



National Survey of Children's Health: Newborn Screening

Advisory Committee on Heritable Disorders in Newborns

May 14, 2021

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Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People



Outline

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1. Overview of the National Survey of Children's Health (NSCH)
2. Key Estimates from the 2018-2019 NSCH
3. Accessing and Using the Data
4. NSCH Innovations

National Survey of Children's Health: Overview



National Survey of Children's Health




- Sponsored by the **Health Resources and Services Administration's Maternal and Child Health Bureau**; conducted by the U.S. Census Bureau. Co-sponsorship by CDC and USDA.
- **Annual**, cross-sectional, address-based survey that collects information via the web and paper/pencil questionnaires.
- Designed to collect information on the health and well-being of **children ages 0-17**, and related health care, family, and community-level factors that can influence health.
- Provides both **national** and **state-level** estimates for all non-institutionalized children ages 0-17 years in the U.S.
- Data are released annually on **Child Health Day** for the previous year.

OMB No. 0970-0045 Approval Expires 03/31/2016



National Survey of Children's Health

A study by the U.S. Department of Health and Human Services to better understand the health issues faced by children in the United States today.



INFORMATIONAL COPY

The U.S. Census Bureau is required by law to protect your information and is not permitted to publicly release your responses in a way that could identify you or your household. The U.S. Census Bureau is conducting the National Survey of Children's Health on the behalf of the Department of Health and Human Services (HHS) under Title 13, United States Code, Section 833, which allows the Census Bureau to conduct surveys on behalf of other agencies. Title 42 U.S.C. Section 701(a)(2) allows HHS to collect information for the purpose of understanding the health and well-being of children in the United States. Federal law protects your privacy and keeps your answers confidential under 13 U.S.C. Section 6. Per the Federal Cybersecurity Enhancement Act of 2014, your data are protected from cybersecurity risks through screening of the systems that transmit your data.

Any information you provide will be shared for the work-related purposes identified above and as permitted under the Privacy Act of 1974 (5 U.S.C. Section 552a) and 2014 COMMERCIAL CENSUS, Demographic Survey Collection Census Bureau Sampling Frame.

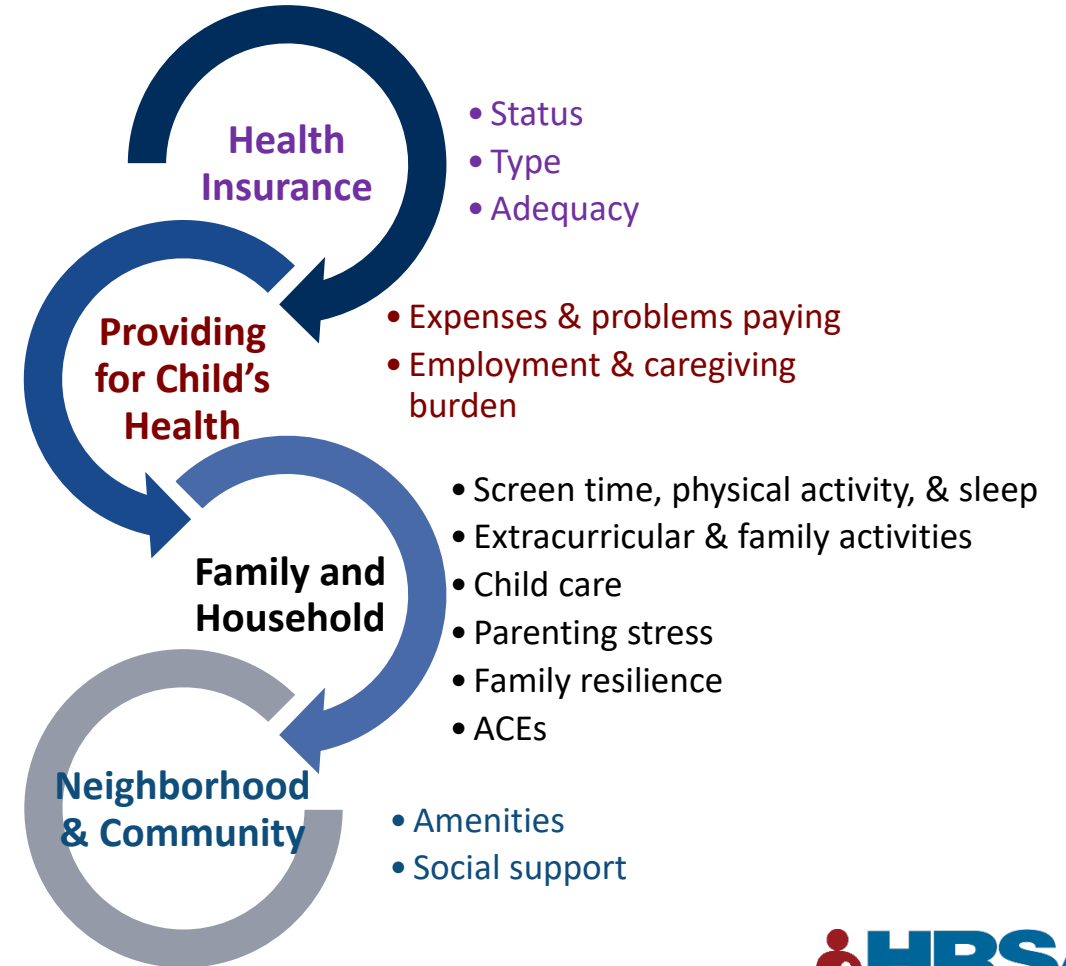
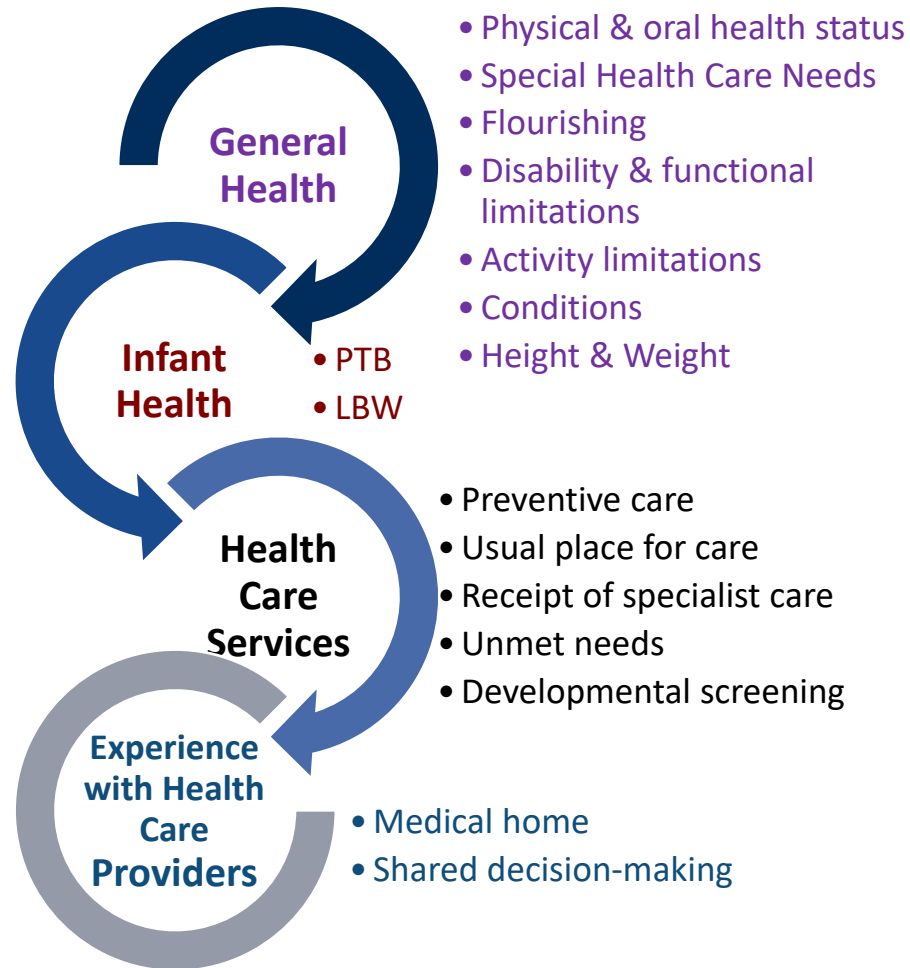
Participation in this survey is voluntary and there are no penalties for refusing to answer questions. However, your cooperation in obtaining this much needed information is extremely important in order to ensure complete and accurate results.

