# Asking Questions about Neurodevelopmental Disorders

Neurodevelopmental Disorders - Overview

- Disorders that affect the brain/nervous system and arise in infancy and/or childhood
- Causes: genetic, metabolic/immune disorders, infectious diseases, environmental factors, physical trauma, and more.
- Can lead to difficulties in many areas of functioning such as movement, communication, thinking, & learning
- Examples: autism spectrum disorders, cerebral palsy, Down Syndrome, Attention-Deficit/Hyperactivity Disorder, intellectual disability

Autism Spectrum Disorder (ASD)

- Characterized by differences in how a person interacts with others, communicates, learns, and behaves
  - Deficits in social communication and social interaction
    - Including difficulty with conversation, abnormalities in maintaining eye contact or making facial expressions, difficulty understanding gestures, and difficulty making and maintaining relationships
  - Restricted, repetitive patterns of behavior, interests, or activities
    - Including repetitive movements or speech, preference for strict routines or patterns, intense interest in limited topics, and sensory seeking or sensory avoidant behavior
- Can be diagnosed at any age, but symptoms generally appear in first 2 years of life
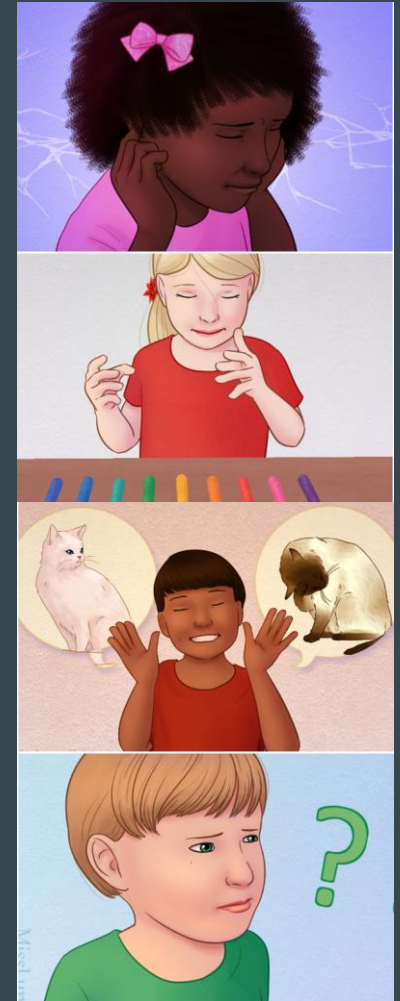
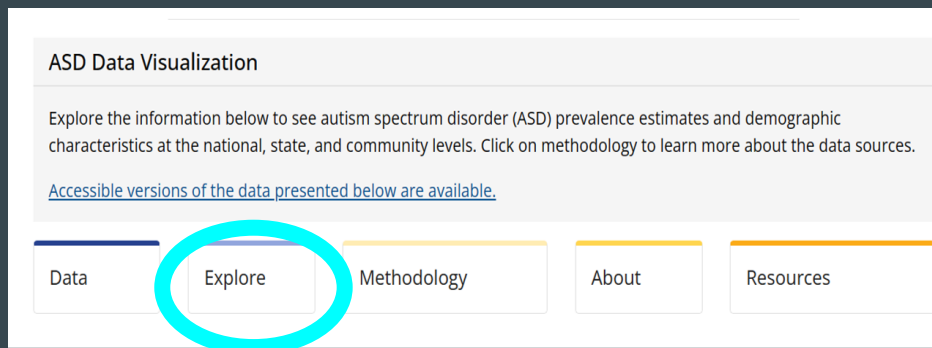# Autism Research Questions and Data Sources

- **Is Autism more common in my state than the rest of the United States?**

[Autism Data Visualization Tool | CDC](#) ← click here

The CDC's Autism Data Visualization tool uses data from 4 different sources to answer questions about Autism. Check out the "Explore" section to use the different data sets to answer your questions about Autism - like looking at the prevalence rates in Pennsylvania compared to the US, or a different state of interest.

