NIH Data Systems and Programs to Improve Intellectual and Developmental Disabilities Research

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I/DD Counts Summit

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National Institutes of Health
Turning Discovery Into Health

Three NIH Tools to Accelerate Research for IDDs

01 **NIH Strategic Plan for Disability Health Research**

02 **INCLUDE Project Down Syndrome Research**

03 **Autism Data Science Initiative**

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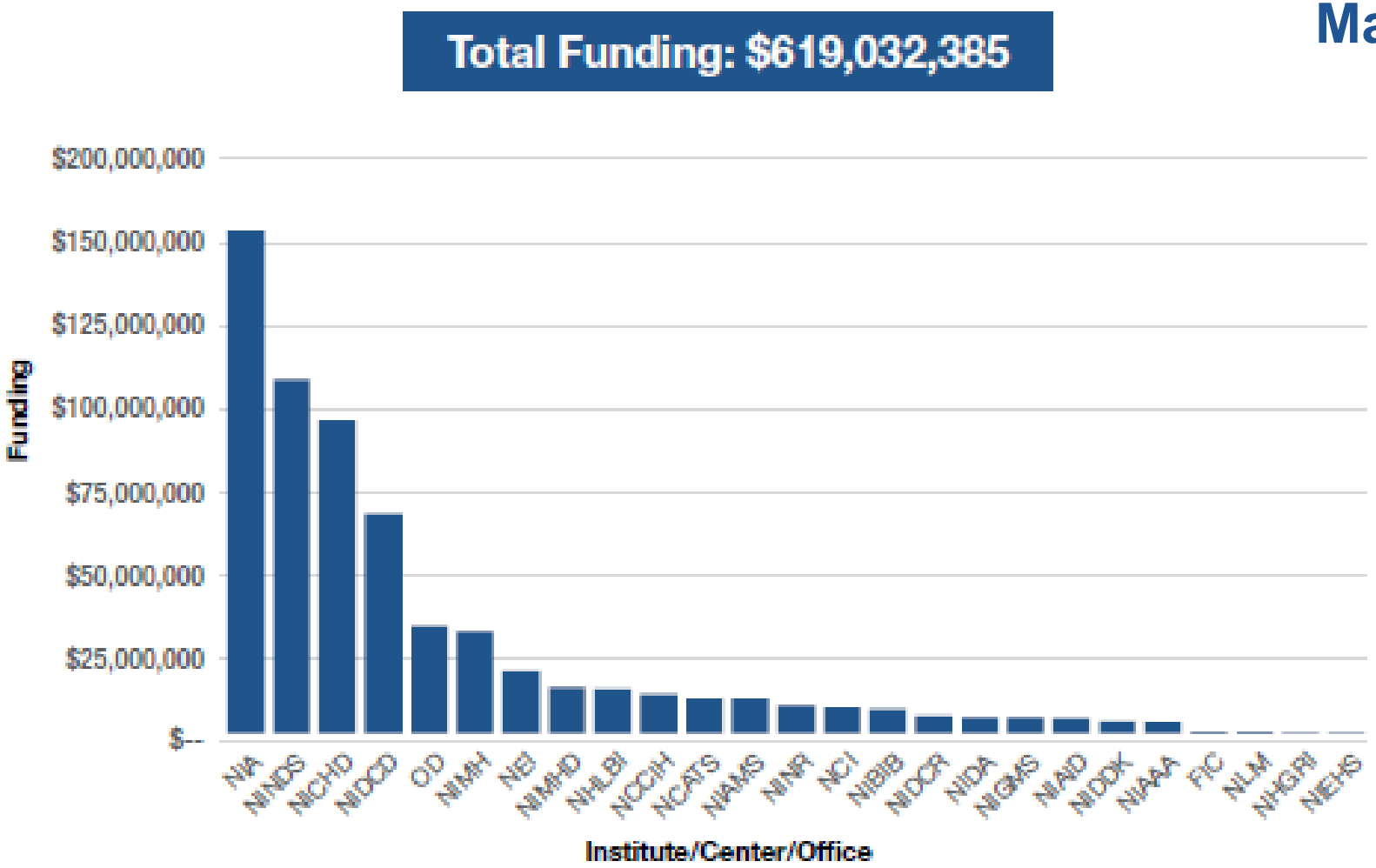
NIH Strategic Plan for Disability Health Research

