National Institutes of Health
Division of Program Coordination, Planning, and Strategic Initiatives

Autism Data Science Initiative

NIH Council of Councils
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Autism Spectrum Disorder (ASD)

Scope

- Autism spectrum disorder (ASD, referred to subsequently as autism) is a neurodevelopmental disorder with a wide range of symptoms, which can include differences in social and communication behaviors, intellectual disabilities, and other physical and mental health conditions.
- It is an extremely heterogeneous condition with a variable clinical presentation and differing service and support needs.

Prevalence

- An estimated 1 in 31 eight-year-olds in the United States have autism as of 2022 (CDC, 2025).
- CDC prevalence estimates show a steady rise in the prevalence of autism since 2000.
- This increase in prevalence is at least partially due to increased quality and accessibility of screening and identification, changing diagnostic criteria, and increased recognition in adults.

Risk Factors

- Known risk factors for autism include genetics, parental health factors, prenatal conditions, neurological and genetic syndromes, and environmental factors, as well as gene-environment interactions.

Sources: CDC Data and Statistics on Autism Spectrum Disorder, https://www.cdc.gov/autism/data-research/index.html
NICHD Autism Spectrum Disorder, https://www.nichd.nih.gov/health/topics/autism

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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.

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ADSI Priority Research Questions

- What newly emerging and/or understudied factors may contribute to autism?
- How do multiple disparate factors (e.g., exposomics) interact to contribute collectively to risk and resilience?
- How might those factors, in combination with diagnostic and other factors, contribute to increased prevalence over time?
- How can utilization patterns of autism interventions and services help pinpoint potential treatment/service targets across the lifespan to inform future clinical trials? Including identification of:
  - Effective and scalable interventions and services across the lifespan
  - Predictors of treatment response
  - Mechanisms of co-occurring conditions to be targeted in future treatment trials

ADSI Strategic Aims

1. Support the innovative integration of 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 of the integrated data resources to explore the contribution of genetic and nongenetic factors to the causes of autism and/or to identify patterns associated with intervention outcomes and the use of services for autism.

4. Support independent validation and replication of the Initiative's findings.

Autism Data Science Initiative

Research Opportunity Announcement (ROA)

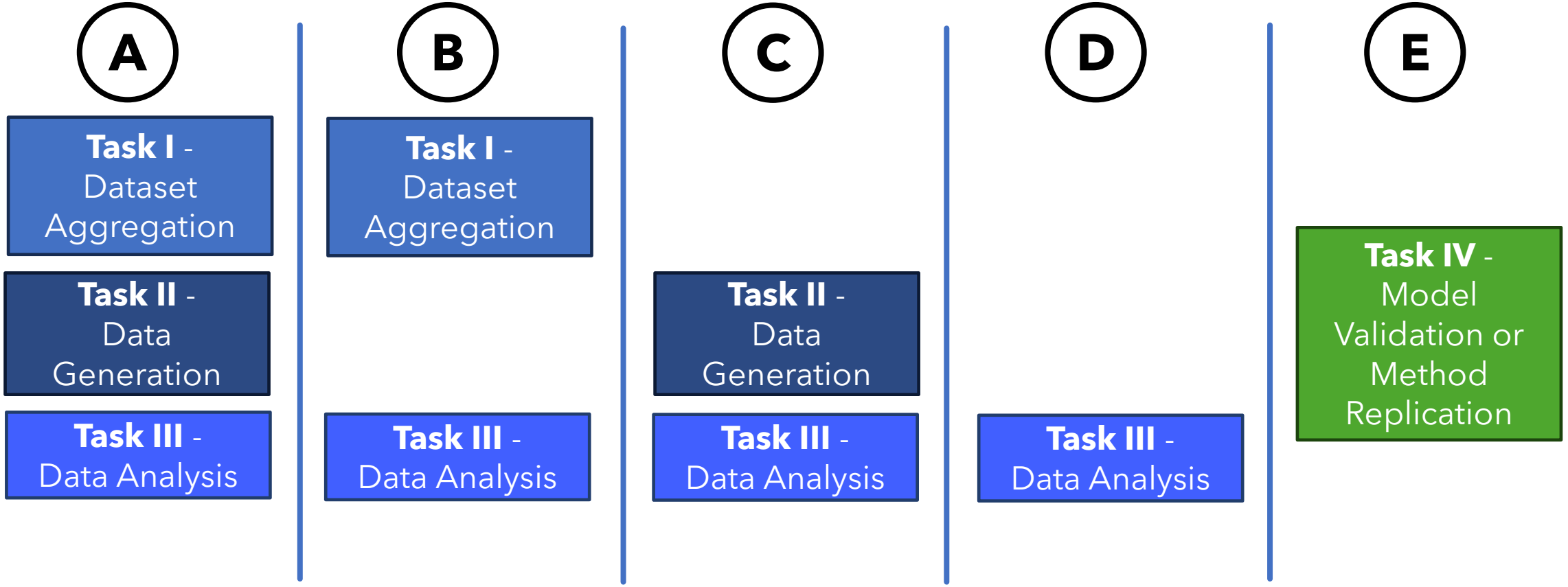
Research Opportunity Number	OTA-25-006
Application Due Date	**June 27, 2025**
Earliest Possible Start Date	September 1, 2025
Funding Instrument	Other Transaction: An assistance mechanism that is not a grant, contract, or cooperative agreement. Other Transaction awards are subject to the requirements of the NIH Other Transactions policy.
Funds Available	**$50,000,000 in FY25** with future funding subject to congressional appropriations and programmatic needs
Award Budget and Project Period	**Up to approximately $5,000,000 award** (total costs) per 24–36-month project period

