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To: Department of Health and Human Services
Administration for Community Living – Administration on Intellectual and
Developmental Disabilities (ACL-AIDD)

Attention: Valerie Bond

Re: Federal Register, Volume 81, Number 60; March 29, 2016/Notices
ACL-AIDD Request for Comment – State Councils on Developmental Disabilities –
Required 5-Year State Plan –

To Whom It May Concern:

Please accept these comments from VOR in response to Notice of Comment Request by the Administration for Community Living-Administration on Intellectual and Developmental Disabilities (ACL-AIDD) on required 5-Year State Plans of State Councils on Developmental Disabilities (SCDDs). Notice requesting comments was published in the Federal Register, Vol. 77, Number 84 (Tuesday, March 29, 2016).

State Councils on Developmental Disabilities operate in every state and are one of four primary programs created under Public Law 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). DD Act programs are funded through the federal government's discretionary appropriations. The DD Act was last authorized in 2000 for a period of seven years. In the intervening 16 years, Congress has not held oversight hearings on the DD Act. Increasingly, DD Act programs/grantees employ appropriations to undermine and eliminate Medicaid-licensed Intermediate Care Facilities (ICFs/MR) and to achieve goals of deinstitutionalization of at-risk persons from their safe congregate care homes.

Any State desiring to receive federal funds under Subtitle B – Federal Assistance to State Councils on Developmental Disabilities of the DD Act “shall submit to the [DHS] Secretary, and obtain approval of a 5-year strategic State plan under this section.” Sec. 124. State Plan, Public Law 106-402, Developmental Disabilities and Bill of Rights Act of 2000 (DD Act).

“On an annual basis the Council must review the plan and make any amendments. The State Plan will be used (1) by any amendments. The State Plan will be used (2) by the Council as a planning document; (3) by the citizenry of the State as a mechanism for commenting on the plans of the Council; (4) by the Department as a stewardship tool, for ensuring compliance with the Developmental Disabilities Assistance and Bill of Rights Act, as one basis for providing technical assistance (e.g., during site visits), and as a support for management decision making.” Notice, Federal Register Vol. 81, No. 60.

ACL-AIDD “specifically requests comments on: (a) Whether the proposed Collection of information is necessary for the proper performance of the function of the agency, including whether the information shall have practical utility; (b) the accuracy of the agency’s estimate of the burden of the proposed collection of information; (c) the quality, utility, and clarity of the information to be collected; (d) ways to minimize the burden of information to be collected; and (e) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection technique comments and or other forms of information technology.” Notice, Federal Register Vol. 81, No. 60.

Interest of VOR

VOR, founded in 1983, is a national, nonprofit, advocacy organization representing individuals with intellectual and developmental disabilities (ID/DD) and their families. VOR advocates for a full array of residential services and supports for individuals with cognitive-developmental disabilities and their families, including own-home, community-based group homes, and licensed facility-based congregate care settings (Intermediate Care Facilities for Persons with cognitive deficits and developmental disabilities). VOR policies and VOR advocacy activities are guided by the Developmental Disabilities and Bill of Rights Act of 2000 (DD Act).

ACL-AIDD is the federal agency designated to represent VOR members and their family members living with life-long cognitive-developmental disabilities. ACL-AIDD is the oversight agency for DD Act programs, including State Councils on Developmental Disabilities.

Comments

There is a tremendous debate in the nation over public policies regarding long-term care services and supports for persons with cognitive - developmental disabilities. This debate centers on two very different populations with disabilities: (1) the unique at-risk population, which includes VOR’s loved ones with disabilities and their peers who have been adjudicated incompetent and whose legal representatives and responsible family members have chosen residential care services in Medicaid-certified congregate care facilities (ICF programs) and (2) the larger population of persons with physical disabilities and persons with slight or mild cognitive impairments with abilities to self - advocate and self – direct their personal services.

