

**TEMPLATE LETTER FOR CONGRESSIONAL OFFICES TO SEND
TO THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**
(to receive a copy of this template letter by email, please contact thopp@vor.net)

June 2014

Sylvia Burwell, Secretary
U.S. Department of Health and Human Services
330 Independence Ave., SW
Washington, D.C. 20201

Marilyn Tavenner, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Room 445-G, Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Burwell and Administrator Tavenner,

I have heard from constituents whose family members with intellectual and developmental disabilities (I/DD), including autism, many of whom have profound I/DD, are medically fragile or have significant behavioral challenges, have been or would be directly impacted by certain U.S. Department of Health and Human Services (HHS) agencies' forced "deinstitutionalization" actions.

Their family members rely on the life-sustaining, highly specialized direct care, health care and other supports available in their Medicaid-licensed or supported specialized, congregate care homes (*e.g.*, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID); nursing facilities for people with I/DD; and Home and Community-Based Waiver services in homes).

HHS' Administration on Intellectual and Developmental Disabilities (**AIDD**) and its Protection and Advocacy (**P&A**), Developmental Disabilities Councils, and University-affiliated programs; the National Council on Disability (**NCD**); and the Centers for Medicaid & Medicare Services (**CMS**) have pursued advocacy, initiatives, lawsuits, publications, and/or regulations in support of widespread "deinstitutionalization" and closures – the forced removal of individuals with disabilities from homes deemed too congregate and not "community enough," without regard to the happiness, well-being and choices of the individuals affected.

My constituents express strong objection to initiatives being pursued without family and legal guardian notice, input and consent, and without regard to the wishes and needs of the individuals impacted. Many of these residents have the cognitive ability of infants or toddlers and no one would question the rights of parents and families to make health care decisions on behalf of one year olds.

These actions strongly appear to violate letter and spirit of federal laws that protect the civil rights of people with I/DD, and their legal representatives to reject residential choices others might make for them. The right to choice is protected by the Americans with Disabilities Act and the U.S. Supreme Court's *Olmstead* decision interpreting it, as well as by Medicaid law and the Developmental Disabilities Act, the authorizing statute for AIDD programs.

These families also express legitimate concerns about the ability of private providers of small settings to provide safe care and access to specialized supports, a concern even acknowledged by proponents of deinstitutionalization (*see e.g.*, Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 *Cardoza L. Rev.* 1, 21 (2012)).

Staffing issues in particular point to predictable problems. In addition to low wages, high turnover, and minimal training of staff in most small settings, there is also no federal requirement for national background checks; "bad apples" float between provider and states continuing to work with, and in some cases, harm vulnerable people.

In addition to responding to my concerns, I encourage HHS to expand its national background check program to mandate national background checks for Medicaid long term care providers, small and large, for people with I/DD, while also providing technical guidance to states for the creation of abuse registries. Thank you for your attention to my request.

Sincerely,

cc:

The Honorable Fred Upton, Chairman of the House Energy & Commerce Committee
The Honorable Joe Pitts, Chairman of the House Energy & Commerce Committee's Health Subcommittee