NSCH-T1
05/24/2016



NSCH Content

Core Content Areas



National Survey of Children's Health

Broad Utility

20 Title V MCH Services Block Grant National Performance and Outcome Measures:

- | | |
|---|--|
| 1. NPM 6: Developmental Screening | 11. NOM 13: School Readiness |
| 2. NPM 8.1: Physical Activity (6-11 years) | 12. NOM 14: Tooth Decay/Cavities |
| 3. NPM 8.2: Physical Activity (12-17 years) | 13. NOM 17.1: CSHCN |
| 4. NPM 9: Bullying (victimization and perpetration) | 14. NOM 17.2: CSHCN Systems of Care |
| 5. NPM 10: Adolescent Well-Visit | 15. NOM 17.3: Autism |
| 6. NPM 11: Medical Home | 16. NOM 17.4: ADD/ADHD |
| 7. NPM 12: Transition | 17. NOM 18: Mental Health Treatment |
| 8. NPM 13.2: Child/Adolescent Preventive Dental Visit | 18. NOM 19: Overall Health Status |
| 9. NPM 14.2: Smoking (household) | 19. NOM 20: Obesity |
| 10. NPM 15: Adequate Insurance | 20. NOM 25: Forgone Health Care |

Federal policy and program development:

- ✓ 15 Healthy People 2030 Objectives;
- ✓ CDC investments in ADHD, ASD, and Developmental Conditions;
- ✓ MCHB investments in early childhood (Home Visiting and Healthy Start);
- ✓ Children with Special Health Care Needs.



National Survey of Children's Health

Broad Utility

SUPPLEMENT TO
ACADEMIC PEDIATRICS
The Official Journal of the Academic Pediatric Association



SEPTEMBER/
OCTOBER
2017
VOLUME 17
NUMBER 75

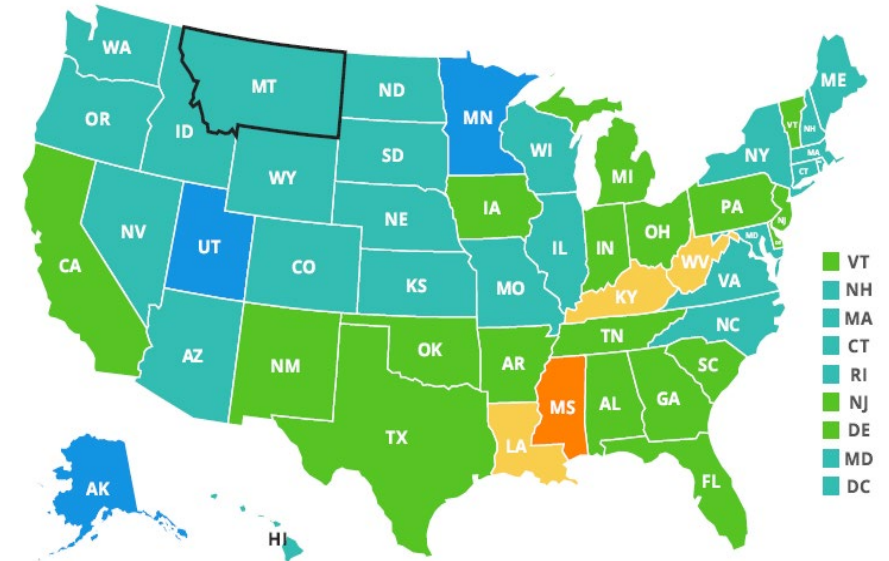
Child Well-being and

FOREWORD
Child Well-being and Adverse Childhood Experiences in the United States *Christina D. Bethell, et al*

