

SERVING UNDERREPRESENTED POPULATIONS

What do you know?

Vicki Hunting, FL3 2021



Today's Discussion

- Underrepresented populations – defined
- Getting started (if you haven't)
- Where can you find data?
- Demographics poll example
- What will you do next?



NOFO/FOA Definitions



FL3:

For the purposes of this funding opportunity, “**underrepresented populations**” is intended to be inclusive of but is not limited to:

- underrepresented *racial and ethnic groups* (i.e., Hispanic or Latino, American Indian or Alaskan Native, Asian, Black or African-American, Native Hawaiian or Pacific Islander, two or more races (OMB),
- *nationality, language, locality, sex, sexual orientation, gender identity, disability, socio-economic status,*
- and those who have *adopted* children who are DHH, etc.

State:

...ensure that the state or territory’s EHDl system activities are inclusive of and address the needs of the populations it serves, including *geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.*

MCHB/HRSA-20-047 (states), page 11

HRSA State Program Goal

By the end of year 2, develop a plan to **address diversity and inclusion** in the EHDI system to ensure that the state or territory's EHDI system activities are **inclusive of and address the needs** of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.

MCHB/HRSA-20-047: NOFO, page 11, #5



Starting where you are...

1. Determine/document your **Aim** (purpose/goals/policies) for collecting demographics data
2. What do you have, what do you need?
3. Do your research: talk to other EHDI Programs, family-based organizations; what worked, what didn't



Starting where you are...continued

4. How will you get the data, who is responsible for compiling it?
5. Use the data to inform your focus!
6. Continue to evaluate progress, continuous improvement



Types of data to consider

- Age
- Gender, gender identity and sexual orientation
- Residence (Urban, Suburban, Rural)
- Race/Ethnicity (standard categories already in place)
- Language in the home
- Household Income
- Other disabilities
- State/territory/province/country
- Role (in supporting families, some other role; parent, caregiver, etc.)
- Freeform comments



Where can we find data?



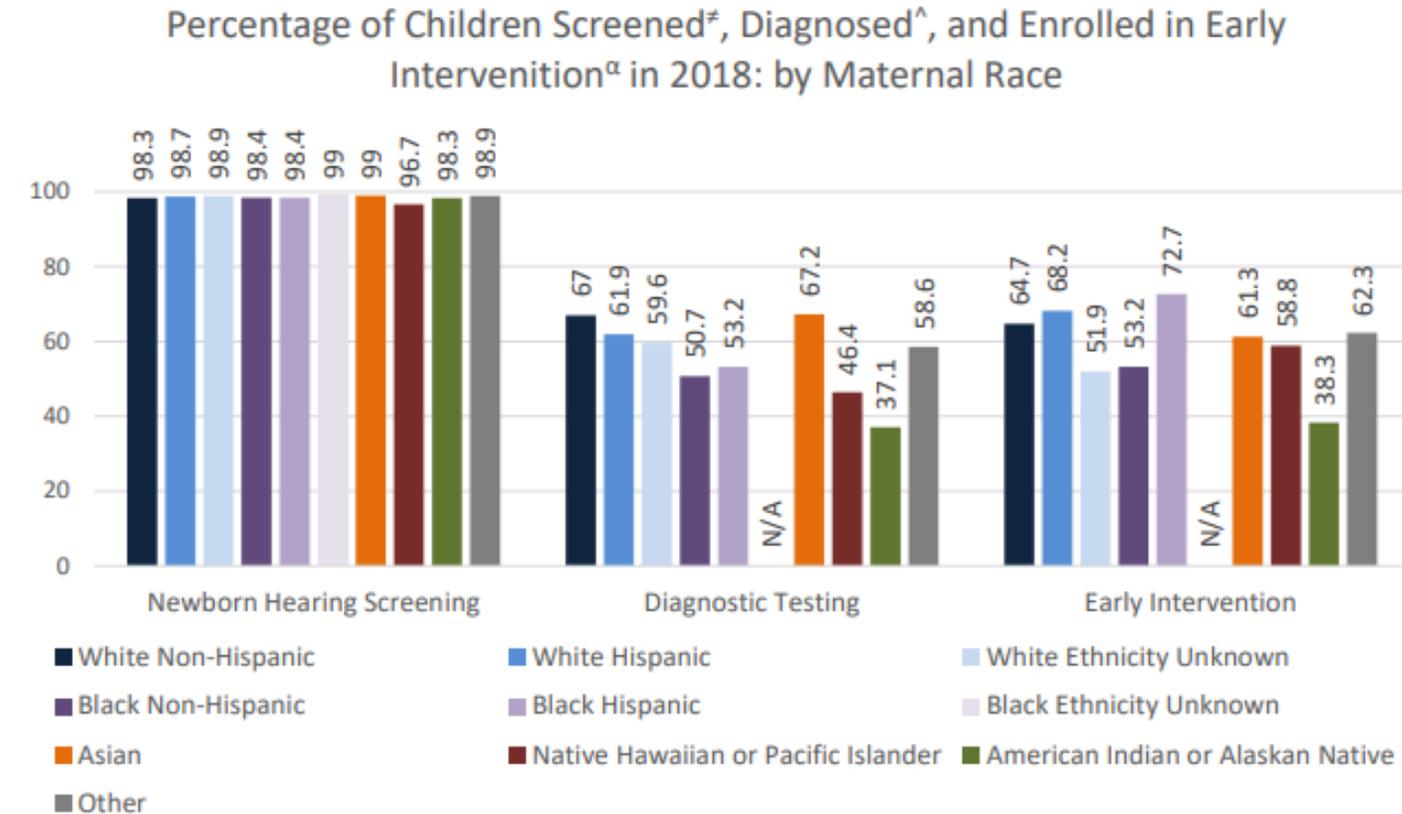
Many different places...



