April 11, 2022

Sent electronically

ophelia.mclain@acl.hhs.gov.

Administration for Community Living,
Department of Health and Human Services.
330 C Street SW
Washington, DC 20201,

Attention: Ophelia McLain

Re: Agency Information Collection Activities: Proposed Collection; Public Comment Request; of the One Protection and Advocacy Annual Program Performance Report OMB #0985–0063

> *This IC Revision solicits comments on the information collection requirements relating to the One Protection and Advocacy Annual Program Performance Report [OMB #0985–0063].*
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> *ACL invites comments on our burden estimates or any other aspect of this collection of information, including: (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; (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; (3) ways to enhance the quality, utility, and clarity of the information to be collected; and (4) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques when appropriate, and other forms of information technology. This is a revision to a currently*

To Whom It May Concern:

Families & Friends of Care Facility Residents (FF/CFR), Arkansas' statewide parent-guardian association, submits the following comments on the reporting requirements of the nation's protection and advocacy systems. We appreciate the opportunity.

Interest of FF-CFR

Most, but not all, members of FF-CFR have loved ones with life-long intellectual & developmental disabilities receiving residential treatment and training services at one of the state's publicly operated intermediate care facilities (ICFs). The five human development centers (HDCs) provide good homes and training to over 850 citizens unable to care for themselves. The majority of Arkansas HDC residents are non-verbal and function in the profound range of cognition impairing their abilities to self-advocate or self-direct their service needs without assistance from others. HDC residents are our state's most at-risk citizens. There is no cure for their life-long cognitive deficits/developmental disabilities. The five HDCs undergo annual, unannounced evaluations and surveys by the State Office of Long-Term Care and also periodic reviews and surveys by the international accreditation organization, Commission on Accreditation of Rehabilitation Faculties (CARF). All HDCs are certified by these two organizations. We are grateful.

Policies and practices of Administration for Community Living, Department of Health and Human Services and its grantees, including protection and advocacy systems (PAs) have a direct impact on our family members with disabilities.

Comments

In its Notice requesting input from the public on reporting by DD Act protection and advocacy systems (P&As), Administration for Community Living, Department of Health and Human Services asks the following:

(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.

FF-CFR Comment:

Yes. Reporting of use of public funds to the administering agency by federal grantees is necessary. Accurate, non-partisan reporting by the protection and advocacy systems must be foundational for ACL. As the administering agency, ACL must assure accountability for the proper use of federal funds from the programs for which it is responsible. ACL's responsibilities include oversight of the activities of four programs created under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act): (1) Protection and Advocacy System for Persons with Developmental Disabilities (PADD), (2) State Councils on Developmental Disabilities (CDD), (3) University Centers for Excellence in Developmental Disabilities (UCEDD) and (4) Projects of National Significance (PNS).

(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;

FF-CFR Comment:

DD Act programs operate in every state. Accurate reporting to ACL by the four DD Act programs, including protection and advocacy systems for persons with developmental disabilities (PADD) is fundamental in meeting accountability requirements for programs receiving federal funds. It is necessary that the administering agency (ACL) understand PADDs' goals, activities and outcomes for the nation's diverse populations with developmental disabilities, the situations of their families and the range of services offered by states. The impact of PADD's activities on families of persons with disabilities and the states' human service systems have not been accurately reported. The report forms used by PADD do not transmit the information of vulnerable people living with lifelong disabilities and of federal grant programs which use litigation as a tool to eliminate long-term care facilities for citizens unable to care for themselves (PADD's "systems change" goals). Further, it is not a requirement of PADD to submit data in their reports to ACL on mortality and sentinel events (911 calls or ER visits) of citizens with cognitive and developmental disabilities. See for example the deaths of vulnerable residents in GA and VA following their forced transitions from long-term care facilities.

(3) ways to enhance the quality, utility, and clarity of the information to be collected;

FF-CFR Comment:

Persons who are impacted by ACL policies and DD Act program activities, including P&As have been excluded from policymaking by the agency. ACL last held public hearings ("Listening Sessions") in 2010. The nearest ACL Listening Session to Arkansas families was in Dallas, Texas and three of our family members attended. Our experience was that families of persons with high-needs-care and who receive services in a long-term care facility were excluded from Day Two of the listening session. Despite our request (submitted in writing to ACL) to come to D.C. to participate in the agency's strategic planning sessions, we were not notified or invited. Later, we found the published reports of the listening sessions to be inaccurate and highly partisan.

Our families ask: how may we participate in formulating goals and objectives of the federal agency (ACL) and its grantees (P&As) which affect our loved ones with life-long disabilities? In what forum may families report on the activities of the DD Act programs which use federal funds to undermine and eliminate good facilities which care for persons unable to care for themselves? Why does ACL permit DD Act programs' harmful work which include P&A class action litigation and also lobbying state policy makers by the protection and advocacy systems and other DD Act funded programs?

and

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

FF-CFR Comment:

Simple forms with boxes to check are insufficient to accurately and fully report the diverse and complex realities of the population with developmental disabilities to ACL. Health and safety of persons unable to care for themselves who are nonverbal and for whom there is no cure, their aging primary caregivers, the lack of specialized, licensed long-term care facilities for persons with cognitive and developmental disabilities, and the use of jails and hospitals as emergency placements for high-needs persons are but some of the information which ACL should be receiving.

Respectfully submitted,

FAMILIES AND FRIENDS OF CARE FACILITY RESIDENTS
By: Carole L. Sherman
Mother and Guardian of John, age 53, who functions as a young toddler
President Arkadelphia Human Development Center Families & Friends Association
Co-Chair FF-CFR Public Affairs Committee

Cc: HON Xavier Becerra, Secretary U.S. Department of Health & Human Services
HON John Boozman
HON Tom Cotton
HON Steve Womack
HON Rick Crawford
HON French Hill
HON Bruce Westerman