The vast majority of the people VOR represents are adults with mental ages/cognition of newborns or young toddlers. They cannot care for themselves and many are also nonverbal, unable to report their hurts or needs. Many of these individuals are medically fragile. Many have behavioral or psychiatric disorders that require a higher level of care and increased levels of training for caregivers. Many of VOR’s family members with disabilities receive life-sustaining, high quality residential supports in congregate care settings, which are Medicaid-certified and funded (Intermediate Care Facilities for Individuals with cognitive and developmental disabilities - ICFs).

Individuals with competencies to self - advocate and self - direct their services have expressed preferences for home and community – based services (Waiver programs). Both program models (ICF

and Waiver) are options offered to eligible persons under CMS through Medicaid. A Bill of Rights for persons with developmental disabilities and assurances for both service models is included in the Developmental Disabilities and Bill of Rights Act of 2000 (DD Act). AIDD has oversight of programs created under the DD Act, including State Councils on Developmental Disabilities. DD Act programs operate in every state; DD Act program policies and activities directly affect VOR's family members with life - long developmental disabilities.

Fundamentally, ACL-AIDD, a government entity, should be seen by stakeholders as impartial when conducting the agency's oversight activities and programs. Fundamentally, DD Act programs and their grantees should act impartially, with transparency in the use of public funds and in the actions of their agents.

ITEM #1 FOR REVIEW AND COMMENT:

Use of Plans by Department as stewardship tools, for ensuring compliance with the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

(ACL-AIDD reviews State Councils' 5-Year plans to ensure that Councils are in compliance with the DD Act).

Questions and Comments to the Agency from VOR

(1) Inclusion of All Stakeholders

Are all stakeholders represented in State Councils' 5-Year Plans? Based on the reports of our members, State Councils' 5-Year plans do not always include the requests and observations of all stakeholders. State Council agents and their grantees routinely engage in advocacy activities to bar access to congregate care facility services (ICFs) upon which many individuals with disabilities depend for their well-being and for necessities of their lives. ACL-IDD permits State Councils to engage in advocacy activities which eliminate the choice of congregate care facilities with their "bundled services" which offer in addition to safe environments, realistic opportunities for practical economies of scale in their specialized services. For VOR families, the ICF model provides experiences with high qualities of life for persons with disabilities.

(2) Council Membership

Are the agency and State Councils in compliance with the DD Act regarding category requirements for Council membership? DD Councils' State Plans are required to describe the membership of each Council. Sec. 124 of the DD Act. Councils are required to have at least 1 member who "shall be an immediate relative or guardian of an individual with a developmental disability who resides or previously resided in an institution or shall be an individual with a developmental disability who resides or previously resided in an institution." Sec. 125 (6) Institutionalized Individuals.

(3) Rights of Individuals with Developmental Disabilities – Institutional Programs (Sec. 109 of DD Act)

Do goals and strategies in State Councils’ 5-Year Plans affirm the rights of individuals with developmental disabilities to receive residential treatment habilitation services in an array of program-options, including institutional programs? See:

Rights of Individual with Developmental Disabilities

(a) in General – Congress makes the following findings representing the rights of individuals with developmental disabilities:

(1) Individuals with developmental disabilities have a right to appropriate treatment, services and habilitation for such disabilities, consistent with section 101(c).

(2) The treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.

(3) The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs and other community programs, including educational programs in which individuals with developmental disabilities participate that -

Sec. 109, DD Act
42 USC15009

VOR members report that some DD Councils’ 5-Year Plans include goals to eliminate the choice of institutional programs and are therefore not in compliance with the DD Act.

Example – Connecticut Council

“GOAL # 1”

Self-Determined Lives

The CT Council on Developmental Disabilities will defend and promote the civil rights of individuals with disabilities through activities that result in access to services and supports for individuals with developmental disabilities that enable them to participate in community life as they choose.

- *Close Southbury Training School and the five Regional centers.
- *Increase self-determination through self-direction
- *Promote Supported Decision Making ...”