- EHDI Program
- State Department of Public Health – Epidemiology, Vital Records
- CDC EHDI Data (Annually by state/territory), aggregated demographics
- US Census Bureau
- **Data Resource Center for Child & Adolescence Health**
(National Survey of Children's Health Interactive Data Query)

2018 EHDI Demographic Data

https://www.cdc.gov/ncbddd/hearingloss/2018-data/documents/2018-HSFS_Demographic-Summary.pdf



N/A: Not applicable - The number of infants reported is too small to draw any conclusions about this group.

Step 1: Select Birth/Maternity

Path: IBIS-PH » Topic

About • Health Topics • Health Indicator Reports • Explore Communities • Publications • Data Portal • Resources •

Topics Index
Health Topics

Births/Maternity

Description

Improving the well-being of mothers, infants, and children is an important public health goal for the United States. Their well-being determines their health behaviors, and health systems indicators that affect the health, wellness, and quality of life of women, children, and families.1

1. Healthy People 2020 Topics and Objectives, Maternal, Infant, and Child Health, accessed on 8/11/2014 from <http://www.healthypeople.gov/>

Why It's Important

Who Is at Risk

How It's Tracked

Indicator Reports (data tables, maps, charts, more detailed information)

Queryable Datasets

Births

Fertility Rates

Adolescent Births

Prenatal Care

Infant Birth Weight

Preterm Births (<37 weeks)

Fetal Mortality (20 weeks or more gestation)

Infant Mortality (age 364 days or less)

Neonatal Mortality (age 0-27 days)

Postneonatal Mortality (age 28-364 days)

Birth Defects (prevalence per 10,000 live births)

Pregnancy Risk Assessment

Folic Acid Consumption

Publications

FAQs and Resources

About • Health Topics • Health Indicator Reports • Explore Communities • Publications • Data Portal • Resources •

Public Health Indicator Based Information System (IBIS)
Utah's Public Health Data Resource
Path: IBIS-PH » datasets » selection

About • Health Topics • Health Indicator Reports • Explore Communities • Publications • Data Portal • Resources •

Submit the Query Definition

Reset to Default Selections

Select a Different Measure To Query

My Saved Query Definitions List

Save Query Definition

View This Query Definition's XML

Query Builder for Birth Query Module for Utah Counties and Local Health Districts

Overview

The birth data in this IBIS-Q query module come from the Utah Birth Certificate database. The database

Getting Started

Follow the steps to narrow your query and display your results. When you are done forming your query,

Step 1: Select year (2019)

Step 2: Select mother's age group

Step 3: Select mother's race and medicaid status

Step 4: Select mother's characteristics

Step 5: Select infant characteristics

Step 6: Select health care system characteristics

Step 7: Select resident or occurrent births (All live births to Utah resident mothers regardless of where they occurred)

Step 8: Select mother's geographic area

Step 9: How to display the data (Grouped By: Year. Chart: None. Map: Default 2015)