**You can scroll down to the "Explore" section or click to jump directly to it

ASD Data Visualization

Explore the information below to see autism spectrum disorder (ASD) prevalence estimates and demographic characteristics at the national, state, and community levels. Click on methodology to learn more about the data sources.

Accessible versions of the data presented below are available.

Data	Explore	Methodology	About	Resources

Autism Research Questions and Data Sources

[Autism Data Visualization Tool | CDC](#) <- click here

You can download the full data sets by jumping to the "Resources" section. In the blue box you can download Excel files with the data set (ADDM data), or you can download a combined data set that includes information from all 4 databases.
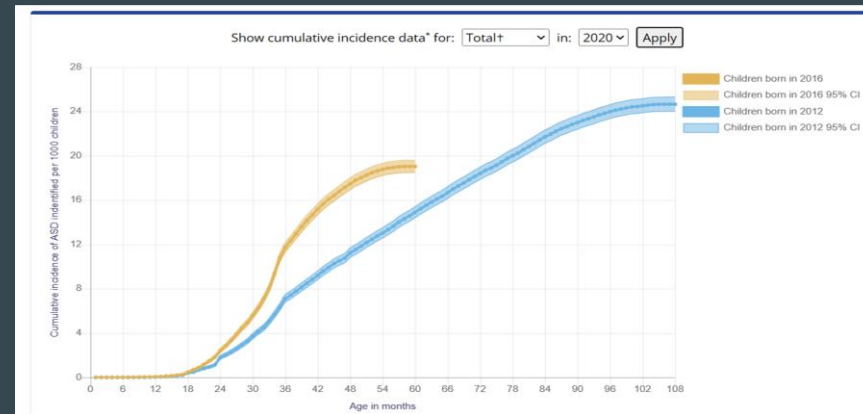
Autism Research Questions and Data Sources

- **How old are most kids when they get diagnosed with autism?**

  Use the "Data Visualization Tool" link above and scroll down to #5 under the Prevalence Data. You can select the US Total, or look at different states in the AADM Network, to see how the average age at time of diagnosis has changed from 2012 to 2016.

  You can also download the full data sets (previous slide).

Autism Research Questions and Data Sources

- **Are boys or girls more likely to have autism?**
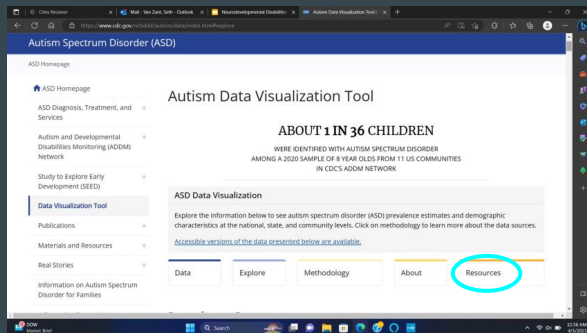
  <u>Autism Data Visualization Tool | CDC</u> ←click here

  Head back to the CDC Autism Data Visualization Tool. Scroll down to #3 under the "Prevalence Data" and toggle through different states and study years to learn more about diagnosis rates in boys and girls and how they have changed over the last 20 years!

  You can download the full dataset(s) under the "Resources" tab.

#1

#2

Attention Deficit Hyperactivity Disorder (ADHD)

- ADHD is the most common neurodevelopmental disorder diagnosed in children in the United States (prevalence of ~10%)

- ADHD can have symptoms of hyperactivity and impulsivity (fidgety, always moving, blurting things out), inattention (difficulty with organization and focus), or a combination of the two