FY26-FY30

Learn more and read the full plan

https://dpcpsi.nih.gov/disabilityhealthresearch/strategicplan

Disability Health Research Landscape at NIH in FY24



Major Developments

- **2022**: NIH Advisory Committee to the Director Issues Disabilities Report
- **2023**: People with Disabilities are given NIH Health Disparity Designation
- **2024-2025**: Disability Health Research Working Group (DHRWG)
- **2026**: Strategic Plan for Disability Health Research published

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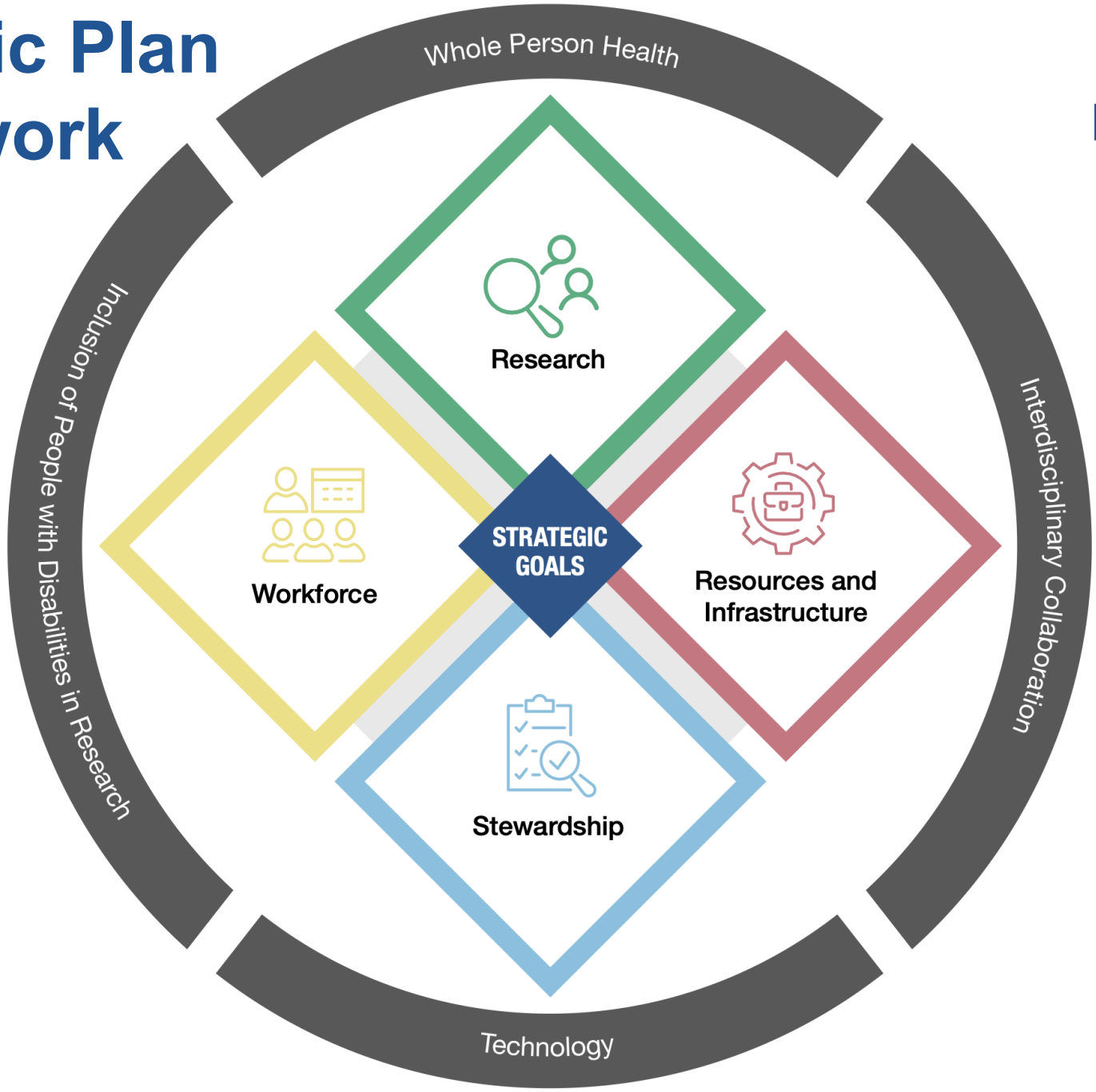
Strategic Plan Framework