Submit Reset

Example: Utah's Public Health Data System

Step 5: Select display by Mother's race/ethnicity

Step 3: Narrow selection by Year

About • Health Topics • Health Indicator Reports • Explore Communities • Publications • Data Portal • Resources •

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Step 9: How to display the data (Grouped By: Year. Chart: None. Map: Default 2015)

To display a map, you must select Geographic Area in Display By (category) and None in Group By (series)

Display By (category) Mother's Race/Ethnicity

Group By (series) None

Chart None

Map Default 2015

Submit Reset

ct the races and medicaid status you would like to include in your analysis.

ce

All races

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Other Pacific Islander

Other Racial Entries NEC

ce/Ethnicity

All

American Indian or Alaska Native

Asian

Black or African American

Hispanic/Latino

Native Hawaiian or Other Pacific Islander

White

Two or More Races

Unknown

medicaid status

Medicaid

Not Medicaid

Public Health Indicator Based Information System (IBIS)
Utah's Public Health Data Resource
Path: IBIS-PH » Topic

About • Health Topics • Health Indicator Reports • Explore Communities • Publications • Data Portal • Resources •

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Why It's Important

Who Is at Risk

How It's Tracked

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Queryable Datasets

Births

Count of Births

- Count of Births (state, county, and local health districts [LHDs])
- Count of Births (state, county, and LHDs by mother's race and Medicaid status)
- Count of Births (Utah Small Areas)
- Count of Births (Utah Small Areas by mother's race and Medicaid status)

Birth Rate (number of live births per 1,000 persons in the population)

- Birth Rate (state, county, and LHDs)
- Birth Rate Trend Analysis (state, county, and LHDs)
- Birth Rate (Utah Small Areas)
- Birth Rate Trend Analysis (Utah Small Areas)

FAQs and Resources

About • Health Topics • Health Indicator Reports • Explore Communities • Publications • Data Portal • Resources •

Step 2: Select births by county, LHD, Race, and Medicaid

Step 4: Narrow selection by race and Medicaid status

Step 1: Select Geography, Level, and State

The screenshot shows the United States Census Bureau website interface. At the top, there is a search bar and navigation tabs for 'All', 'Tables', 'Maps', and 'Pages'. On the left, a sidebar menu lists 'Topics', 'Geography', 'Years', 'Surveys', and 'Codes'. The 'Geography' section is expanded, showing options for 'Nation', 'Region', 'Division', 'State', 'County', 'Tract', 'Block Group', 'Block', and 'Zip Code Tabulation Area (Five-Digit)'. The 'State' option is selected. On the right, a 'STATE' section lists various states with checkboxes, and 'Georgia' is checked. There are also toggle switches for 'Show Summary Levels' and 'Show Geographic Components'.

Example: Georgia Census Data

Step 3: Review data, can refine more through the customize table option

The screenshot shows search results for '10,711,908 Total Population in Georgia'. Below this, there are sections for 'Tables' and 'EXPLORE DATA'. The 'Tables' section lists three results: 'RACE' (Decennial Census, 2020, 2010), 'ANNUAL ESTIMATES OF THE RESIDENT POPULATION: APRIL 1, 2010 TO JULY 1, 2019 - FOR FULL ESTIMATES DETAIL, VISIT https://www.census.gov/programs-surveys/popest.html' (Population Estimates, 2019), and 'ACS DEMOGRAPHIC AND HOUSING ESTIMATES' (American Community Survey, 2019-2010).

Step 2: Browse the data options and select one of interest (this ex is ACS)

The screenshot shows detailed ACS demographic and housing estimates for Georgia. The page title is 'ACS DEMOGRAPHIC AND HOUSING ESTIMATES'. The survey/program is 'American Community Survey' and the product is '2019: ACS 1-Year Estimates Data Profiles'. The table ID is 'DP05'. A 'CUSTOMIZE TABLE' button is visible. The table has columns for 'Label', 'Estimate', 'Margin of Error', 'Percent', and 'Percent Margin'. The data is filtered for 'Georgia'.