COMMENTARIES
Promoting Lifelong Health and Well-being: Staying the Course to Promote Health and Prevent the Effects of Adverse Childhood and Community Experiences *Martha Davis, et al*
Aligning Community Capacity, Networks, and Solutions to Address Adverse Childhood Experiences and Increase Resilience *Margaret B. Hargreaves, et al*
The Community and Public Well-being Model: A New Framework and Graduate Curriculum for Addressing Adverse Childhood Experiences *David E. Ford*
Reclaiming the Patient Encounter *Sandra G. Hassink*
Prevent, Screen, Heal: Collective Action to Fight the Toxic Effects of Early Life Adversity *Nadine Burke Harris, et al*
ACEs Implications for Nurses, Nursing Education, and Nursing Practice *Shirley Girouard, Nellie Bailey*
Lessons From ACEs: Pay Now or Pay (More) Later *Katherine E. Grimes*
"Nothing About Us Without Us" *Melissa Clark Vickers, Nora Wells*
Culture Matters: Direct Service Programs Cannot Solve Widespread, Complex, Intergenerational Social Problems. Culture Change Can *Laura Porter, et al*
Translating Brain Science Research into Community-Level Change *Jennifer Jones, et al*
How Social Journalism Accelerates the ACEs Movement *Jane Stevens*
Mitigating Adverse Childhood Experiences Through Investments in Early Childhood Programs *Katherine A. Beckmann*
ACEs and State Maternal Child Health Programs *Bradley Flaney*
et al

STATE of CHILDHOOD OBESITY

Helping All Children Grow Up Healthy



Starbucks announces new backup childcare benefits, by Danielle Wiener-Bronner, [CNN Business](#). New York

Starbucks is sweetening the pot for employees with a new family care benefit. The company announced on Tuesday that it will provide workers with ten subsidized backup care days for children or adults. The new care policy "is the final piece of the puzzle," said Ron Crawford, vice president of benefits at Starbucks. Starbucks noted that 2 million working parents quit their jobs in 2016 because of child care, according to the National Survey of Children's Health.

