

## THE SUPPORTING STATEMENT

### Specific Instructions

#### A. Justification

##### *1. Circumstances Making the Collection of Information Necessary*

Section 104 (a) (42 USC 15004) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000) directs the Secretary of Health and Human Services to develop and implement a system of program accountability to monitor the grantees funded under the DD Act of 2000. The program accountability system shall include the National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service authorized under Part D of the DD Act of 2000. In addition to the accountability system, Section 154 (e) (42 USC 15064) of the DD Act of 2000 includes new requirements for a UCEDD Annual Report. The Annual Report Template appears in Attachment C.

Essentially, the DD Act of 2000 states that the UCEDD Annual Report should contain information on progress made in achieving the projected goals of the Center for the previous year, including (1) the extent to which the goals were achieved; (2) a description of the strategies that contributed to achieving the goals; (3) to the extent to which the goals were not achieved, a description of factors that impeded the achievement; and (4) an accounting of the manner in which funds paid to the Center under this subtitle for a fiscal year were expended; information on proposed revisions to the goals; and a description of successful efforts to leverage funds, other than funds made available under the DD Act of 2000.

In addition, the DD Act of 2000 states that grantees must also report on data collected regarding the following consumer satisfaction with the advocacy, capacity building, and systemic change activities initiated by the UCEDD; the extent to which the UCEDD's advocacy, capacity building, and systemic change activities provided results through improvements; and the extent to which collaboration was achieved in the areas of advocacy, capacity building, and systemic change.

The National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) is a discretionary grant program. It supports in the States the operation and administration of a national network of UCEDDs that are interdisciplinary education, research, and public service units of universities or public or not-for-profit entities associated with universities that engage in core functions (e.g., provision of interdisciplinary pre-service preparation and continuing education of students and fellows; provision of community services, including training or technical assistance; conduct of research; and dissemination of information) addressing, directly or indirectly, one or more of the areas of emphasis (e.g., quality assurance, education and early intervention, child care, health, employment, housing, transportation, recreation, and other services available or offered to individuals in a community, including formal and informal community supports, that affect their quality of life).

As liaisons to service delivery systems, UCEDDs serve to positively affect the lives of individuals with developmental disabilities and their families and work towards increasing their independence, productivity, and integration into communities. The national network has evolved considerably during its history. Established in 1963, the development of the national network is marked by growth in three phases (Fifield & Fifield, 1995). The first phase from 1963-1974 involved the construction of institutions closely associated with Universities and the development of centralized expertise, training programs, and clinical, diagnostic, and treatment services for persons with mental retardation. The second phase from 1975-1986 promoted community-based services, developmental concepts, and the provision of services through a person's full life span. This period also saw the creation of the three major components of the present developmental disabilities system: State Developmental Disabilities Planning Councils, Protection and Advocacy Agencies, and University Centers. The third period from 1987 to present has emphasized a consumer focus, as exemplified by the completion of an extensive national consumer satisfaction evaluation study, which brought to the forefront the issues of consumer empowerment, independence, and inclusion.

Currently, UCEDDs engage in four broad tasks: conducting interdisciplinary training, promoting exemplary community service programs and providing technical assistance at all levels from local service delivery to community and state governments, conducting research, and disseminating information to the field.

UCEDD accomplishments include:

- Directing exemplary training programs. The provision of training is offered in an interdisciplinary format where faculty and trainees represent a variety of disciplines, such as pediatrics, education, psychology, and nursing thereby expanding opportunities for students to learn about the differing perspectives of various professionals providing services to individuals with developmental disabilities and their families.
- Providing community services and technical assistance. Staff offer expertise through training and technical assistance activities to individuals with developmental disabilities, family members of these individuals, professionals, paraprofessionals, students, systems, support service organizations, volunteers, among others.
- Contributing to the development of new knowledge through research and information dissemination. UCEDDs develop and field test models of service delivery and evaluate existing innovative practices, which are then disseminated to the field to translate research into practice.

Currently, there are 67 UCEDDs in every State and Territory, as mandated. H.R.4818, the Consolidated Appropriations Act of 2005, supports the expansion of the national network of UCEDDs.

## *2. Purpose and Use of the Information Collection*

According to Section 105 (42 USC 15005) of the DD Act of 2000, the information provided in the Annual Reports from the UCEDDs will be combined from information reported by the

State Developmental Disabilities Councils and Protection and Advocacy agencies to develop and submit at least once every 2 years to the President, Congress, and the National Council on Disability a report that describes the goals and outcomes of programs supported under the DD Act of 2000.