Label	Estimate	Margin of Error	Percent	Percent Margin
SEX AND AGE				
Total population	10,617,423	*****	10,617,423	
Male	5,170,126	±8,608	48.7%	
Female	5,447,297	±8,608	51.3%	
Sex ratio (males per 100 females)	94.9	±0.3	(X)	
Under 5 years	639,713	±5,784	6.0%	
5 to 9 years	678,013	±12,671	6.4%	
10 to 14 years	758,925	±12,425	7.1%	
15 to 19 years	746,150	±10,303	7.0%	
20 to 24 years	714,400	±9,108	6.7%	
25 to 34 years	1,458,596	±12,386	13.7%	
35 to 44 years	1,401,934	±10,196	13.2%	
45 to 54 years	1,397,014	±9,743	13.2%	
55 to 59 years	685,356	±12,102	6.5%	
60 to 64 years	614,130	±11,884	5.8%	

Current Search Criteria

Survey: 2018-2019 National Survey of Children's Health
Starting Point: Child and Family Health Measures
State/Region: Nationwide
Topic: Physical, Oral Health
Question: Hearing problems

Edit Search Criteria

Select a Region to Compare
Race/ethnicity of child

Current Search

Survey: 2018-2019

Starting Point: Child

State/Region: Nation

Topic: Physical, Ora

Question: Hearing p

Sub Group: Race/et

Does the child

Black, non-H

Other, non-H

Children who have deafness or problems with hearing

Survey Items: Survey instrument item number for children 0-5 years: A5a; for children 6-11 years: A7d; for children 12-17 years: A7e
Variable in public use data file: K2Q43B

Denominator: Children age 0-17 years

Numerator: Has problems with hearing; Does not have problems with hearing

Revisions and Changes: There have been no substantive changes to this measure since 2016.

Additional Notes: The measure was derived from a single item.

Treatment of Unknown Values: Missing values may be due to non-response (i.e. a skipped item) or a "don't know" response. The way these items are handled can vary by measure. For NPMs and NOMs, having missing values for all items in an indicator will lead to the case being given a missing value on the overall measure. For some other measures, if there is a missing value on any of the items, the case will be set to missing. How missing values are handled is documented in the "Additional notes" field above when required. Missing values are not included in 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:

About NSCH

The National Survey of Children's Health (NSCH), funded and directed by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), is designed to provide annual 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 data 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, federal and state stakeholders, clinicians and researchers. In 2016, the NSCH underwent a significant redesign which combined content from both the NSCH and the National Survey of Children with Special Health Care Needs (NS-CSHCN). Further information on that redesign can be found in ["The Design and Implementation of the 2016 National Survey of Children's Health"](#).

The NSCH is conducted as a household survey, and one child per household is selected to be the subject for the detailed age-specific questionnaire. The respondent to this questionnaire is a parent or guardian who is living in the home and has knowledge of the sampled child. Survey participants complete either web-based or self-administered paper-and-pencil questionnaires. Data from the NSCH is used for scientific research, federal policy and program development, and state-level planning and performance reporting. Information is collected on factors related to the health and well-being of children, including access to and utilization of health care, receipt of care in a medical home, systems of care for CSHCN, family interactions, parental health, school and after-school experiences, and neighborhood characteristics.

More information about the survey can be found in the ["About the National Survey of Children's Health"](#) section of this website and HRSA's [MCHB website](#).

Close

Pop. Est.	114,030	7,825,763
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C.I. = 95% Confidence Interval.

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

DATA ALERT: Missing values for this subgroup were imputed separately in each individual year. The estimates were calculated using a single imputation.

Data

www.childhealthdata.org/browse/survey/results?subgroup=650&r=1&g=794

Current Search Criteria

Survey: 2018-2019 National Survey of Children's Health
Starting Point: Child and Family Health Measures
State/Region: Nationwide

Edit Search Criteria

Select a Region to Compare
Age in 3 groups

Data

Current Search Criteria

Survey: 2018-2019 National Survey of Children's Health
Starting Point: Child and Family Health Measures
State/Region: Nationwide
Topic: Physical, Oral Health and Functional Status
Question: Hearing problem 
Sub Group: Age in 3 groups

Edit Search Criteria

Select a Region to Compare
Age in 3 groups

[Change Question, Topic or Survey](#)

Does the child have deafness or problems with hearing?