CT 5-Year Plan 2017-2021 (Attached hereto).

Additional Examples - (LA, KS, and MO) follow in (4).

(4) Rights of individuals with disabilities and their families as “primary decision-makers”

Does ACL-IDD assure State Councils’ actions (as guided by 5-Year Plans) affirm that individuals with disabilities and their families are the “primary decision-makers” regarding services, supports and policies, including regarding choosing where their family members with disabilities live, as required by the DD Act?

Individuals with developmental disabilities and their families are the primary decision-makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options and play decision-making roles in policies and programs that affect the lives of such individuals and their families.

Sec. 101, DD Act
42 USC15001

VOR members report that some Councils and Councils’ 5-Year Plans do not respect the right of individuals with developmental disabilities and their families to choose residential treatment habilitation services in institutional/ congregate care (ICF) settings. Examples from 5-Year Plans follow:

Example #1 – Louisiana Council

Louisiana Developmental Disability Council 5 Year Plan (FFY 2007-2011) contains Strategies 6.3.1 & 7.3 “Advocate for Louisiana to begin to reallocate resources away from developmental centers.” Strategies 6.3.2 & 7.4 “Advocate for Louisiana to continue transitioning individuals out of developmental centers...and begin to close its existing developmental centers.”

Louisiana Developmental Disability Council 5 Year Plan (2012-2015) Objective:
“Admissions to developmental centers will cease...“The number of people at large public residential facilities will decrease thirty percent.”

Louisiana Developmental Disability Council 5 Year Plan (FFY 2012-2016, FFY 2016 Plan) contains the following goal: “The number of people at large public residential facilities will decrease thirty percent.”

Example #2 – Kansas Council

Kansas Council on Developmental Disabilities(KCDD) adopted Policy Priorities 2013:
“Establishing a timeline to end the provision of long term services in state-run DD Institutional settings and direct funds to help eliminate the waiting list.”

Kansas Council Legislative Priorities: “Systems Restructuring....Close the two state Developmental Disabilities facilities and provide adequate community based services and supports.”

Example # 3 - Missouri

The MO State DD Council’s 5 – Year Plan for 2012-2016 included the goal of closing 3 public ICFs. The MO Council’s actions against ICFs has included paying for a full page ad denigrating ICF care in a widely circulated newspaper and MO DD Council agents testifying before state legislative committees against funding for public ICFs.

Note: In 2012, two MO state ICFs closed, the Nevada Habilitation Center and the Northwest Habilitation Center . A third state center, Marshall Habilitation Center is currently being closed.

Councils and their 5-Year Plans are therefore not in compliance with the DD Act when they do not respect individuals with developmental disabilities and their families as primary decision-makers in their choices of congregate care facilities (ICFs).

(5) Activities of State self-advocacy organizations led by individuals with developmental disabilities

State Councils’ 5-Year Plan goals are required to include a goal for each year to establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities. Sec. 124. (4) Plan Goals (A) of DD Act. VOR members report actions by self-advocates which are not in compliance with the DD Act. Further, actions by self-advocates have been and are dangerous to VOR’s loved ones with disabilities who have been adjudicated incompetent and have lacked a capacity to self-advocate or defend themselves. Examples of Self – Advocacy activities funded through State Council grants follow:

Example #1 - Wisconsin

2012 - 2016 State Plan

Goal 3 (Self-Advocacy): People with DD and their families will be effective advocates and leaders resulting in systems change on issues they feel are most important to them.

FACT: The Wisconsin Board for People with Developmental Disabilities (WI State Council on DD) funds a self-advocacy organization, People First Wisconsin, which has adopted a goal of closing all state care facilities serving individuals with developmental disabilities.

Example #2 – Tennessee

Proposed 2017 – 2021 State Plan

“Goal 2: Developing Leaders...Prepare Tennesseans to serve in leadership roles and influence policy....

