **Opportunities to partner** with other stakeholders to discuss, interpret and act on the data findings
- **Concrete examples** of potential uses and models of how data can be used

Thinking about ways data could be used in your state

- **Identifying/documenting needs**
 - How many children in your state have what needs?
 - How does data support what you're hearing from the field (providers, families, other agencies)?
- **Building partnerships**
 - What partners could use this data: Public Programs, Health plans, Hospitals, Providers, community groups, faith based organizations?
 - How can you share data to support common efforts, improve care?

Additional ways data might be used:

- **Educating Policymakers**
 - What are key policy issues for your state ?
 - What programs need what information?
 - What data could help them learn about child health needs?
- **Advocacy**
 - Are there key pressure points in program budgets or priorities coming up?
 - What methods would be most effective in presenting your case?
 - How could you use data in Fact Sheets, Testimony, the media, along with family stories?
- **Grant Writing**
 - How can you use data to strengthen your proposal?

National Survey of Children with Special Health Care Needs

- Conducted for the first time during 2000 – 2001
- Random-digit dial telephone survey administered in 12 languages
- Uses **SLAITS** (State & Local Area Integrated Telephone Survey) sampling mechanism
- Sponsored by the Maternal and Child Health Bureau
- National Center for Health Statistics of the CDC oversees sampling and administration

Purpose:

- To provide **national and state estimates** for the numbers of CSHCN in the population
- To provide **national and state baseline measures** to compare with future survey results over time
- To provide information for the **Title V Block Grant needs assessment** states are required to conduct every five years
- To provide state-level information about **insurance status for all children**
- To provide information about CSHCN and their families to help guide policy makers, advocates, and researchers

National Survey of CSHCN



372,174 children, 0 - 17 yrs, in the 198,888 households contacted screened for having special health care needs



In-depth CSHCN interview collects information on:

- Child **health and functional status**
- Child **health insurance status** and adequacy of coverage
- **Access to health care** — including amounts and types of health care services used by child and any unmet needs for services
- **Care coordination**
- **Family-centeredness** of child's health care
- **Impact** of child's health on family

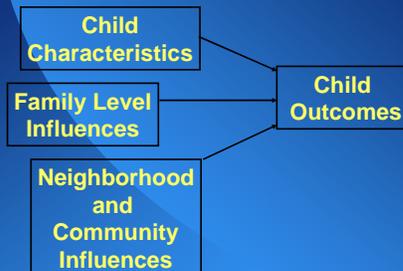
National Survey on Children's Health

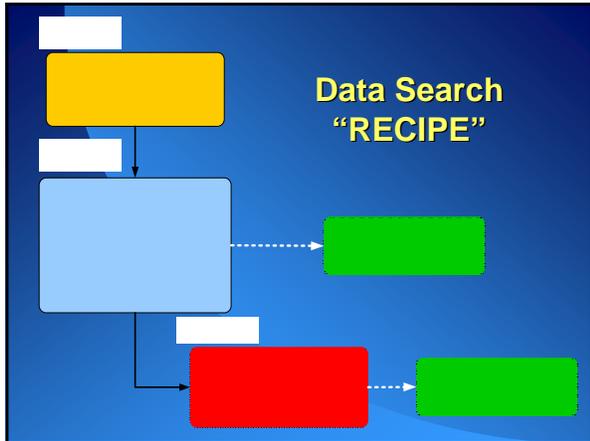
- **102,353 completed interviews**
 - Minimum: 1,483 in Utah
 - Maximum: 2,241 in Louisiana and Ohio
 - 25 states have more than 2,000 each
- **Overall response rate: 55.3%**
 - Minimum: 49.6% in New Jersey
 - Maximum: 64.4% in South Dakota
 - 32 states were above 55%