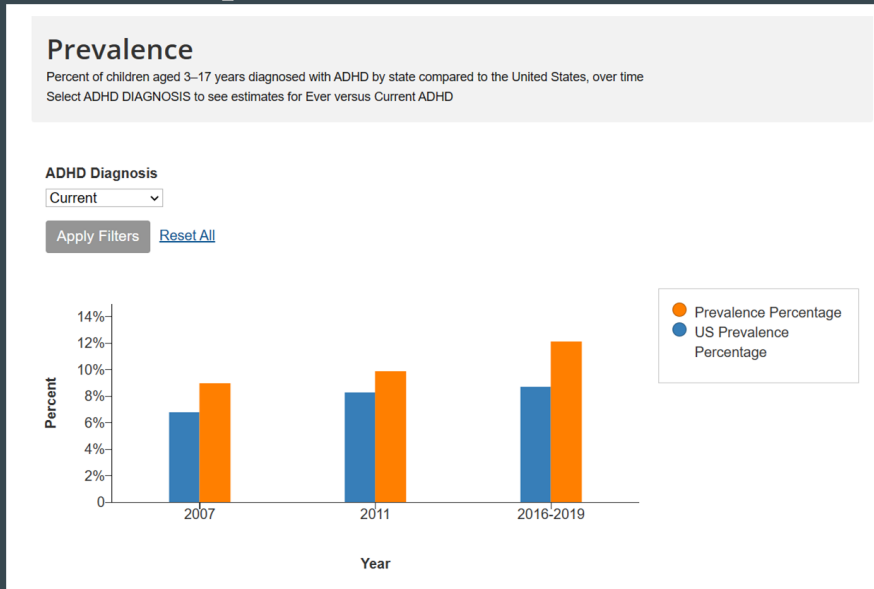- ADHD is diagnosed in childhood but symptoms can last into adulthood

Attention Deficit Hyperactivity Disorder (ADHD)

- **How common is ADHD in my state?**
  - Use the data from the National Survey of Children's Health (NSCH) and the CDC's Data Visualization Tool to see how the prevalence of ADHD

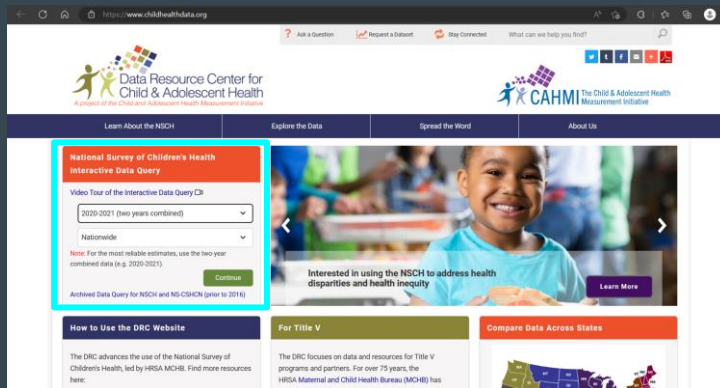   compares state to state – <u>ADHD State Profiles</u> ← click here

You can also explore differences in treatment types, including medication treatment and behavioral treatment.

Attention Deficit Hyperactivity Disorder (ADHD)

- **Are people of a certain racial or ethnic background more likely to be diagnosed with ADHD than others?**
  - Use the NSCH Data Inquiry Tool to answer this question: <u>NSCH Data Tool</u>
  - Start by choosing a survey time period and a location (#1)
  - Then, find survey items related to ADHD under Child Family Health Measures (#2) → Emotional and Mental Health → Indicator 2.7 (#3)

#1

#2

#3

Continued on next slide

Attention Deficit Hyperactivity Disorder (ADHD)

○ After clicking on indicator 2.7, you can choose "Select a Subgroup" in the Edit Search Criteria box to see how prevalence rates change by race and ethnicity

○ Try out some other subgroup comparisons to learn more!

Now that you've gotten an idea for how you might answer some of these questions about ADHD using data from the National Survey of Children's Health, check out the next page to learn how to download the full dataset and keep exploring!

Attention Deficit Hyperactivity Disorder (ADHD)

You can download the full data sets from the US Census Bureau Website

NSCH Datasets (census.gov) ←click here

You can download data files for the 2016-2021 survey releases (these can be transformed to excel files)

    -The survey is divided into 2 parts ("Screener Data" and "Topical Data")

    -You can also access PDF files that list the variables in the survey, the survey data "code book," and frequently asked questions documents to help you as you analyze the data.