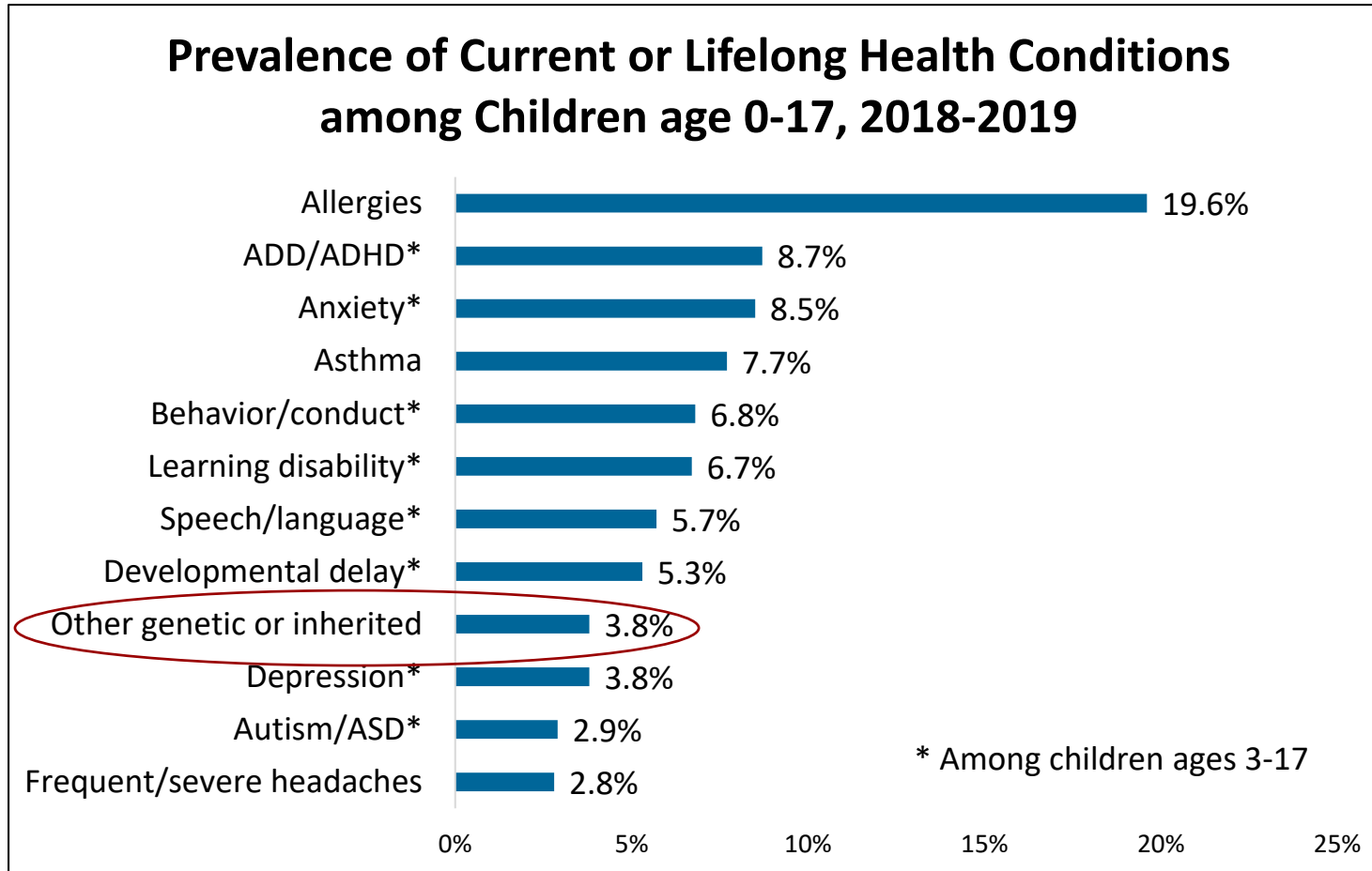


National Survey of Children's Health: Key Estimates



Key Estimates 2018-2019

Health Conditions

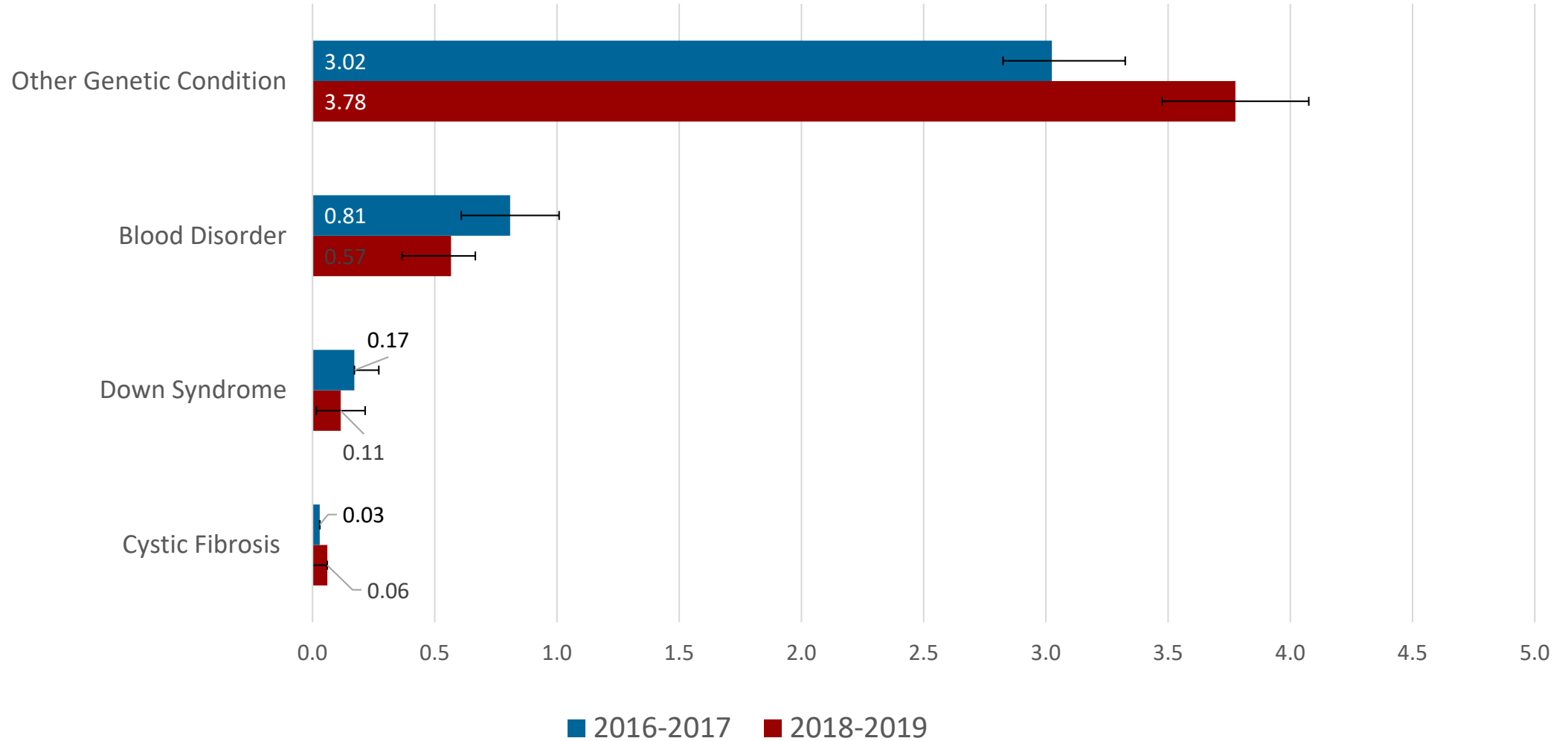


Note: Conditions with prevalence rates near or below 1% are not presented here.

- In 2018-2019, the most prevalent health condition among children was allergies (19.6%).
- Eight of the most frequent conditions were developmental delays.

Key Estimates 2018-2019

Heritable Conditions



Newborn Screening Questions

A17 Has a doctor or other health care provider EVER told you that this child has...
Blood Disorders (such as Sickle Cell Disease, Thalassemia, or Hemophilia)?

Yes No

↳ If yes, is it:

Mild Moderate Severe

Was this child diagnosed with:

Sickle Cell Disease? Yes No

Thalassemia? Yes No

Hemophilia? Yes No

Other Blood Disorders? Yes No

Were any of these blood disorders identified through a blood test done shortly after birth?
These tests are sometimes called newborn screening.

Yes No

A19 Other genetic or inherited condition?

Yes No

↳ If yes, specify: ↴

Is it:

Mild Moderate Severe

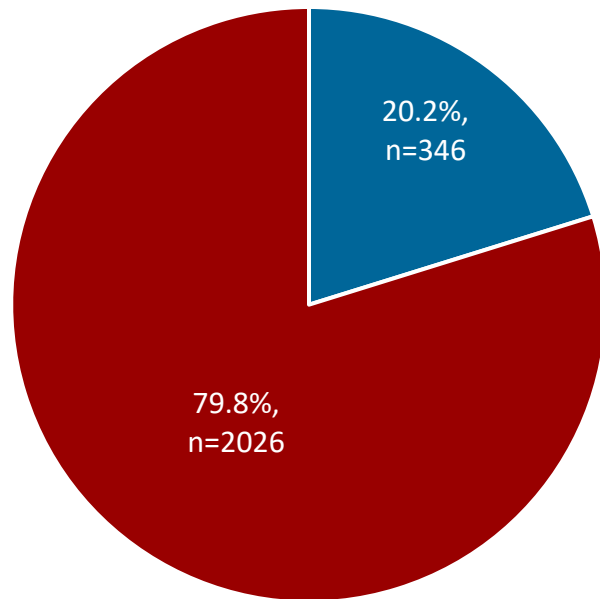
Was this condition identified through a blood test done shortly after birth? *These tests are sometimes called newborn screening.*

Yes No

Key Estimates 2018-2019

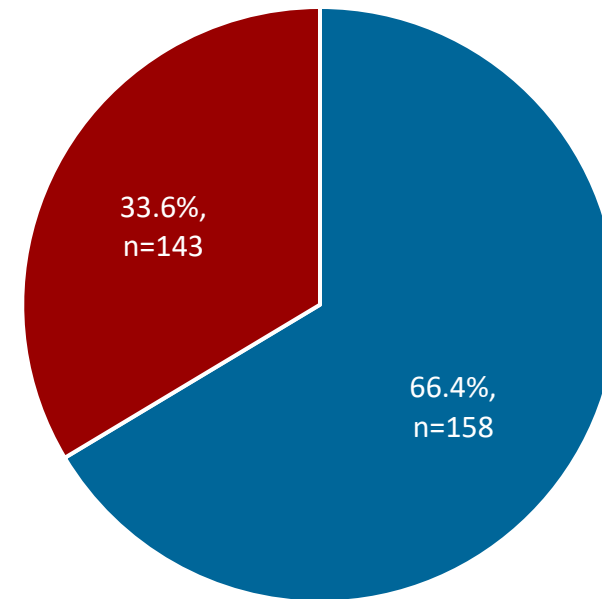
Percent of children with blood disorders or other genetic condition identified by newborn screening (NBS)

