

## NCBDDD PROJECT DESCRIPTION

**Division:** NCBDDD/DBDDD

**Title of Project/Activity:** Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

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**Proposed funding mechanism:** Cooperative Agreement (FOA DD14 - 1401)

**Number of Awards:** Up to 12 ADDM awards and up to 12 Early ADDM awards

**Project Period Length:** 4 years

**Funding Commitment (first year and future years):** \$24,000,000

### **1. Administrative Background of the Project (rationale, based on prior awards, competitive renewal, Congressional Intent or Earmark, or New Program). If this activity is a CDC policy or legislatively mandated, please indicate.**

Since 2000, NCBDDD has funded several state-based programs to conduct surveillance of autism and other developmental disabilities. Eleven sites were awarded cooperative agreements in 2010 to continue these activities through May 2014 under Phase 3. These Autism and Developmental Disabilities Monitoring (ADDM) Network sites are funded exclusively to engage in public health practice, and have established population-based surveillance systems to monitor the prevalence of autism and selected other developmental disabilities among residents in a defined geographic area. All sites utilize a consistent surveillance methodology based on CDC's established Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).

### **12. Summary of the Project - Describe the project or activity being proposed. Include the specific aims or objectives of the proposed project and list the types of activities projected as well as appropriate scientific background :**

ADDM Network mission: Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy.

Specific aims:

- To obtain as complete a count as possible of the number of children with ASD in each project area
- To provide comparable, population-based ASD prevalence estimates in different sites
- To study whether autism is more common in some groups of children than in others and whether rates are changing over time
- To provide data to characterize the ASD population

The ADDM Network methodology involves review and abstraction of existing administrative evaluation records at multiple health and educational sources. Data collection for ADDM surveillance is based on record review and does not require direct contact with individuals. The project is implemented within each site through technical assistance from CDC and collaboration across ADDM sites. CDC provides technical support for data collection, case determination, and data analysis, without receiving any identifiable data from funded sites.

ADDM methods do not rely solely on documented diagnoses for case ascertainment. Rather, children's files are requested at various health and special education data sources and reviewed by surveillance staff. Requests are based on a broad list of related diagnostic codes in health settings, or on eligibility classifications in educational settings. Children's records are screened for the presence of pre-defined behavioral triggers or diagnostic statements mentioned in health/educational evaluations. Those records meeting initial screening criteria are abstracted in full to record all available evaluation data through the target surveillance year. Evaluations from all data sources are compiled into one composite record for each child. When record abstraction is completed for the surveillance year, these composite records are systematically reviewed by an independent team of trained clinicians in order to determine case status. For the next funding cycle, sites will be required to produce ASD prevalence estimates based on both DSM-IV-TR and DSM-5 diagnostic criteria.

### **3. Describe the projected methods to be used to collect and/or analyze the data or information. If the activity/project is essentially public health practice, is there projected to be an outcome evaluation component? :**

Evaluations are requested for a specified population defined by year of birth, diagnostic or educational classification, and residency within a defined geographic area. Files are screened at multiple sources with an effort to include a range of clinical and school sources

that provide evaluation services for children with Autism Spectrum Disorder (ASD) or other developmental disabilities (DDs). When possible, agreements to access files allow data requests and record review based on institutional rather than individual authorization.

Specific demographic, behavioral, and psychometric characteristics are abstracted using the ARCHE database, a SQL Server DBMS with a web-based front-end interface, which was developed by contractors at CDC. Each ADDM site hosts and maintains a local production copy of the ARCHE database, and all personal identifiers remain on sites' local data servers. Following abstraction of records at multiple sources, de-identified evaluations are systematically reviewed by specially trained clinician reviewers who are employed or contracted by each ADDM site. These clinician reviewers assign case status for ASD and/or other DDs and code a variety of functional, behavioral, and diagnostic criteria to characterize the surveillance case population. Coded data generated by clinician reviewers are then entered into the ARCHE database database.