2021

2021 Screener Data and Input Files

SAS data file [2.86 MB]

STATA data file [5.05 MB]

2021 Topical Data and Input Files

SAS data file [10.4 MB]

STATA data file [5.05 MB]

Special Geographies Files

Special Geographies data supplement

SAS data file [< 1.0 MB]

STATA data file [< 1.0 MB]

Variable List

Variable names and corresponding response options used in the survey.

2021 NSCH - Screener Variable List [1.15 MB]

2021 NSCH - Topical Variable List [1.45 MB]

Frequencies

Unweighted and weighted counts and distribution by variable.

2021 NSCH – Screener Frequencies [< 1.0 MB]

2021 NSCH – Topical Frequencies [2.27 MB]

Guidance for Data Users

Helpful Documentation for using NSCH data.

2021 NSCH – Data User Frequently Asked Questions (FAQs) [<1.0 MB]

Guide to Multiply Imputed Data Analysis [<1.0 MB]

Guide to Multi-Year Analysis [<1.0 MB]

Intellectual Disability (ID)
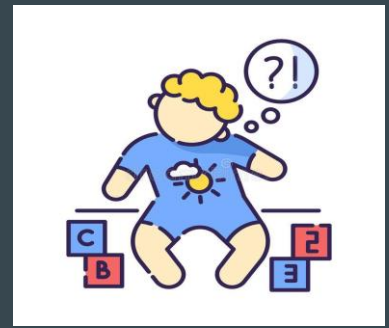
- An individual is diagnosed with an ID when intellectual function is in a lower range (typically measured by a general cognitive test) and they have difficulties with adaptive functioning (the ability to complete daily tasks, communication skills, and/or social skills)
- There are different causes of ID including:
  - Genetic disorders (e.g., Down Syndrome)
  - Childhood illness or injury (e.g., whooping cough, measles, head trauma)
  - Exposure to toxins during development (e.g., lead, mercury)
  - Exposure to toxins when in the womb (e.g., drugs, alcohol)
  - Labor and delivery related events (e.g., lack of oxygen to the brain)
- ID is diagnosed in childhood
- It can co-occur with other neurodevelopmental disorders such as autism spectrum disorder

Intellectual Disability (ID)

Potential Research Question

- How often does intellectual disability co-occur with autism spectrum disorder?

You can answer this question by downloading the NSCH data set at NSCH Datasets (census.gov) ← click here

Additional information about what questions are asked on the survey and what data is available can be found here: NSCH Topics & Question Guide ← click here

(see slide 12 for instructions on how to use this data set)

Down Syndrome (DS)

- Genetic disorder caused by an extra copy of Chromosome 21 (also called Trisomy 21)

- Can include motor and speech delays, learning difficulties, and other physical health symptoms
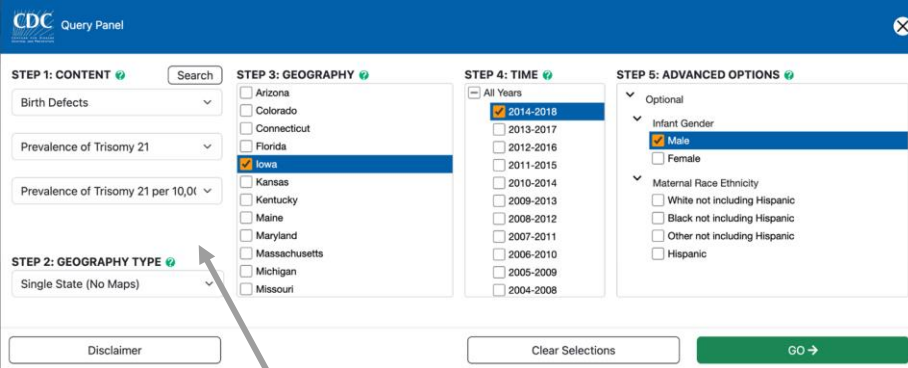
- Older maternal age is a risk factor

Down Syndrome (DS)

Potential research question: Are rates of Down Syndrome higher in males or females? Does this vary by maternal age?