Genetic/Inherited Condition



■ NBS ■ Not NBS

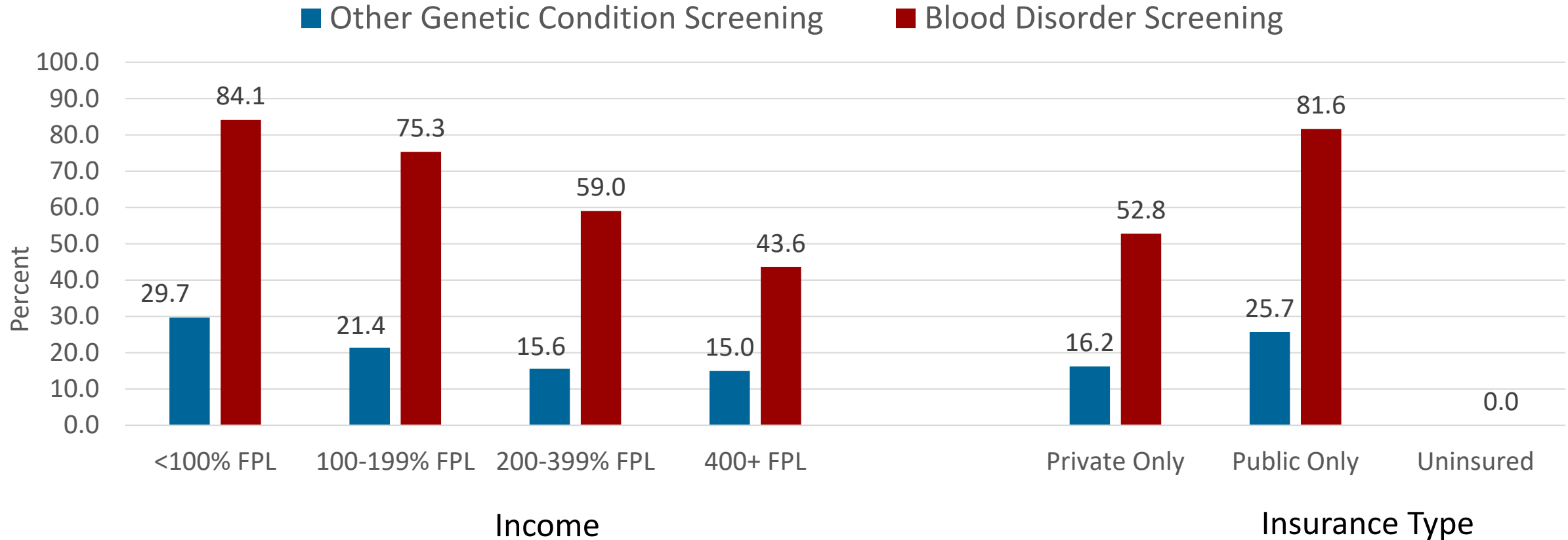
Blood Disorders



■ NBS ■ Not NBS

Key Estimates 2018-2019

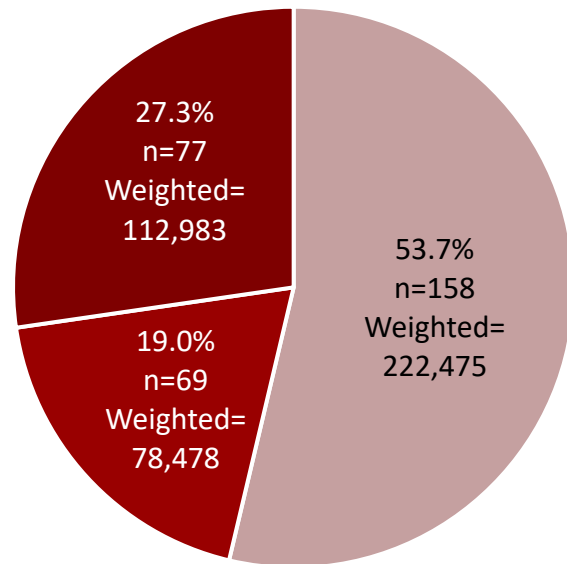
Newborn Screening (NBS)



Key Estimates 2018-2019

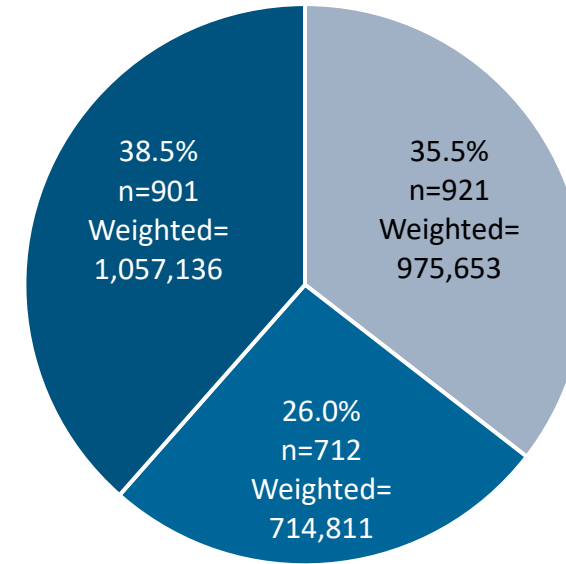
Heritable Conditions and Functional Limitations

Percent of children with BLOOD DISORDERS who have 0, 1, or ≥ 2 functional limitations



■ None ■ 1 functional limitation ■ 2 or more limitations

Percent of children with 'OTHER GENETIC CONDITIONS' who have 0, 1, or ≥ 2 functional limitations