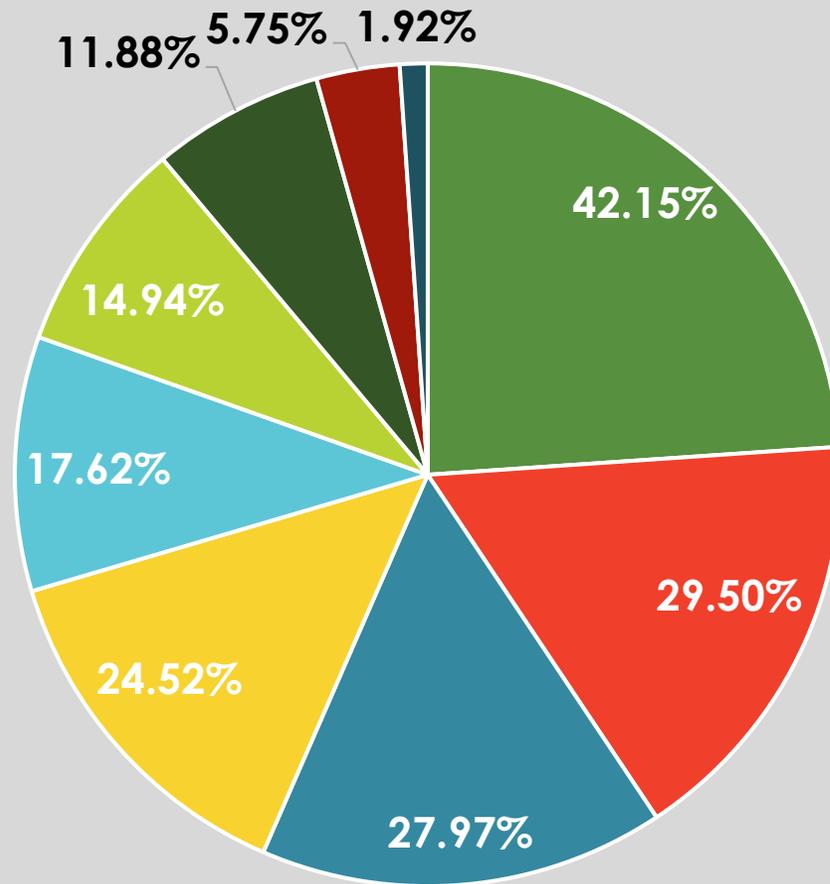
6-11 years old	Sample Count	270	18,056	
	Pop. Est.	407,671	24,195,615	
12-17 years old	%	1.4	98.6	100.0
	C.I.	1.1 - 1.8	98.2 - 98.9	
	Sample Count	314	24,358	
	Pop. Est.	346,365	24,558,836	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

<https://www.childhealthdata.org/browse/survey/results?q=7650&r=1&g=787>

FL3 Examples

Role in Supporting D/HH Families



- Family of a child who is D/HH
- Educator
- EI Provider
- Family-based Organization (FBO)
- Advocacy Group
- D/HH Adult
- EHHI Coordinator/Staff
- Medical Provider (ENT, Physician, Nurse, Audiologist, Hospital/Birthing Center)
- Student

FL3 Example

I identify as?: (select all that apply)		
Answer Choices	All Responses	Family of DHH Child
White	80%	74%
Hispanic, Latino or Spanish origin	9%	14%
Prefer not to answer	6%	7%
Black or African American	4%	6%
Asian or Asian American	3%	2%
American Indian or Alaska Native	1%	2%
Middle Eastern or North African	1%	1%
Native Hawaiian or Other Pacific Islander	1%	0%
Not listed here or prefer to self-describe:	0%	0%

What language(s) are used in your home? (check all that apply)

Answer Choices	All Responses	Family of DHH child
English	97%	95%
ASL	28%	47%
Spanish	7%	13%
Other or Prefer to Describe:	4%	6%
French	1%	3%
Arabic	1%	2%
Tagalog	0.37%	1%
Chinese	0.37%	0%
Vietnamese	0.00%	0%



WHAT DATA ARE YOU COLLECTING ON UNDERREPRESENTED POPULATIONS?

Or thinking about collecting?

DATA



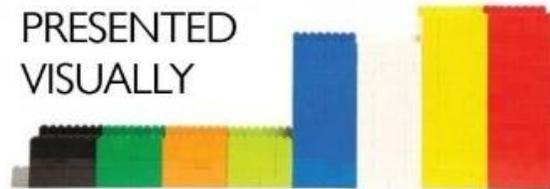
SORTED



ARRANGED



PRESENTED
VISUALLY



EXPLAINED
WITH A STORY



Wrap Up

- ✓ What type of data do you want to examine and why
- ✓ Consider what you already have
- ✓ Where else can you find data?
- ✓ Identify areas of need
- ✓ Gather it and share it
- ✓ Monitor for continuous improvement