- Example using the National Environmental Public Health Tracking Network
  - Go to CDC Data Explorer ←click here

"Prevalence of Trisomy 21 per 10,000 Live Births to Mothers <35 Years of Age at Delivery over a 5-year Period"
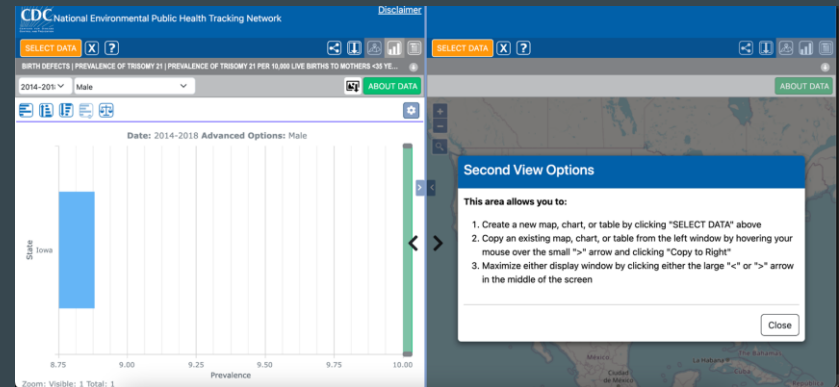
Left side of screen: Prevalence of Down Syndrome in Male Infants Born in Iowa Between 2014 and 2018 in Mothers <35 Years of Age

Down Syndrome (DS)

- Are rates of Down Syndrome higher in males or females? Does this vary by maternal age?
  - Click orange "Select Data" button on right half of the screen & select same options in the Query Panel, EXCEPT for Step 5: Advanced Options
    - Change "Infant Gender" to "Female"
  - To see if this varies by maternal age:
    - Repeat process but under "Select Measure" drop-down, click "Prevalence of Trisomy 21 per 10,000 Live Births to Mothers >=35 Years of Age at Delivery over a 5-year Period"
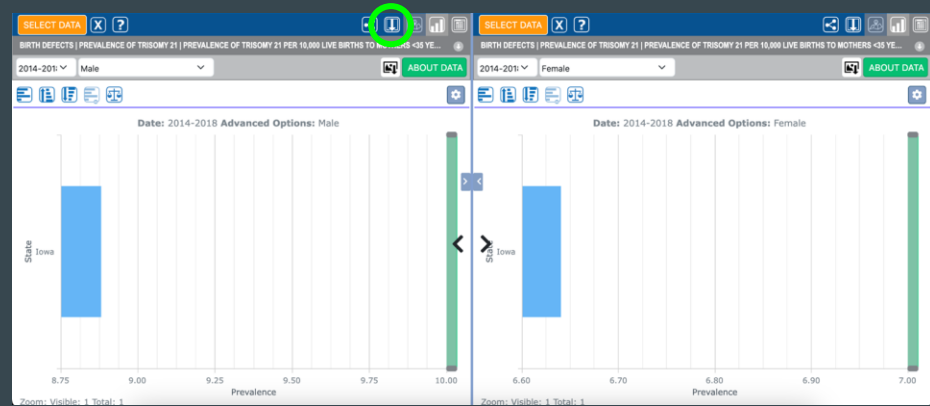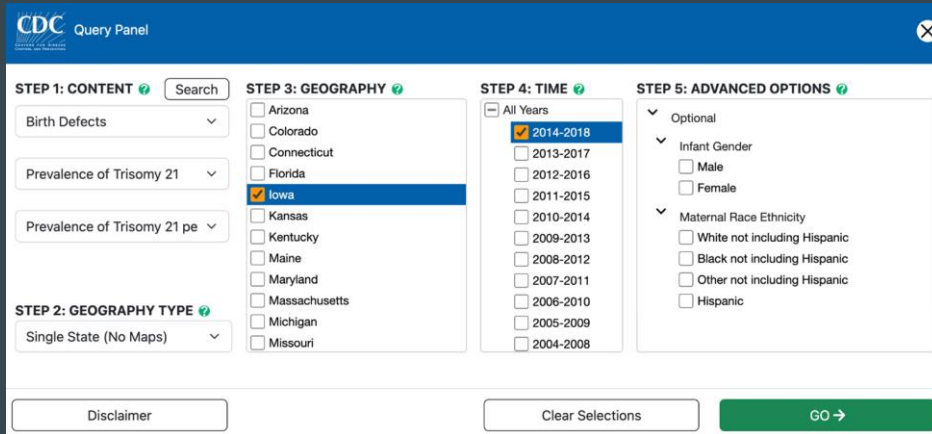

