

Public Health Service Act, [42 U.S.C. Sections 241, 243, and 247b-4, as amended].

Purpose: The Centers for Disease Control and Prevention (CDC) announces the availability of fiscal year (FY) 2004 funds for a cooperative agreement program for a new Data Coordinating Center (DCC) to support surveillance data and research data management related to developmental disabilities, such as Autism Spectrum Disorders (ASD) and other Developmental Disabilities (DD). This program addresses the "Healthy People 2010" focus area of Maternal, Infant, and Child Health.

The purpose of the program is to support a DCC to coordinate and facilitate data management activities across both the Autism and Developmental Disabilities Monitoring Network (ADDM) surveillance grantees, and the Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) surveillance and epidemiologic research grantees. The Children's Health Act of 2000 established a national mandate for autism surveillance activities and for research to address etiologic questions and identify effective interventions. The DCC is the third component necessary to provide a coordinated and standardized collection and output of information between and from these two grantee programs. The DCC is necessary to ensure accurate and timely processing and reporting of both surveillance data and research data related to ASD and DD. The data collected from these grantee sites will be stored at the DCC. Data activities related to other birth conditions and developmental disabilities may be added in the future, based on needs.

The ADDM, CADDRE, and DCC cooperative agreements have been developed to assist us with our goal of preventing ASDs and DDs. The first step in preventing these conditions is to understand their scope. Specifically, we need to know how many children are affected, the health outcomes for these children, the costs to the family and to the community, and the risk factors or protective factors for each condition. This information is needed to set priorities, design studies of causes and develop effective interventions in the public setting.

Measurable outcomes of the program will be in alignment with the following performance goals for the National Center on Birth Defects and Developmental Disabilities (NCBDDD): To improve the data on the prevalence of birth defects and developmental disabilities, and find causes and risk

factors of birth defects and developmental disabilities in order to develop prevention strategies.

Activities:

Awardee activities for this program are as follows:

a. Support the cooperative activities of the research sites through meetings, telephone conferences, and web support.

b. Develop, after the initial meeting/discussions with research sites, a work plan for all activities proposed for the DCC (See Attachment 1 posted with this announcement on the CDC Web site).

c. Develop the needed documentation, testing requirements, and a relational database application after CDC's approval of the work plan. This application should contain all of the necessary computerized data collection forms for autism and other DD surveillance.

d. Develop a secure Web site for surveillance and research sites to access the individual and pooled data sets for analysis. Note that all data collected and accessible through the secure Web site is confidential and should be maintained in accordance with all federal, state, and local rules, regulations, and laws governing privacy of personal health and health-related data (no personal identifiers will be forwarded to the DCC).

e. Assist the research sites in administering questionnaires to individuals they identify.

f. Develop manuals and plans for training of research site personnel, and conduct on-site training on the use of the relational database application and transmission of study data to DCC.

g. Prepare written system documentation for the relational database application and secure Web site.

h. Develop a plan to transfer the data and source code to CDC at the end of the funding period.

In a cooperative agreement, CDC staff is substantially involved in the program activities, above and beyond routine grant monitoring. CDC activities for this program are as follows:

a. Assist with protocol development, including reviewing and commenting on each stage of the program before subsequent stages are started.

b. Assist in the analysis and interpretation of findings.

c. Assist in the reporting of findings in scientific literature, other media, and among the public.

d. Assist in the development of a research protocol for Institutional Review Board (IRB) review by all cooperating institutions participating in the research project. The CDC IRB will

review and approve the protocol initially, and on at least an annual basis until the research project is completed.

e. Provide technical guidance as to the development of the relational database application and secure Web site.

II. Award Information

Type of Award: Cooperative Agreement. CDC involvement in this program is listed in the Activities Section above.

Fiscal Year (FY) of Funds: 2004.

Approximate Total Funding: \$700,000 per budget period.

Approximate Number of Awards: 1.

Anticipated Award Date: April 1, 2004.

Budget Period Length: 12 months.

Project Period Length: Five years.

Throughout the project period, continuation awards will be based on the availability of funds, and evidence of progress as documented in required reports.

III. Eligibility Information

Eligible Applicants: Applications may be submitted by:

- Public nonprofit organizations.
- Private nonprofit organizations.
- For profit organizations.
- Small, minority, women-owned businesses.
- Universities.
- Colleges.
- Technical schools.
- Research institutions.
- Hospitals.
- Community-based organizations.
- Faith-based organizations.
- Federally-recognized Indian tribal governments.
- Indian tribes.
- Indian tribal organizations.
- 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).

If you are applying as a bona fide agent of a state or local government, you must provide a letter from the State as documentation of your status. Place this letter behind the face page of your application form.

Other Eligibility Requirements:

To be eligible applicants must:

1. Propose a Principal Investigator who shall expend at least 20 percent annual effort on the award in each year of support. This 20 percent effort may not be in-kind support.

2. Proposed Principal Investigator cannot be the current Autism and