In addition, the information derived from data collection activities will be used by multiple recipients for multiple purposes:

- (1) As a tool for UCEDD grantees to measure and report on progress in reaching goals and identify areas for which revisions are indicated;
- (2) To enhance the Federal project officers' monitoring of UCEDD progress in reaching projected outcomes;
- (3) To provide a set of standardized performance measures that will yield a national portrait of UCEDD program impact;
- (4) To streamline the Administration for Children and Families and the Department of Health and Human Services reporting to Congress on accomplishments and progress toward reaching program goals.
- (5) For Congress and the Administration in making funding and appropriation decisions with regard to the UCEDD program.

### *3. Use of Improved Information Technology and Burden Reduction*

ADD has built upon a successful web-based system entitled the National Information Reporting System (NIRS) developed by the Association for University Centers on Disabilities (AUCD) and uses this information technology system for collecting data. The development of the NIRS system was supported in part by funds authorized in Section 153(c)(4) (42 USC 15063) and Section 163(d) (42 USC 15083) of the DD Act of 2000. The instrument that accompanies this Supporting Statement will guide the development of items to be included in NIRS for reporting purposes.

### *4. Efforts to Identify Duplication and Use of Similar Information*

With regard to the UCEDD Annual Report requirement, there is no similar information available. Individual UCEDDs collect annually data on some of the information being requested; however, all UCEDDs have not produced material in a uniform format and in response to the requirements of the DD Act of 2000.

Moreover, because the collecting and reporting on the data being requested is based on the area(s) of emphasis chosen by each UCEDD and because these in turn were required to reflect particular needs of the state in which the UCEDD is located, duplication is unlikely.

UCEDDs will use the Annual Report template to report on Government Performance and Results Act (GPRA) measures. In the case of the GPRA measures, ADD has coordinated data collection efforts with the Maternal and Child Health Bureau (MCHB). MCHB funds Leadership Education in Neurodevelopmental and Related Disabilities (LEND) grants at 34 of the 67 UCEDDs in the Network. This overlap in funding could lead to duplication in the collection of data. To avoid this potential for duplication, ADD worked with AUCD and MCHB to identify common GPRA measures that could apply to both programs. The GPRA measures that appear on the Annual Report template for the UCEDD program reflect two measures that are currently used by MCHB for the LEND program.

5. *Impact on Small Businesses or Other Small Entities*

The information to be collected does not involve or result in assignment of burden to any small business or other small entity. It will be collected from 67 UCEDD grantees.

6. *Consequences of Collecting the Information Less Frequently*

Section 154(e) of the DD Act of 2000 requires annual reporting. Less frequent collection of data to be included in reports would violate statute. Furthermore, the data to be provided will enable timely monitoring of grantee activity and revision of goals if projected goals and outcomes are not being met.

7. *Special Circumstances Relating to the Guidelines of 5 CFR 1320.5*

There are no special circumstances requiring the collection of information to be conducted in a manner:

- Requiring respondents to report information to the agency more often than quarterly;
- Requiring respondents to prepare a written response to a collection of information in fewer than 30 days after receipt of it;
- Requiring respondents to submit more than an original and two copies of any document;
- In connection with a statistical survey, that is not designed to produce valid and reliable results that can be generalized to the universe of study;
- Requiring the use of a statistical data classification that has not been reviewed and approved by OMB;
- That includes a pledge of confidentiality that is not supported by authority established in statute or regulation, that is not supported by disclosure and data security policies that are consistent with the pledge, or which unnecessarily impedes sharing of data with other agencies for compatible confidential use; or

There are special circumstances requiring the collection of information to be conducted in a manner:

- Requiring respondents to retain records, other than health, medical, government contract, grant-in-aid, or tax records for more than three years. The proposed GPRA measures require that the UCEDD program survey their former trainees at 1, 5, and 10 years post-training. The UCEDDs will have to maintain confidential records for

their trainees for more than 3 years to ensure they are following the data collection schedule. The records to be maintained by the UCEDD will contain information about an individual's education, employment history, and demography. Individual records will be protected through a coding system.

- Requiring respondents to submit confidential information, however, there will be procedures to protect the information's confidentiality to the extent permitted by law. Information gathering techniques are to be conducted without inclusion of names or other identifying information of the respondents. Responses are voluntary and confidential information is not to be recorded. Respondents are to be assured that the information they provide is confidential and that their answers will be used for the purpose for which they were collected. In keeping with agency practices with respect to cultural competence issues, literacy, and visual or auditory ability, alternative formats will be made available.