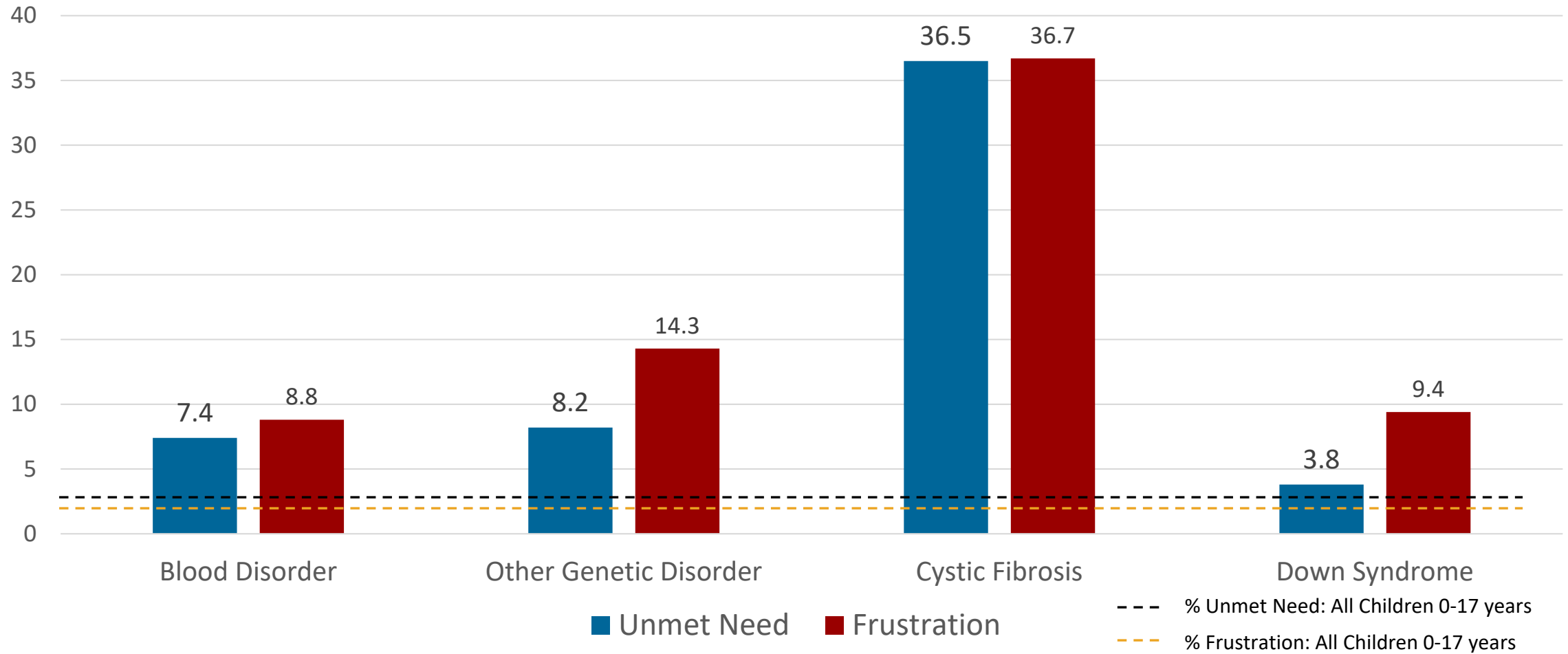
■ None ■ 1 functional limitation ■ 2 or more limitations

12 Functional Limitations: DIFFICULTY (1) breathing, (2) eating/swallowing, (3) digesting food, (4) using hands, (5) moving around, (6) concentrating (6-17 years), (7) walking/climbing stairs (6-17 years), (8) dressing/bathing (6-17years), (9) doing errands alone (12-17years); or (10) chronic physical pain, (11) deafness/problems with hearing, or (12) blindness/problems seeing even when wearing glasses



Key Estimates 2018-2019

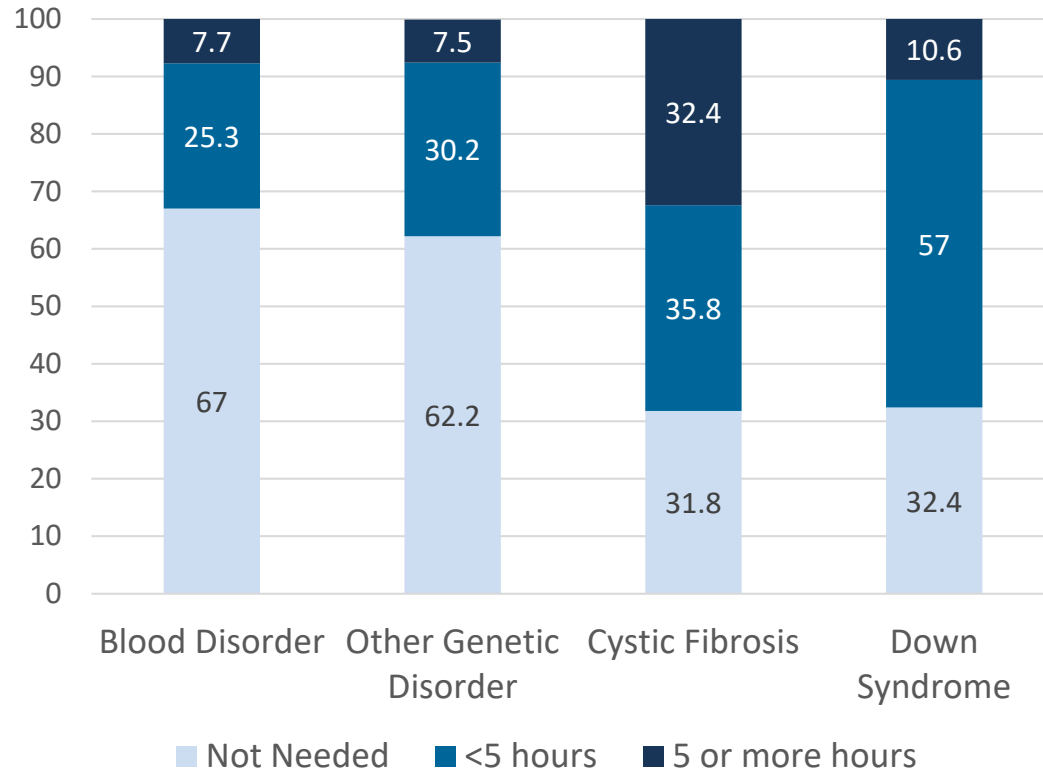
Heritable Disorders: Unmet needs and Frustration getting care