1. Yearly, provide resources and support to strengthen Tennessee self-advocacy organizations and statewide self-advocacy initiatives led by individuals with developmental disabilities.”

FACT: Tennessee People First was the recipient of a grant from Self-Advocates Becoming Empowered (SABE) which originated from Administration on Intellectual and Developmental Disabilities (ACL-IDD) to strengthen self-advocacy organizations. Tennessee People First, a self-advocacy organization, initiated a “closing institutions” campaign.

http://peoplefirstoftennessee.org/?page_id=27

http://www.sabeusa.org/wp-content/uploads/2014/02/31_Closing-Institutions.pdf

Example #3 – New Hampshire

Proposed FY 2017 – FY 2021 State Plan

“Goal 3: Personal Choice: People with developmental disabilities will lead meaningful lives with an increased level of personal choice and greater control over their lives including medical, dental and behavioral support and services, in home and community service delivery and choice and social activities...supporting the formation and strengthening of self-advocacy organizations and activities led by people with disabilities, including cross-disability advocacy initiatives.”

FACT: People First of New Hampshire, a self-advocacy organization, initiated an “Institutions: Close Them” campaign. <http://www.peoplefirstofnh.org/institutions-close-them.html>

Does AIDD review and monitor State Council grants to self-advocacy organization for compliance with the DD Act?

ITEM #2 FOR REVIEW AND COMMENT:

Use of Plans by Department for Oversight and Accountability

(ACL-AIDD will use State Councils 5-Year plans for Oversight and Accountability).

Comment to the Agency From VOR

To better assure transparency and accountability:

1. Current and past State Councils’ 5-Year State Plans should be clearly shown on all State Council websites, including annual public policy statements and goals – which is now not the case.
2. Annual performance reports by State Councils to ACL- AIDD on achieving goals of 5-Year State Plans should be clearly shown on the AIDD website, to include the link to each state’s SDDC 5-Year Plan, presently not the case.
3. State Councils’ 5 Year State Plans should be inclusive of all Councils advocacy activities carried out utilizing federal funds, whether the activity is carried out by the Council itself or by a funded project (subsidiary grantees). Currently, in a variety of states, forced deinstitutionalization activities are carried out by self-advocacy organizations which allow a State Council to avoid accountability.

ITEM #3 FOR REVIEW AND COMMENT:

Whether the proposed Collection of information is necessary for the proper performance of the function of the agency, including whether the information shall have practical utility.

(Is the information collected from State Councils' 5-Year plans necessary for the proper performance and function of ACL-AIDD?)

Comment to the Agency from VOR

The development of 5-Year State Plans by State Councils on Developmental Disabilities is required by the DD Act. 5-Year State Plans are absolutely necessary for the proper functioning of State Councils on Developmental Disabilities, and should have practical utility for proper oversight and accountability.

CONCLUSION

ACL-AIDD provides insufficient oversight, transparency and accountability to DD Act programs, which include State Councils on Developmental Disability and their 5-year State Plans. The agency is not responsive to our members' objections and experiences.

1. Use of Public Funds by State Councils on Developmental Disabilities and Their Grantees.

There should be no public funding for advocacy activities by State Councils on Developmental Disabilities and their grantees which work to weaken and eliminate the choice of institutional care. There should be no public funding for advocacy activities by State Councils on Developmental Disabilities and their grantees which do not respect individuals with developmental disabilities and their families as primary decision-makers regarding services and supports such individuals and their families receive, including regarding choosing where individuals live.

2. State Councils on Developmental Disabilities and Their Grantees' Goals of "Community Integration" and "Self-Determination."

State Councils which adopt goals of "community integration" and "self-determination" for all persons with developmental disabilities in their 5-Year Plans and which also adopt strategies to achieve these goals by advocating for closure of Medicaid-certified congregate facilities have harmed a segment of their constituency. Such actions deny access to the life-sustaining services required by eligible citizens with developmental disabilities for their health and safety. In the

case of incapacitation, families and/or legal representatives have chosen residential placement in a specialized congregate care facility. VOR and its members can support State Councils and Council projects which encourage the States to offer a continuum of service options, including institutional care, to meet the diverse care and support needs of individuals with developmental disabilities.