Key Elements

- Research to better define disability
- Research to reduce disparities
- Health promotion and disease prevention
- Train researchers
- Maximize inclusion of people with disabilities in research
- Promote data sharing
- Ensure scientific integrity

INCLUDE Project: INvestigation of **C**o-occurring conditions across the **L**ifespan to **U**nderstand **D**own syndrom**E**

The INCLUDE Project launched in June 2018 to address a Congressional directive that called for a new **NIH-wide research initiative** on critical health and quality-of-life needs for individuals with Down syndrome (DS).

The INCLUDE Project:

- **Supports research that investigates conditions** that affect individuals with DS and the general population, such as Alzheimer's disease, autism, cataracts, celiac disease, congenital heart disease, and diabetes.
- **Aims to increase the number of investigators and trainees** studying DS.
- Works in partnership with the Down syndrome community to identify areas of need and **support work that benefits everyone.**

DS-CDP: A $32 Million Study of Down Syndrome

from birth through adulthood

INCLUDE
Collaboration for Down Syndrome Progress

GOAL

Learn about health across the lifespan

- Learn how health needs differ from person to person.
- Learn how often other health conditions occur.
- Study how life experiences and environment affect health.
- Learn which treatments may help improve health.

STUDY STATUS

1. **One shared study plan**
   Research and clinical teams created a common protocol.

2. **Enrollment began**
   People began joining the study in spring 2026.

DS-Connect®

The Down Syndrome Registry

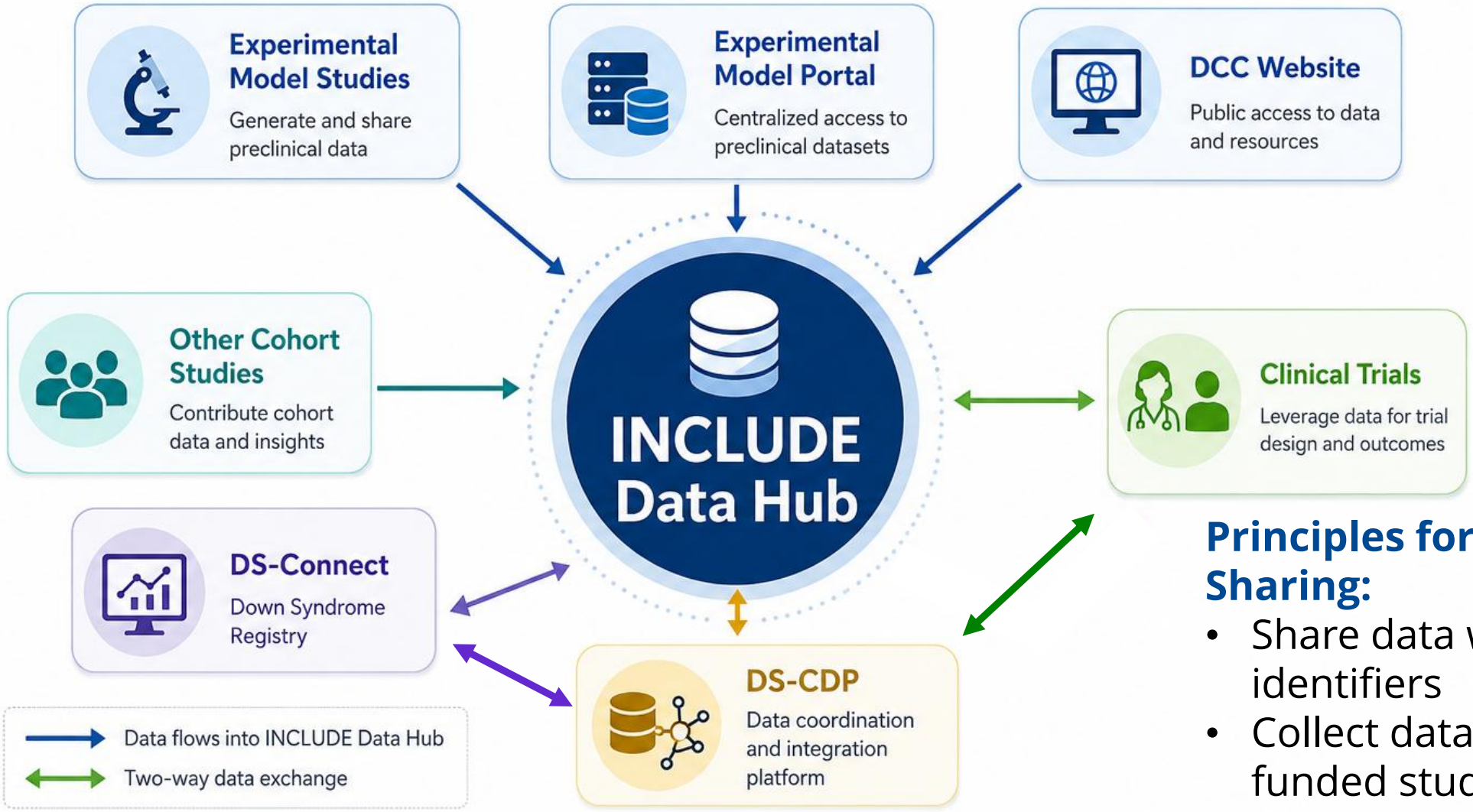
A **secure, online survey-based** tool to collect basic information about people with Down syndrome