View the ROA at: dpcpsi.nih.gov/autism-data-science-initiative

ADSI ROA Components

Task	Task Summary
Task I: Dataset Aggregation	Formation of a novel dataset/s, by integrating data from multiple scientific, administrative, and/or healthcare sources.
Task II: Data Generation	Limited new data generation to fill gaps in available data sources.
Task III: Data Analysis	Advanced data science and statistical methods to analyze integrated dataset/s for either hypothesis testing and/or discovery science.
Task IV: Model Validation or Method Replication	The validation of models and tools, or the unbiased duplication of study conditions and methods to reproduce results from research funded by this ROA.

Allowable ADSI Application Configurations



All other configurations were considered non-responsive to this ROA.

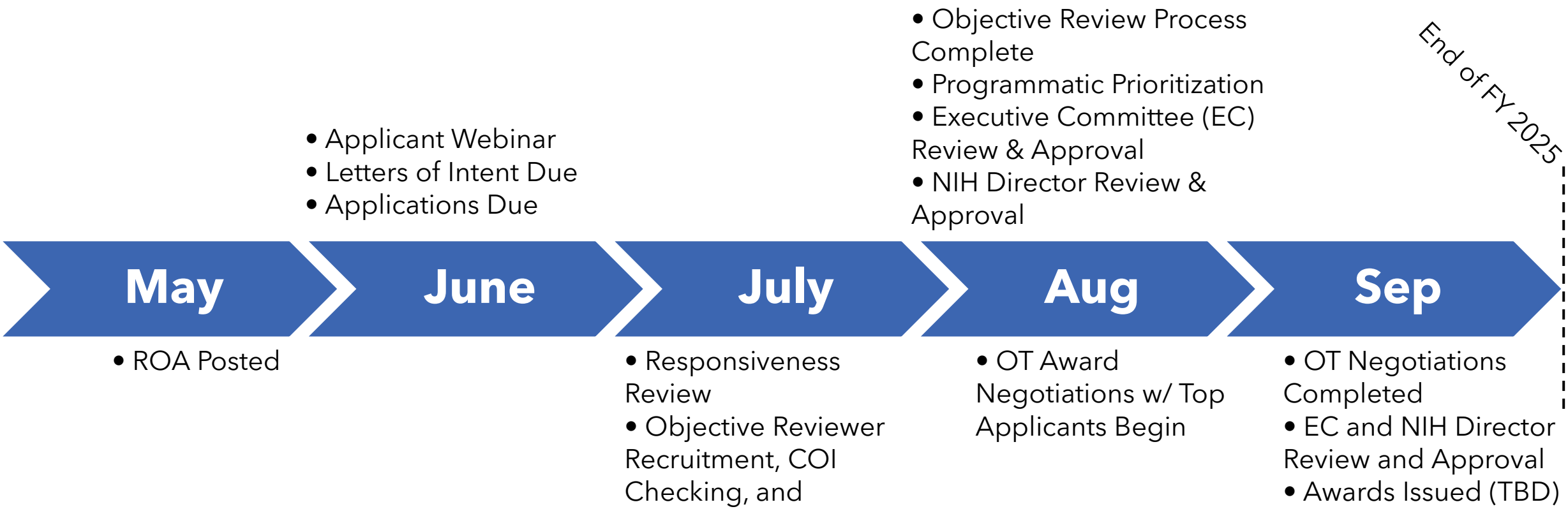
Community Engagement & DMSP Plans

Community Engagement Plan	Data Management & Sharing Plan (DMSP)
Proposes or describes how community engagement strategies and community-engaged research will be employed during the project period. The plan should: • Identify community partners that represent communities of interest. Partners can include, but are not limited to, people on the autism spectrum, their family members or caregivers, clinicians and service providers, and advocacy organizations. • Describe how the community partners will be collaboratively engaged in the research project. • Demonstrate the feasibility of engaging the community partners in the research at the planned level of involvement.	• The DMSP is expected to address the elements as described in *Supplemental Information to the NIH Policy for Data Management and Sharing: Elements of an NIH Data Management and Sharing Plan* (NOT-OD-21-014). • For applications that aim to analyze existing data, the DMSP should describe where and how other researchers can access that data to enable reproducibility and reuse. • The DMSP should reflect the goals of the program including respecting governance requirements for sharing the linked dataset/s, based on a detailed policy analysis.

Data Requirements

- **All use of data within this initiative shall be compliant with:**
  - privacy and confidentiality requirements,
  - applicable federal and state laws and regulations,
  - HHS and NIH policy,
  - determinations of any involved Institutional Review Board,
  - data use limitations from informed consent documentation,
  - associated data use agreements, and
  - data repository policies.