The Supreme Court, in its landmark Olmstead v. L.C. ruling, embraced the need for a range of services to respond to the varied and unique needs of the entire disability community. A majority of Justices in Olmstead recognized an ongoing role for publicly and privately-operated institutions:

We emphasize that nothing in the Americans with Disabilities Act or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. 119 S. Ct. at 2187.

Unjustified isolation, we hold, is properly regarding as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand. 119 S. Ct. at 2185.

The plurality opinion in Olmstead stated:

Each disabled person is entitled to treatment in the most integrated setting possible for that person - recognizing on a case-by-case basis, that setting may be an institution. 119 S. Ct. at 2189

3. Agency for Individuals with Cognitive and Developmental Disabilities.

The federal agency, AIDD, with oversight for DD Act programs should be led by a Commissioner on Developmental Disabilities (as referenced in the DD Act), with a link to the Commissioner's contact information posted on the AIDD website, which is not now the case.

4. Opportunities for In-put on Agency Policies Which Affect VOR's Family Members with Developmental Disabilities and Their Peers.

AIDD should provide opportunities for stakeholders affected by the DD Act to communicate with the agency.

5. Oversight Hearings on Public Law 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

Congressional hearings should be scheduled and held on the DD Act with opportunities for testimony from the public.

Respectfully Submitted On Behalf of VOR,

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Mothers & Co-Guardians of Adult Children,
Residents of Public Intermediate
Care Facilities (ICFs)

And Representing Stakeholders in Arkansas

Submitted this 30th day of May, 2016.

Sent electronically to:

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Attn: OMB Desk Officer for ACL

Copies sent to:

*Chairman Lamar Alexander
U.S. Senate Health, Education, Labor &
Pensions Committee*

*Chairman Tim Murphy,
U.S. House Energy & Commerce
Oversight & Investigations Sub-Committee*



Goals for 2017-2021

GOAL #1: Self-Determined Lives

The CT Council on Developmental Disabilities will defend and promote the civil rights of individuals with disabilities through activities that result in access to services and supports for individuals with developmental disabilities that enable them to participate in community life as they choose.

- Close Southbury Training School and the five Regional centers.
- Increase self-determination through self-direction
- Promote Supported Decision Making
- Hold a second Building a Great Life Conference

GOAL #2: Self-Advocacy

Self-advocates and families will have increased access to leadership training and leadership opportunities.

- Offer Partners in Policymaking Leadership Training
- Support the Cross Disability Lifespan Alliance, candidates forums and policy initiatives
- Offer financial support through the Consumer Involvement Fund to support attendance at conferences and other leadership opportunities
- Provide training and support to parents who have intellectual disabilities

GOAL 3:

Community Inclusion and Participation

People with disabilities will have access to increased information and opportunities for meaningful participation as citizens of their communities

- **Develop customized employment opportunities for people with developmental disabilities**
- **Influence communities to become livable communities that include people with disabilities as members of those communities.**
- **Identify post-secondary education opportunities for so that people with disabilities can access higher education.**
- **Increase on demand transportation options**
- **Support CT KASA (Kids As Self Advocates) to promote transition of youth into adult health care.**
- **Address policies that are barriers to housing, so that people with developmental disabilities can live in the community of their choice.**

The Council wants to know what you think about our plans for the next five years!

- **Will our goals and activities help us achieve our mission of promoting the full inclusion of people with disabilities in our community?**

- **Do these goals and activities address the major issues and challenges facing people with disabilities in our state?**

- **Is there something missing from our goals that you think the Council should be doing?**

TELL US WHAT YOU THINK!

We are taking public comment on these goals until April 30, 2016.

Send your comments to:
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