Finally, there are special circumstances with the regard to the regulations for the DD Act of 2000. The regulations are currently in departmental clearance. Upon approval, the Notice of Proposed Rulemaking will be forwarded to OMB. Information in the pending rulemaking regarding the UCEDDs annual reporting requirements are consistent with the materials contained within and that accompany this Supporting Statement.

8. *Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency*

The Federal Register notice soliciting comments for a 60-day period was published on April 19, 2011 in Volume 76, Number 75, page 21910.

A comment was received by the ACF Reports Clearance Officer, Office of Information Services. The A set of comments was received from Arnold Birenbaum, Ph.D. Associate Director, Rose F. Kennedy University Center for Excellence in Developmental Disabilities and Professor of Pediatrics Albert Einstein College of Medicine, Bronx, New York . The comment and ADD's response is provided below.

Please note that over the lifetime of this information collection, efforts have been made to consult with persons outside ADD to obtain feedback on the Annual Report template, including the Executive Director of AUCD, Directors of and staff from several UCEDD programs, and staff at Maternal and Child Health Bureau (HRSA). In addition, ADD reviewed materials and documents relevant to the collection of information in the preparation of the Annual Report template. Consequently, ADD is quite familiar with the issues raised by the commenter.

The following is the comment we received, and the ADD response.

There was concern that the qualitative information furnished by the UCEDDs should be reviewed by a committee of UCEDD directors/associate directors, some ADD staff, and some consumers to identify any innovative evidence-based practices that could be widely

shared in the network as well as identification of poor practices that could be eliminated so we can shrink the quality chasm.

The ADD accepts this feedback in terms of the process used to evaluate the information provided in the reports, and agrees that it is good idea. The comment does not recommend, however, any structural changes to the form itself. In concert with the concern, ADD is continuing to evaluate the process by which we evaluate the information provided in the reports, and is open to discussions with AUCD, UCEDD professionals and multiple stakeholders regarding development of alternative ways and procedures to review the information provided in the reports.

9. *Explanation of Any Payment or Gift to Respondents*

No payments or gifts are to be implied or offered to respondents.

10. *Assurance of Confidentiality Provided to Respondents*

Confidentiality will be assured before collection of data for the UCEDD Annual Report. The information collected will not be used for any purposes other than statistical and that any information disclosed will not be not identifiable.

The proposed Annual Report template includes measures of improvement and consumer satisfaction. The data for these measures will be collected as part of evaluations of formal trainings, workshop presentations, provision of services, and products. ADD will instruct the UCEDDs to implement the following steps in the collection of information that will ensure confidentiality of the information collected:

- In conducting the evaluative activities, the UCEDDs will ensure the respondents' confidentiality in a variety of formats, including oral and written statements. If UCEDDs use written survey techniques, a standard written statement about confidentiality must be included. All statements about confidentiality will explain that responses are voluntary, confidential information will not be shared with others, and that answers will be used for the purpose for which they were collected. In keeping with agency practices with respect to cultural competence issues, literacy, and visual or auditory ability, alternative formats will be made available.
- When recording information collected through the various evaluative activities, the UCEDDs must maintain a coding system that protects the identity, if known, of the respondent. Measures should be taken to ensure the confidentiality of files, including the use of locked file cabinets and passwords on computers where data is kept.
- None of the data that is entered into NIRS will be confidential. No personally identifiable information should appear in NIRS.

11. *Justification for Sensitive Questions*

In the collection of information for the Annual Report, UCEDDs will not ask questions of a sensitive nature, such as sexual behavior and attitudes, religious beliefs, and other matters that are commonly considered private. In addition, respondents will not be asked questions related to community activities of a character which indicate political affiliation and attitudes; mental and psychological problems potentially embarrassing to

respondents; sex behavior and attitudes; religion and indicators of religion; illegal, anti-social, self-incriminating and demeaning behavior; critical appraisals of other individuals with whom respondents have close relationships, e.g., family, pupil-teacher, employee-supervisor; legally recognized privileged and analogous relationships, such as those of lawyers, physicians and ministers; and records describing how an individual exercises rights guaranteed by the First Amendment.

