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Federal Law Supports Choice: ADD urged to immediately remove recommendations to eliminate specialized programs for people with profound disabilities

VOR offers these comments in response to the Administration on Developmental Disabilities' (ADD's) "Envisioning the Future, Prioritization Meetings – Summary of Summaries."

Summary

ADD's recommendation to "develop and implement plans to close public and private institutions," and related recommendations that limit individual and family choice, purportedly in support of the "Obama Administration Agenda for Americans with Disabilities," are in direct conflict with –

- The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and related Congressional intent;
- The Americans with Disabilities Act and the *Olmstead* decision interpreting it;
- The Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) program; and
- President Obama's "Year of Community Living" Initiative which specifically calls for "opportunities for individuals to receive long-term services and supports ***in institutional and community settings***." (The White House, June 22, 2009) (***emphasis added***).

Conclusion

As will be explained, ADD's recommendations to eliminate institutional settings should be abandoned for two primary reasons:

1. They exceed ADD's authority and directly violate federal law by eliminating choice.

2. They represent bad public policy by narrowing, rather than expanding, options for people with profound intellectual disabilities and exalting the ideology of lawyers over the choices of individuals with developmental disabilities and their parents and guardians.

ADD's federal mandate requires it represent all people and all choices

ADD is a federal agency within the U.S. Department of Health and Human Services (HHS) that is entrusted and funded to represent ***all*** Americans with developmental disabilities and their families. ADD's recommendation to eliminate "institutions," which include ICFs/MR, is contrary to federal law and policy, and potentially harmful to citizens with profound developmental disabilities who are receiving high quality, life-sustaining ICF/MR supports. It is ADD's job to carry out federal law, not to override it, and to abide by Supreme Court decisions.

ICFs/MR are funded and licensed by the Centers for Medicare and Medicaid Services (CMS), another HHS program. ADD's recommendation is not only harmful to people it purportedly represents and contrary to federal law, but it amounts to one HHS program calling for the elimination of another HHS program – an absurd use of federal time and money.

Federal law and policy in support of a full array of residential and service options reflect societal values which respect individual and family decisionmaking. In the context of service options for people with profound intellectual disabilities, no federal agency should define "choice" so narrowly as to disenfranchise an entire segment of the disabled population – indeed, that segment who most needs representation and protection.

VOR calls on ADD to immediately remove the recommendation to "develop and implement plans to close public and private institutions," and related recommendations (see below) that limit choice and encourage DOJ and Arc collaboration.

ADD should not use its public funds to sponsor programs and promote policies which undermine and eliminate necessary, life sustaining care options, contrary to well-founded federal law and policy.

Objectionable Recommendations

The following recommendations and related goals appear in the Section titled: "Team 2: Obama Administration Agenda for Americans with Disabilities":

- Promote access to community living services (Olmstead/Dept. of Justice enforced) – "Develop and implement plans to close public and private institutions and segregated workshops" (p. 12)

- Collaboration – "ADD and the Administration on Aging should jointly plan and pool resources at the Federal and State levels while maintaining the DD Act values. Caution against taking on any values/programs that involve congregration and segregation" (p. 13).

- Community Living – "Keep people with disabilities out of congregate institutions" and "Harness the supports and influence of The Arc" (p. 14. Note: The Arc expressly supports the elimination of institutional supports).

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

Recommendations that support the elimination of facility-based options are in direct conflict with the DD Act and related Congressional intent.

Section 15001(c) of the DD Act, adopted in 1993, added a policy section to the Act, including the following paragraph:

> “(3) individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive*, including regarding choosing where the individuals live from available options,* and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families” (*the italicized language was added in 2000*).

In the 1993 section-by-section analysis, the House Energy and Commerce Committee included the following explanation of the intent:

> “The Committee recognizes that, with the appropriate resources and support, many individuals with developmental disabilities will live lives that are fully integrated into their respective communities. This potential, however, should not be seen as limiting the choice of individuals and their parents to seek living arrangements that are most suitable to their needs and wishes, whether they be in the community or in institutions.
>
> “The Committee has heard from many parents of individuals with developmental disabilities who reside in large institutional facilities. Among the concerns expressed by these parents is that the goal of independent, community-based living for some individuals not be seen as a mandate for all individuals with disabilities. The Committee recognizes and supports the belief that each individual and each respective family have different goals and needs. The Act should in no way be read to support one kind of residential placement over another. [House Committee Report, No. 103-378 (November 18, 1993)]

The Conference report retained this language and added the following:

> “First, the goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions.
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> * * * *
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> “Third, Protection and Advocacy systems established under Part C of the Act shall use the resources made available under this Act in accordance with the purposes and statement of policy set forth in the Act and are authorized to pursue appropriate remedies to address the violation of rights under the laws in all settings, including community and ICF/MR institutions . . . . [(H. Rep. 103-442 (March 21, 1994)]

Olmstead and the Americans with Disabilities Act

In 1999, six years after the “primary decisionmaking” language was added to the DD Act, the U.S. Supreme Court handed down its landmark *Olmstead* decision. Just as Congress intended with the DD Act, the Supreme Court’s *Olmstead* decision balanced the benefits of community integration with indivdiual and family choice. The Court recognizes that while community integration is preferred for many people, some individuals have needs that are so great that they may require institutional care and the ultimate decision of whether to leave an institution resides with the individual, not with so-called professionals:

> "We emphasize that nothing in the ADA 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." Justice Ginsburg went on to say, quoting from VOR's *Amici Curiae* brief, that "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.

President Obama's Year of Community Living Initiative

On June 22, 2009, President Obama commemorated the 10th anniversary of Olmstead v. L.C. by launching "The Year of Community Living," a new effort to assist Americans with disabilities. According to the President's press release:

> The Administration acknowledges that strides have been made, and knows and accepts that there is much work to do in order to **maximize the choices** and opportunities for individuals to receive long-term services and supports ***in institutional and community settings***. (The White House, June 22, 2009) (***emphasis added***).

Just as the Congress and the Supreme Court have done, the President appropriately balanced the goal of community living with the need for a full range of services to meet all needs within the disabled population.

Conclusion

ADD's recommendations to eliminate institutional settings should be abandoned for two primary reasons:

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2. They represent bad public policy by narrowing, rather than expanding, options for people with profound intellectual disabilities and exalting the ideology of lawyers over the choices of individuals with developmental disabilities and their parents and guardians.