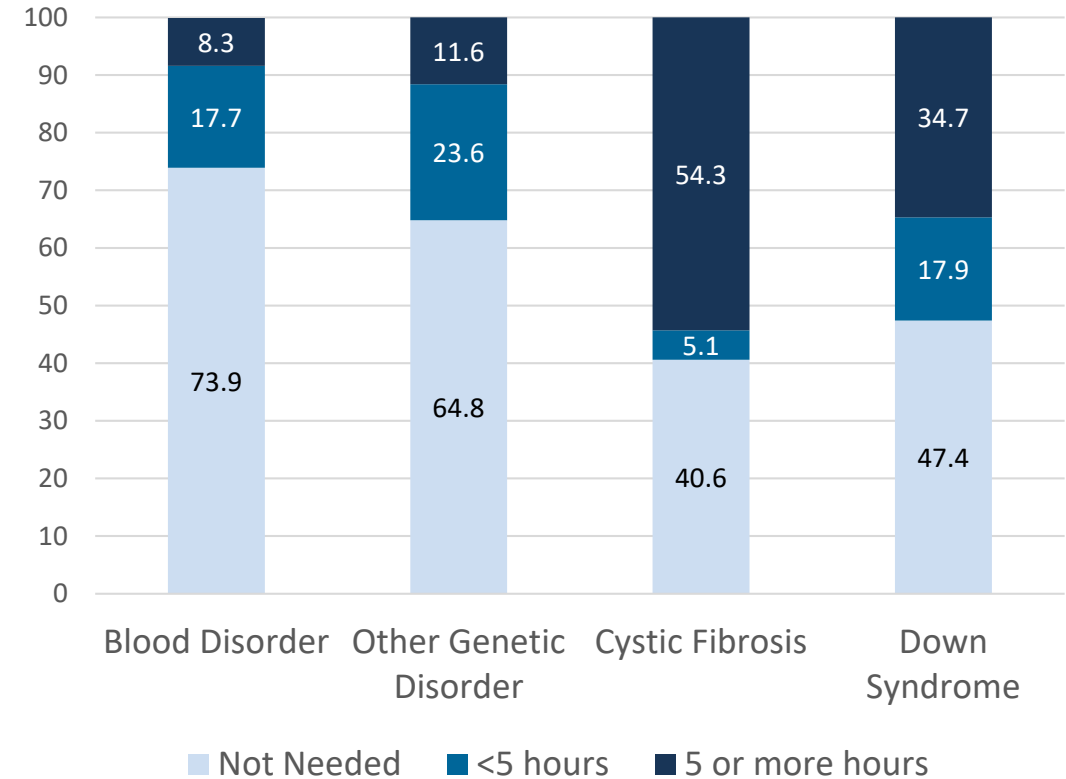
Key Estimates 2018-2019

Hours spent arranging health care or providing health care at home

Percent of parents reporting <5 hours or > 5 hours per week **ARRANGING** health care



Percent of parents reporting <5 hours or \geq 5 hours per week **PROVIDING** care at home



Accessing and Using the Data



National Survey of Children's Health

The National Survey of Children's Health (NSCH), funded and directed by HRSA MCHB, provides national and state level estimates of key measures of child health and well-being. These data are essential to understanding the health status and health services needs of children across the nation and in your state and community.

What's New in the 2019 NSCH?

Learn more about the National Survey of Children's Health:

- [Access the 2019 Data](#)
- [2018-2019 Mental and Behavioral Health Data Brief](#) (PDF - 146 KB)

2018 Data Briefs

- [2017-2018 Rural/Urban Differences in Children's Health](#) (PDF - 195 KB)
- [2017-2018 National Survey of Children's Health - Overview](#) (PDF - 660 KB)
- [2017-2018 Children with Special Health Care Needs Data Brief](#) (PDF - 942 KB)
- [2017-2018 Title V Block Grant Measure Data Brief](#) (PDF - 311 KB)
- [2017-2018 Adverse Childhood Experiences Data Brief](#) (PDF - 450 KB)
- [Press Release: New Estimates of Childhood ACEs, from the 2017-2018 NSCH](#)

Frequently Asked Questions

Data Users

Want to review or use data from the Survey? [View Frequently Asked Questions on the NSCH](#) (PDF - 410 KB)

URL:

<https://mchb.hrsa.gov/data/national-surveys>

Access point to all survey related materials.

Learn About the NSCH | Explore the Data | Spread the Word | About Us

Explore this Topic:

- NSCH Interactive Data Query (2016 - Present)
- Ways to Compare Data Across States on the DRC
- Comparison Tables: Compare NPM/NOMs Across States
- US Maps: Compare NPM/NOMs Across States
- Archived Data Query - NSCH and NS-CSHCN Prior to 2016
- Archived Data Resources and Snapshots - NSCH and NS-CSHCN Prior to 2016

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. 2018-2019).

[Watch a Video Tour of the Interactive Data Query](#)

Data Source:
National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau.
<https://mchb.hrsa.gov/data/national-surveys>

Citation:
Child and Adolescent Health Measurement Initiative. [Title of the document] [Insert name and year of survey]. 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].

1. Select a Survey Year and Geographic Area

Select a Year
2018-2019 (two years combined) ▼

Select a State/Region
Nationwide ▼

2. Select a Starting Point

- + Child and Family Health Measures (Content Map [A](#))
Over 300 indicators and survey items for child and family health and well-being
- + Title V Maternal and Child Health Services Block Grant Measures (Content Map [A](#))
Title V Maternal and Child Health Services Block Grant National Performance and Outcome Measures

URL:

<https://www.childhealthdata.org/>

User-defined query system; point-and-click access to state data.

NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Information for Respondents

Data

Technical Documentation

Contact Us

[Back to Our Surveys & Programs](#)

Sponsored By:



National Survey of Children's Health (NSCH)

The National Survey of Children's Health (NSCH) is sponsored by the [Maternal and Child Health Bureau](#) of the Health Resources and Services Administration, an Agency in the U.S. Department of Health and Human Services.

The NSCH examines the physical and emotional health of children ages 0-17 years of age. Special emphasis is placed on factors related to the well-being of children. These factors include access to - and quality of - health care, family interactions, parental health, neighborhood characteristics, as well as school and after-school experiences.

The NSCH is also designed to assess the prevalence and impact of special health care needs among children in the US and explores the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance, access to needed services, and adequate care coordination. Other topics may include functional difficulties, transition services, shared decision-making, and satisfaction with care. Information is collected from parents or guardians who know about the child's health.



URL:

<https://www.census.gov/programs-surveys/nsch.html>

Microdata files; all technical documentation.

NSCH Data

2019 NSCH Data Release

Access the 2019 public use microdata files.