*12. Estimates of Annualized Burden Hours and Costs*

Based on UCEDD reporting experience, current data and reporting efforts constitute approximately a 1,412 hour burden per grantee for a total of 94,604 hours. The change in burden is a result of UCEDD experience in obtaining data and is a more accurate estimate. The table below outlines the estimate for the hour of burden of the collection of information.

**ANNUAL BURDEN ESTIMATES**

INSTRUMENT	NUMBER OF RESPONDENTS	NUMBER OF RESPONSES PER RESPONDENT	AVERAGE BURDEN HOURS PER RESPONSE	TOTAL BURDEN HOURS
UCEDD Annual Report	67	1	1,412	94,604

Estimated Total Annual Burden Hours: 94,604

An estimate of the annualized cost to the respondents for hour burdens for Collection of information annual cost of burden to the respondents resulting from the collection of information was developed using a representative sample of UCEDDs. The estimate was calculated using the mode for the hourly rate paid to individuals performing each task, a mean cost by task across UCEDDs, and a fringe rate of 30%. Chart below outlines the estimate of the annual cost of burden.

CURRENT ANNUAL EFFORT	# Hours Dedicated to Task		Hourly Rate Of Task		Totals	
	Mean	Range	Mean	Range	Average Effort Per Center	Across the Network (Average Effort x 67 Centers)
Design of data collection tools	23	1-50	\$25.75	\$18-30	\$592	\$39,664.00
Staff training on data collection and entry	60	20-110	\$24.00	\$18-30	\$1,440	\$96,480.00
Data gathering & verifying	860	200-2,184	\$17.00	\$12-20	\$12,903	\$864,501.00
Data entry & cleaning	570	380-820	\$17.00	\$12-20	\$9,690	\$649,230.00

Subtotal	1,412	728-2,706			\$24,625	\$1,649,875.00
Fringe Rate 30%					\$7,388	\$494,962.00
Total Current Burden1					\$32,013	\$3,794,712.50

*13. Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers*

There are no out of pocket expenditures resulting from this collection of information.

*14. Annualized Cost to the Federal Government*

The computation is based on an estimated \$35 per hour for the efforts of a program specialist. This rate includes fringe benefits.

Program specialists will devote an estimated 80 hours per year to review, analyze, and report on the information provided. With 67 grants currently being monitored, the estimated annualized cost would be  $67 \times 80 = 5360$  hours  $\times$  \$35/hour = \$187,600.

*15. Explanation for Program Changes or Adjustments*

There are no program changes.

There is an adjustment due to the estimates being revised based on actual practice. The original burden estimates were based on this being a new information collection system. Given that the system has been in place for several years, time studies based on actual experience were used to develop a more accurate estimate of the time taken to collect the information.

*16. Plans for Tabulation and Publication and Project Time Schedule*

Results from the collection of information will be used by ADD to monitor an individual UCEDD's performance using measurable goals; measures of improvement, consumer satisfaction, and collaboration; and GPRA measures. This individual monitoring activity will not be published.

Data collected from across the UCEDDs on the measures of improvement, consumer satisfaction, and collaboration and the GPRA measures will be tabulated and reported in aggregate form in bi-annual reports to Congress and in annual GPRA reports. The timeline and tabulation procedures are outlined below:

- Data will be collected throughout the UCEDD fiscal year (July 1 to June 30). All data must be entered into the NIRS system by June 30. No data will be accepted after that date.
- Reports are due 30 days after the close of the UCEDD fiscal year (July 30).
- ADD will tabulate the measures of improvement and consumer satisfaction data once the 67 UCEDDs have submitted Annual Reports. Raw data will be stored in a data file (e.g., Microsoft excel, Microsoft access) for each measure of improvement and consumer satisfaction. Once all data has been entered, ADD staff will tabulate the



measures of improvement and calculate overall percentages for the measures of consumer satisfaction.

- ADD will also tabulate the GPRA measure by entering raw data for the GPRA measures into a data file (e.g., Microsoft excel, Microsoft access). ADD staff will calculate the overall percentages for the GPRA measure.
- The tabulations and calculations of the data will be completed by November 30.

*17. Reason(s) Display of OMB Expiration Date is Inappropriate*

Not Applicable

*18. Exceptions to Certification for Paperwork Reduction Act Submissions*

Not Applicable

**B. Statistical Methods (used for collection of information employing statistical methods)**

1. Respondent Universe and Sampling Methods
2. Procedures for the Collection of Information
3. Methods to Maximize Response Rates and Deal with Nonresponse
4. Test of Procedures or Methods to be Undertaken
5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data