6300+ registered globally as of Aug 2026

ds-connect.org

Connecting families with researchers since 2013!

INCLUDE Project: Data Ecosystem



Principles for INCLUDE Data Sharing:

- Share data without personal identifiers
- Collect data from majority of funded studies
- Encourage secondary data use
- Engage the community

Autism Data Science Initiative (ADSI)

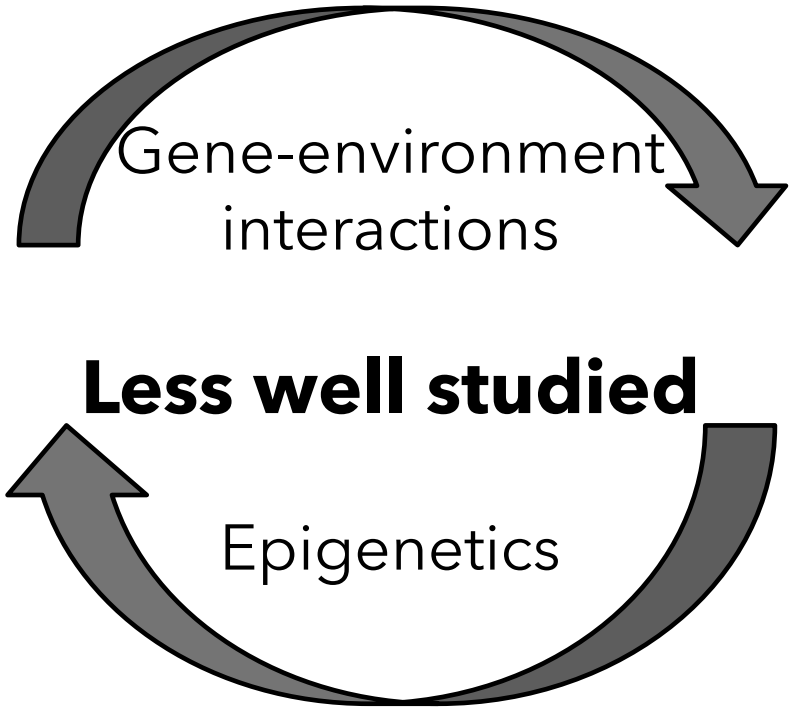
The overarching goal of the **Autism Data Science Initiative** (ADSI) is to further our understanding of autism and develop new knowledge that could be used to improve health outcomes for people on the autism spectrum.