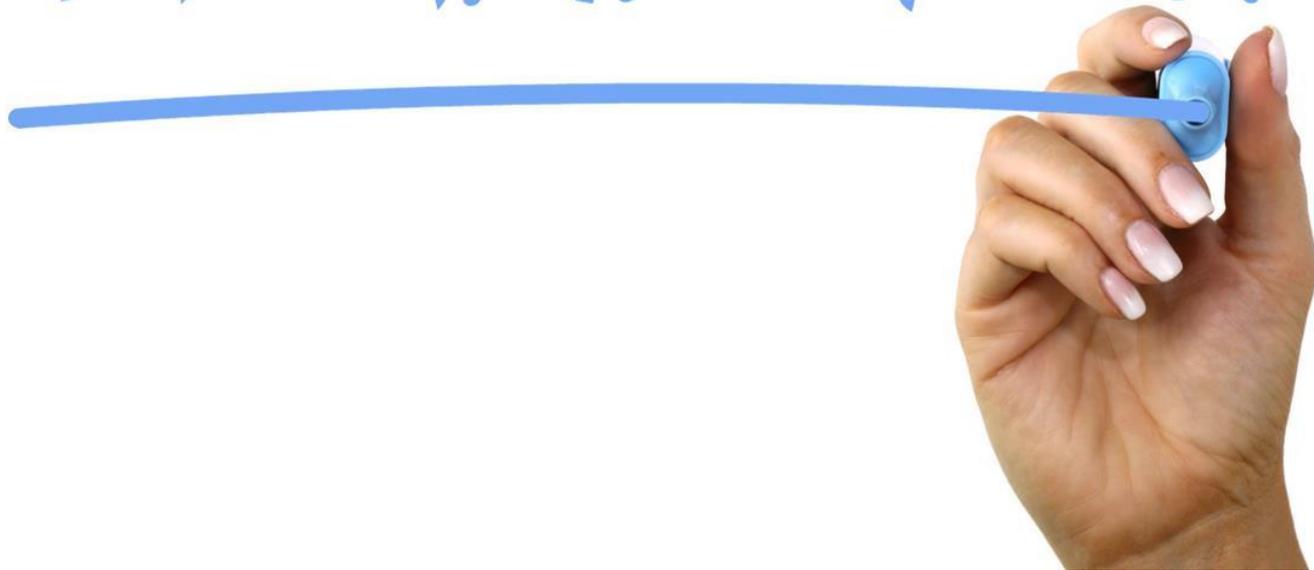
What will you do by next week?

- ✓ What questions do you have about underserved or disparate populations in your state/territory?
- ✓ What data will you examine?
- ✓ Where do you think you'll focus your efforts?

Resources

- DHHS/HRSA Policy Statement on Workforce Diversity and Inclusion. <https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents//diversity.pdf>
- US Census Bureau. <https://www.census.gov/>
- Data Resource Center for Child & Adolescence Health. <https://www.childhealthdata.org/>
- CDC EHDI Data (Annually by state/territory). <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data2019.html>
- 2018 CDC EHDI Demographic Data (2018 HSFS). https://www.cdc.gov/ncbddd/hearingloss/2018-data/documents/2018-HSFS_Demographic-Summary.pdf
- NCHAM eBook Chapter 31, EHDI Information Management. https://www.infanthearing.org/ehdi-ebook/2015_ebook/31-Chapter31InfoManagement2015.pdf
- Utah Public Health example. <https://ibis.health.utah.gov/ibisph-view/>
- *More Than Numbers: A Guide Toward Diversity, Equity and Inclusion in Data Collection*, from Schusterman Family Philanthropies. <https://www.schusterman.org/sites/default/files/More%20than%20Numbers-%20A%20Guide%20Toward%20Diversity%2C%20Equity%20and%20Inclusion%20%28DEI%29%20in%20Data%20Collection.pdf>
- *The Cultural and Linguistic Competence Assessment for Disability Organizations*, from the National Center for Cultural Competence. <https://nccc.georgetown.edu/assessments/clcado.php>
- *Equity vs. Equality and Other Racial Justice definitions*, from Annie E. Casey Foundation. <https://www.aecf.org/blog/racial-justice-definitions>
- *Racial Equity, Getting to Results*, from Local and Regional Government Alliance on Race & Ethnicity. <https://www.raciaequityalliance.org/tools-resources/>

THANK YOU



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