ADSI Application Review Process & Timeline



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Objective Review of Applications

- **Purpose:** Provide an expert assessment of the strengths and weaknesses of each application to the program staff responsible for making funding recommendations.
  - Assess how the proposed work advances our understanding of autism etiology, autism prevalence, and/or develops new knowledge that could be used to improve health outcomes for people on the autism spectrum.
  - Determine what is innovative and feasible about the proposed milestone-driven study.
  - Whether the plan for community involvement and input is appropriate.

- Conducted by internal and external subject matter experts with knowledge of topics including, but not limited to, autism etiology and clinical diagnosis, autism interventions and services, data science / bioinformatics / EHR-based research, community-engaged research experience methods and/or lived experience with autism.

- Criteria used by reviewers to assess each Task within the application as well as overall impact and feasibility are specified in the ROA.

ADSI Application Summary Categorization

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
- Clinical practice

Outcomes:

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

NIH's ADSI vs. Real World Data Platform

Autism Data Science Initiative

- **Research** initiative
- Will support investigators in the identification and integration of existing data resources to conduct state-of-the-art analyses
- Will not support a new, centralized data platform
- Focused on autism causes, prevalence, treatments and interventions

Real World Data Platform

- **Data infrastructure** initiative
- Will integrate and link data from various real-world sources and provide advanced computational analysis resources
- Will provide data via a secure NIH platform to accelerate research and translation
- Will be an optional data resource & tool for autism and other researchers

Community partners and researchers will be collaboratively engaged throughout both initiatives.

Thank You to the ADSI Team!

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Executive Committee (EC)
Dr. Nicole Kleinstreuer (OD/DPCPSI), Dr. Alison Cernich (NICHD), Dr. Rick Woychik (NIEHS), Dr. Walter Koroshetz (NINDS), Dr. Andrea Beckel-Mitchener (NIMH), Dr. Susan Koester (NIMH)

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Project Management Team: Natalia Millan and Amanda Holmes