State Oversampling in the National Survey of Children's Health

National Survey of Children's Health Innovations: Oversamples, and New Content



2019 NSCH and Beyond

Recapping Planned Innovations

2020 Survey:

- Content changes/revisions:
 - ✓ Concussion or brain injury;
 - ✓ Discrimination due to sexual orientation or gender identity;
 - ✓ Employment.
- First year of State oversamples.
- Launched July 27, 2020.
- Available October, 2021

2021 Survey:

- New content:
 - ✓ Early childhood nutrition;
 - ✓ COVID-19 related impacts on the child and family;
 - ✓ Discrimination due to physical ability.
- National oversample of young children and new additional State oversamples.

2022 Survey:

- Possible new/revised content:
 - ✓ Healthy Ready to Learn;
 - ✓ Housing insecurity;
 - ✓ Disordered eating;
 - ✓ Parental leave;
 - ✓ Urgent care.



NSCH State Oversampling

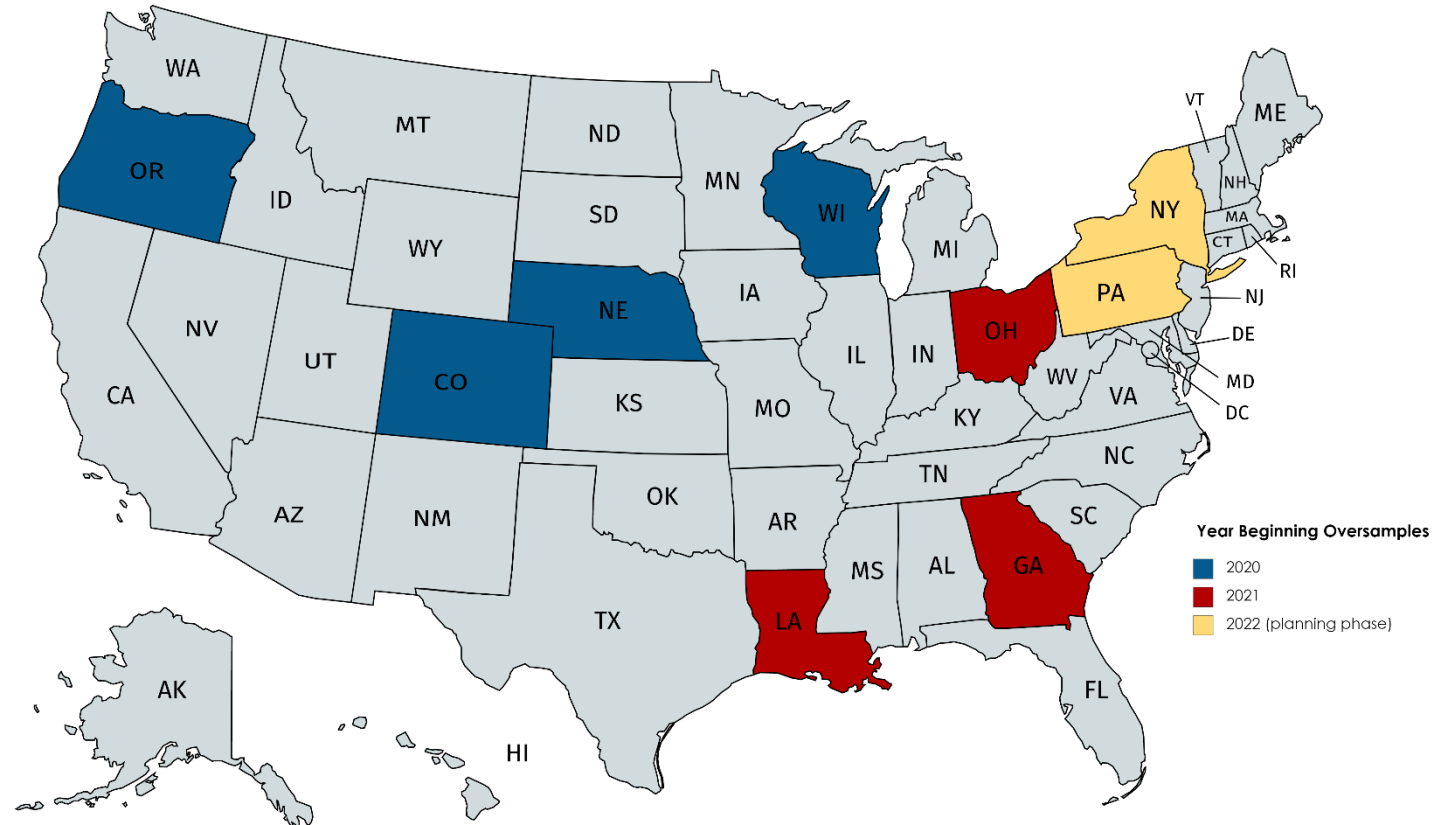
Goal: To inform targeted assessment and program planning/evaluation

- 1) General oversample
 - Smaller population group or rare outcome estimates (e.g., CSHCN by minority race/ethnicity)
 - 2) Sub-state oversample
 - Local area estimates (e.g., county or region)
- The option to sponsor an oversample began with the 2020 survey year with a total of 9 states having sponsored or planning to sponsor an oversample
 - Plans and agreements must be finalized by mid-July before the survey year
 - Cost depends on the type and size of the oversample
 - Actual costs have ranged from 20k to 500k



NSCH State Oversampling

State	Oversampling Type
CO	Sub-state – Regional
GA	Sub-state – Metro Atlanta
LA	General
NE	General
NY	General – Race/ethnicity targets Sub-state – Regional
PA	General
OH	General – Race/ethnicity targets
OR	General – Race/ethnicity targets
WI	General



National Oversample of Young Children

- For the 2021 NSCH, MCHB is partnering with the CDC's Division of Nutrition, Physical Activity, and Obesity in order to:
 1. Include five new survey items on early childhood nutrition and outdoor play. Questions will ask about the consumption of fruits, vegetables, sugar sweetened beverages, as well as time spent playing outdoors, among children ages 1 to 5 years old
 2. Conducted a national oversample of young children, in order to support state-level reporting of these new items after one year of data collection.



Contact Information

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Web: mchb.hrsa.gov



Thank you!
Questions?



Connect with HRSA

Learn more about our agency at:

www.HRSA.gov



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