

April 20, 2020

ATTN:  
Pamela O'Brien,  
Administration for Community Living  
Washington, DC 20201  
Pamela.Obrien@acl.hhs.gov

**RE:** The Federal Register notice (OMB #0985-0030) requesting formal comment on the proposed collection of information on the revision on the information collection requirements related to the University Centers of Excellence in Developmental Disabilities (UCEDD) Education, Research, and Service Final 5 year report.

**Background:** The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000) directs the Secretary of HHS to develop and implement a system of program accountability to monitor grantees funded under the DD Act. The program accountability system shall include the National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service. The DD Act states that the UCEDD Annual Report should contain information on progress made in the projected goals of the Center for the previous year ([www.federalregister.gov](http://www.federalregister.gov))

**Description of Organization Providing Feedback:** JFK Partners, Colorado's UCEDD and LEND program is offered by the University of Colorado School of Medicine (UC-SOM), at the Anschutz Medical Campus in Aurora, Colorado. JFK Partners is a program in the Developmental Pediatrics (DevPeds) Section of the Department of Pediatrics of the UC-SOM, and is conducted in affiliation with Children's Hospital Colorado. Sandra Friedman, MD, MPH, is DevPeds Section Head and Director of JFK Partners. Dr. Friedman, Directors for each core function goal, and Discipline Directors comprise the governance of JFK Partners.

**Comments:**

1. Whether the proposed collection of information is necessary for the proper performance of ACL's functions, including whether the information will have practical utility.

***Yes, documentation of outcomes will inform changes within the UCEDD network, as well as serve accountability functions for continued funding of UCEDD programs.***

2. The accuracy of ACL's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used to determine burden estimates.

***Based upon experiences where the estimated number of hours was very substantially less than the number of UCEDD hours invested in reporting, the estimated number of hours to adapt to and maintain the revised system seems quite low. For example, grantees' internal data collection methods will require substantial revision. All faculty, staff and trainees will need training in their new documentation responsibilities. Each year, training will be repeated for new faculty, staff, and trainees. Furthermore, reporting of the intermediate outcomes for Research, in particular, will be onerous for researchers who already have substantial reporting and publication requirements specified in their grants and contracts. This requirement seems redundant with the required reporting of publications.***

***OIDD should consider identifying and eliminating data elements that may redundant with reporting in other core functions to offset the reporting burden.***

3. Ways to enhance the quality, utility, and clarity of the information to be collected.

***The following paragraph from Part 1.a. Detailed Work Plan Progress Report (annual report) seems to refer to future activities (e.g., “individuals who will work”) and therefore is very confusing as an aspect of a report on progress in a past year:***

*The guidance also requires that the UCEDD provide a list of organizations, cooperating entities, consultants, or other key individuals who will work on the project, along with a short description of the nature of their effort or contribution.*

***Produce a guidance for collection of the data that is very rich in examples to avoid interpretation or categorization differences stemming from the diversity of UCEDD programs and test the clarity of the guidance with at least a sample of UCEDDs.***

4. Ways to minimize the burden of the collection of information on respondents, including through the use automated collection techniques when appropriate, and other forms of information technology.

***AUCD would need to overhaul NIRS to ask all required questions and to provide single-year and cumulative reports summarizing the data. They would need a way to track issues encountered by grantees as they try to input the data into NIRS, and develop FAQs to respond to the issues.***

Sincerely,



Sandra L. Friedman, MD, MPH  
Director, JFK Partners  
Professor and Section Head  
Section of Developmental Pediatrics  
Department of Pediatrics