To download dataset: click arrow button (circled in green)

Down Syndrome (DS)

Potential research question: Do the rates of Down Syndrome vary across different states?

- Example using the
  - Go to [CDC Data Explorer](#)
  - For each side of the screen, select a different state (see orange checkmarks)

Down Syndrome (DS)

Potential research question: Do the rates of Down Syndrome vary across different states?

- Example using the
  - Compare prevalence across states, and download dataset for further use using arrow button (circled in green)
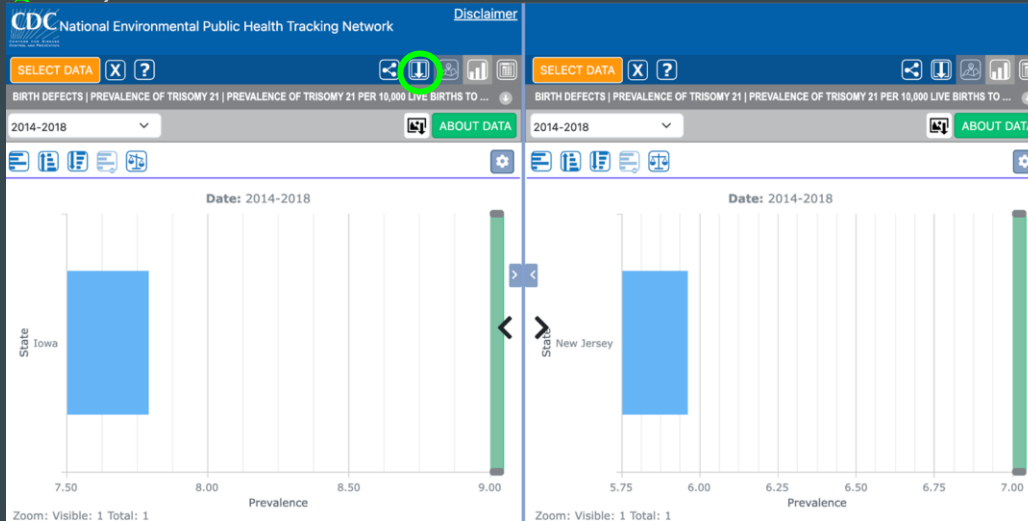
Cerebral Palsy (CP)

- Most common childhood physical disability
- Caused by abnormal brain development (including damage to the developing brain, mutations, and loss of oxygen or bleeding in the brain) that impacts a person's ability to control their muscles
- Depending on which areas of the brain are affected, one or more of the following movement disorders can occur:
  - Spasticity: Movement dependent stiffness
  - Dyskinesia: Uncontrollable movements
  - Ataxia: Poor balance and coordination
- Symptoms vary, but many people with CP use assistive technology, such as arm/leg braces and wheelchairs

More CP Research Questions

What are some other questions about CP that you can answer using the NSCH data source? (see slide 12 for further instructions)

What percent of children with CP have co-occurring mental, emotional, developmental, or behavioral problems?

Does prevalence of CP vary between different races/ethnicities?

Is CP more common in male or female children?

NSCH Datasets (census.gov) ← click here