National Survey on Children's Health Topics

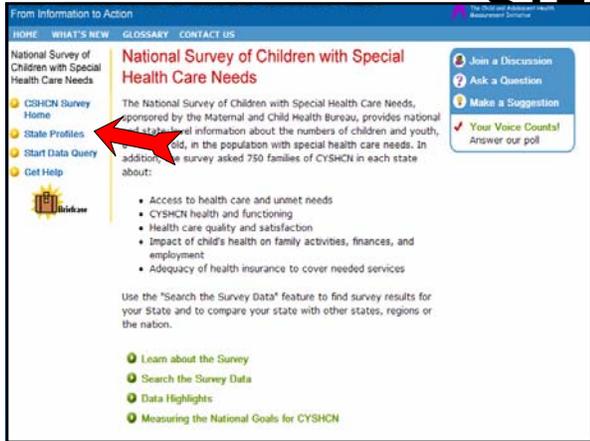
- ★ Access to care
 - ★ Health and dental insurance coverage
 - ★ Acute and chronic conditions
 - ★ Family functioning
 - ★ Parental health
 - ★ Neighborhood and school safety
 - ★ Development and well-being
 - ★ Child and adolescent activities
 - ★ Mental and emotional health
 - ★ Children with special health care needs
- Search these topics – plus MCHB key indicators for the nation's children – by age, gender, race/ethnicity, household income, insurance status, and more.

NSCH Survey Domains





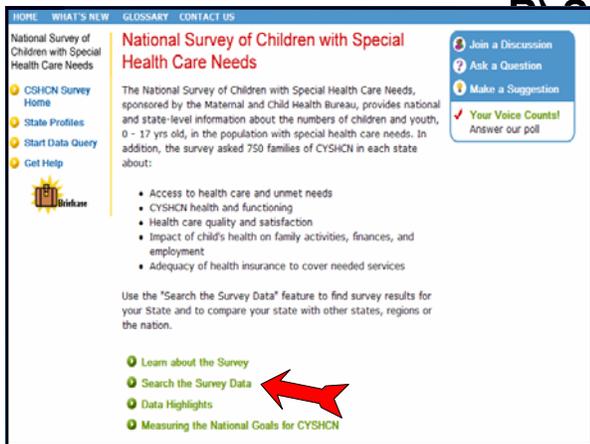
STEP 1



SELECT GEOGRAPHIC AREA of interest
(state, HRSA region, Nation)

STEP 2

A) SELECT a TOPIC



B) SELECT a QUESTION within topic area
Click on "Next" to view **RESULTS**

Click on "Next" to view another question

STEP 3

Click **"COMPARE SUBGROUPS"** to compare results for selected question

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Building Skills Workshops

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From Information to Action:
Making Progress Toward Community-Based Systems of Care for CYSHCN
Select a box for more information.

Resources for State and Family Data Users

[Measuring CYSHCN Six National Goals](#)
[New Data Users](#)
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GLOSSARY CONTACT US

State and National Initiatives

MEDICAL HOME

- AAP National Center of Medical Home Initiatives for CYSHCN**
Clearinghouse for information on medical home activities across the nation. Extensive resources to download, including how to contact the American Academy of Pediatrics (AAP) for technical assistance on medical home.
- Policy Statement on Medical Home – American Academy of Pediatrics (AAP)**
Direct link to the July 2002 updating of the original 1992 AAP Policy Statement on Medical Home with an expanded concept interpretation and operational definition of medical home.
- Center for Medical Home Improvement (CMHI)**
Established in 2001, CMHI is collaborating with the National Initiative for the Children's Healthcare Quality (NIHQ) to bring families, providers, and Title V programs together in a national learning collaborative on the medical home.

CULTURAL COMPETENCY

- National Center for Cultural Competency (NCCC)**
NCCC's Children & Youth with Special Health Care Needs Project is dedicated to helping state Title V CYSHCN programs design, implement, and evaluate culturally and linguistically competent service delivery and support systems.

TRANSITION TO ADULTHOOD

- Healthy & Ready to Work National Center (HRTW)**
HRTW strives to ensure that all youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including adult health care, employment and independence.

ACCESS TO AFFORDABLE INSURANCE

- Maternal and Child Health Policy Research Center**
The MCH Policy Research Center leads national efforts in research and policy analysis and

The Data Resource Center Can Help!

- **Getting Help**

- Insert the “Ask a Question” screen from the www.cshcndata.org website

DRC Workshop Goals

Gain **hands-on experience** with the CYSHCN Data Resource Center website

Learn to conduct **different types of data searches**

Learn how to read data tables & graphs from your data searches and **translate findings** into words for written and verbal communications

Learn about options for **interpreting data findings** and assessing significance of differences

Begin to develop a plan for how you will **share findings** to key partners and stakeholders