In Sept 2025, NIH issued 13 awards with a total investment of $50 M over 24-36 months

Complex Factors that Lead to Variability in Autism

Genetic Risks

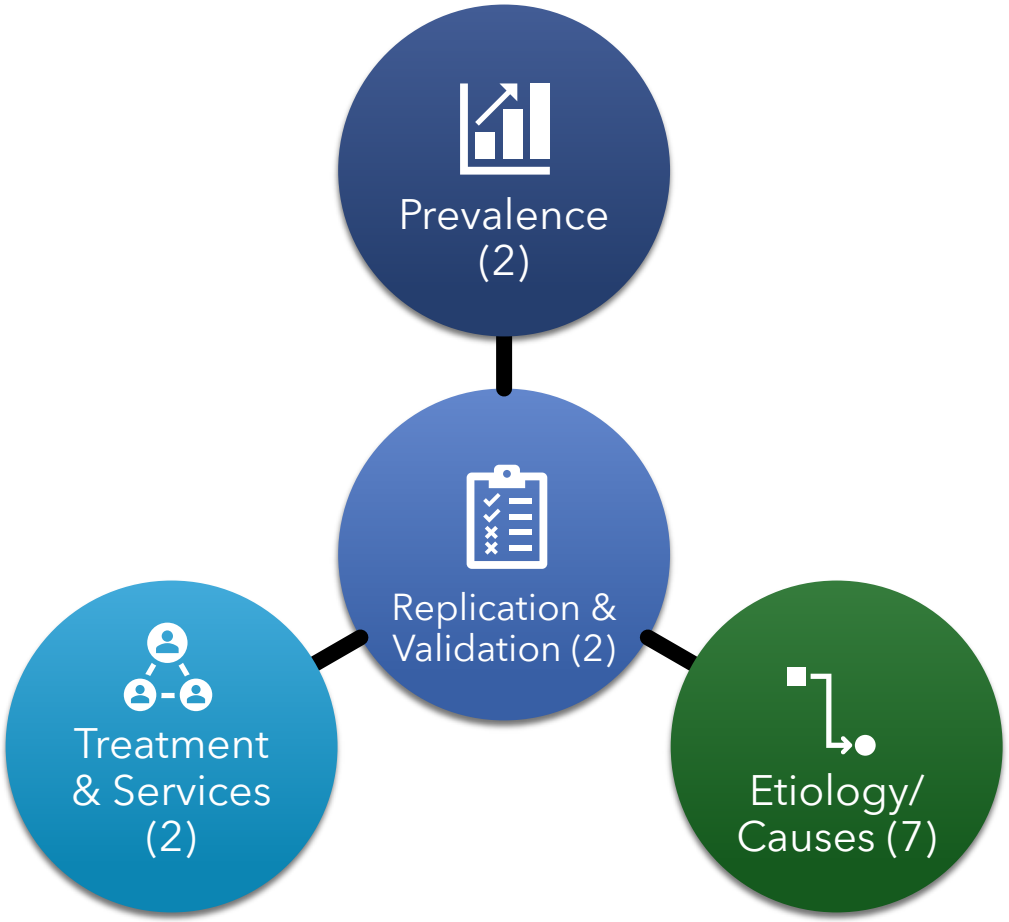
- High recurrence in families
- Complex genetics
  - Single gene syndromes
  - Aneuploidies (T21)
  - Copy number variation
  - New mutations
  - Common gene variants and polygenic risk



Nongenetic Factors

- Complicated exposures (e.g., psychosocial, nutrition/diet, medical, environmental, chemical)
- Windows of susceptibility
- Large range of exposures that could impact brain development during pregnancy

Types of Studies in ADSI: 13 total awards



Contributing Factors:

- Environmental exposures (e.g., pesticides, PFAS, air pollution, heavy metals)
- Pharmaceuticals
- Maternal diet (e.g., ultra-processed foods, folate)
- Community and Neighborhood
- Gene-Environment Interactions
- Maternal health
- Prenatal/perinatal factors

Outcomes:

- Diagnosis and autistic traits
- Longitudinal trajectories
- Mental health
- Community, employment, and educational services
- Language and communication
- Co-occurring conditions

ADSI Key Points

1. **Integrate large existing data resources** with rigorous privacy protections for analysis by autism researchers.

2. **Identify gaps in available data** and support **targeted data generation** specifically to fill those gaps.

3. Support cutting-edge data analysis to understand the contribution of genetic and nongenetic (environmental) factors to the **causes of autism** *and* identify **intervention outcomes and the use of services for autism**.

4. Support independent **validation and replication** of the Initiative's findings **while the studies are ongoing (a first for an NIH program!)**.

THANK YOU!

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