At the conclusion of each surveillance year, sites edit and export data from their local ARCHE databases using queries and reports developed at CDC. Prevalence estimates and other tables of results can be generated locally using analysis datasets extracted using these queries, in combination with a series of SAS programs referencing standard variables in the extracted data, also developed at CDC. The extracted analysis datasets, which contain no identifiable data, along with other de-identified datasets compiled through linkages to (individual) birth certificates and (aggregate) census variables, are then uploaded via the CDC ftp site. Data files from all ADDM sites are compiled at CDC and merged into a single pooled analysis dataset for each surveillance year. These pooled datasets are furnished to all ADDM sites so they may pursue investigator-initiated analyses to a greater depth than the general prevalence reports published at the conclusion of each surveillance year.

A variety of qualitative and quantitative analytic approaches are utilized in evaluating the surveillance system's simplicity, flexibility, data quality, acceptability, representativeness, sensitivity, and predictive value positive. As ADDM sites are funded exclusively to engage in public health practice, none of the evaluation strategies involve research with human subjects. Quality assurance techniques are built into the surveillance methodology to maintain accuracy and consistency in the abstraction and clinician review processes. These primarily involve re-review of a 10% sample of records to ensure adherence to established methods and prevent drift. Analytic techniques are also used to measure the potential impact on sensitivity from factors such as records not being located at data sources, participation of some ADDM sites in surveillance of other DDs, and alternatives to special education enrollment such as private- and home-schooling. Additionally, for the next funding cycle each applicant is being asked to propose and complete a novel, site-specific evaluation project addressing issues of validity, reliability, and/or ability to evaluate changes in prevalence across surveillance years.

Community outreach activities are also vital to surveillance programs. ADDM education and outreach activities have been established with the primary goal of increasing public and professional knowledge to identify, diagnose, and appropriately serve children suspected of having autism or other developmental disabilities. The various ADDM education and outreach activities include informal communications, focus group sessions, attendance at community events, and presentations at annual professional conferences such as state or national associations of school psychologists, medical associations, and boards of education.

#### **4. Describe the target population for the proposed project:**

##### Component A

All funded sites will be required to conduct ASD surveillance among 8-year-old children in two separate cohorts: children born in 2006 who will reach age 8 in 2014, and children born in 2008 who will reach age 8 in 2016. Each site's locally defined surveillance area must be comprised of a contiguous geographic sector lying entirely within one U.S. state or territory, defined by clear state, county, or school district boundaries, with a population base of at least 20,000 8-year-olds according to the latest available postcensal population estimates.

##### Component B

Applicants for the proposed supplemental awards will conduct ASD surveillance among 4-year-old children in two separate cohorts: children born in 2010 who will reach age 4 in 2014, and children born in 2012 who will reach age 4 in 2016. Applicants may propose to reduce their geographic region compared to the 8-year-old surveillance area, as long as the proposed area is entirely contained within the region covered by the 8-year-old project and has a population base of at least 8,000 4-year-olds according to the latest available postcensal population estimates.

#### **5. Describe the type of data or information projected to be collected, including any private information\* on individual persons. Also, include the projected size of populations involved**

Surveillance data elements containing individual identifiers are collected and maintained at each surveillance site, for the primary purpose of locating files at individual data sources and also to prevent duplication of ascertainment across multiple sources. Identifiers are also essential for confirming residency within the site's surveillance area and facilitating linkages to birth and census records used in describing characteristics of the surveillance population. Private health and educational information is routinely collected for the purpose of case ascertainment, and may also serve as descriptive epidemiologic data for the developmental disabilities monitored. Private and identifiable information is collected through established agreements with facilities providing services to children with special needs. These agreements are reviewed periodically and covered by strict confidentiality policies. All identifiable data are

locally secured by the ADDM site and no identifying information is shared with CDC.

The ADDM Network maintains a subset of de-identified variables from all ADDM sites as a pooled dataset for each surveillance year. Extraordinary measures are taken to mask or eliminate any fields which could be considered identifiers or otherwise used to reconstruct variables that may approximate identifiers. No names, dates, or residential components are included in the pooled datasets. Each site contributes approximately 200-500 surveillance cases to the pooled dataset each year.

**6. Indicate if data or information will be collected or accessible that can potentially identify individual persons (i.e. the identity of a person is or may readily be ascertained and associated with private information)? Yes  No**

**If no, state any plans in place to ensure that personally identifiable data or information will not be collected or accessible to you:**

While individual identifiers collected and maintained at individual surveillance sites are not transmitted or reported to CDC in any way, CDC staff may come into contact with personally identifiable data while providing technical assistance during site visits and other activities. In these instances, CDC staff always sign the local site's confidentiality policy and agreement prior to viewing identifiable or other local data. All identifiers are locally secured by the grantee and no identifiable data from ADDM sites are maintained by CDC.

The ADDM Network maintains a subset of de-identified variables from all ADDM sites as a pooled dataset for each surveillance year. Extraordinary measures are taken to mask or eliminate any fields which could be considered identifiers or otherwise used to reconstruct variables that may approximate identifiers. No names, dates, or residential components are included in the pooled datasets.

**7. Eligibility (define those groups/organizations eligible to apply for funding):**

Applicants must submit one application that clearly identifies the component(s) for which they are applying. An application for component A is required, component B is optional. Applicants may not be funded under component B if they are not competitively selected to receive funding under component A.

Applicant sites must demonstrate the capacity to achieve access to surveillance data by maintaining, expanding, and establishing relationships with local healthcare facilities and special education systems to access evaluation records.

Unless eligibility is restricted by statute or regulation, all entities are potentially eligible to apply.

Eligible applicants include organizations that meet any of the following criteria:

- American Indian/Alaska Native tribal governments (federally recognized or state-recognized)
- American Indian/Alaska native tribally designated organizations
- Alaska Native health corporations
- Colleges
- Community-based organizations
- Faith-based organizations
- For-profit organizations (other than small business)
- Hospitals
- Nonprofit with 501C3 IRS status (other than institution of higher education)
- Nonprofit without 501C3 IRS status (other than institution of higher education)
- Political subdivisions of States (in consultation with States)
- Research institutions (that will perform activities deemed as non-research)
- Small, minority, and women-owned businesses
- State and local governments or their Bona Fide Agents (this includes the District of Columbia, the Commonwealth of Puerto Rico, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, American Samoa, Guam, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau)[1].
- Tribal epidemiology centers
- Universities
- Urban Indian health organizations

**8. Intended Outcomes of the Program/Project and how they will be evaluated:**

For the next round of funding (Phase 4) the ADDM Network will focus on maintaining consistency of methods in existing sites to evaluate trends, to further evaluate measurable factors affecting changes in ASD prevalence, to conduct more in-depth evaluations of the surveillance system and utility of data, and to address the larger DD Surveillance Team goals of expanding surveillance to younger age cohorts.

Key considerations in evaluating ADDM ASD prevalence trends include the number of years of available data, especially earliest years, the consistency of sites' surveillance areas, completeness of data sources, population size and diversity, quality of data collection and review, and collection of information to describe service utilization and demographic/diagnostic characteristics of children with developmental disabilities.

**9. Outline how the results or products from the proposed project will be used:**

Results of this project will be published in peer-reviewed journals and presented at professional conferences. One overall prevalence report from each of the two surveillance years (2014 and 2016) will be published to include all sites participating. Additionally, individual- and multi-site publications and presentations will be disseminated in various formats to describe characteristics of the surveillance population in greater detail. Such formats may include informal presentations or summary reports to local stakeholders, oral or poster presentations at professional conferences, responses to media inquiries, and peer-reviewed journal articles.

**10. Describe if the proposed activity or project will be:**

Extramural: X OR Intramural: \_\_\_\_

**Indicate which individuals within CDC and what organizations external to CDC will be involved with the project:**

Scientific and other program staff from the Developmental Disabilities Team in the Division of Birth Defects and Developmental Disabilities will provide technical support to award recipients. External organizations will largely depend on the specific geographic and institutional qualities of award recipients.

This concept is approved as \_\_\_\_\_ Research      \_\_\_\_\_ Non-Research

\_\_\_\_\_  
Associate Director for Science, NCBDDD

\_\_\_\_\_  
Date

**\* Note: Private information includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place. It also includes information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (e.g. medical records).**