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Dear Congress,

Across the country, families and guardians of individuals with intellectual and developmental disabilities (I/DD) **thank you** for your service to our nation.

This week, VOR advocates will be stopping by every Congressional office to share our positions on various federal issues that directly impact the quality of care and civil rights of all people with I/DD. As representatives of the *only* national organization supporting *a full array of quality residential and support options*, we thank you for welcoming them to your office and urge you to listen to their concerns.

These volunteer advocates have unique insights on the serious concerns facing the quality of care received by our nation's citizens with I/DD. They will be seeking your support for investigating through hearings the true impact of a popular, but misguided and federally-supported, "deinstitutionalization" trend. There are ample reasons for concern:

- ✓ The failed deinstitutionalization of the mentally ill that has left many on the streets and in jail;
- ✓ Between 1977 and 2010 the number of residential settings serving people with I/DD increased by **1,598%**, with most of those new settings being small and privately operated. In 2010, non-state agencies served **98.5%** of people living in places with 6 or fewer residents. The number of Home and Community-Based Services recipients outpaced residents receiving specialized Medicaid licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) by **676.1%**;¹
- ✓ A 63% decrease in the number of people receiving ICFs/IID care;² and
- ✓ "I write to you [the Inspector General] today to request that you undertake an immediate investigation into the alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes. In particular, I would like you to focus on the prevalence of preventable deaths at privately run group homes across this nation and the widespread privatization of our delivery system."³

It is undeniable that aggressive deinstitutionalization of people with I/DD has resulted in human tragedy. It's time for Congress to act. Specifically, VOR advocates call on Congress to –

- 1) Support a moratorium on federally-supported deinstitutionalization actions until Congress can hold hearings and investigate the true human impact of these actions.
- 2) Support national background checks for direct care workers in human services industries to better identify bad apples and prevent them from harming more people.
- 3) Request that the Department of Health and Human Services' Office of Disability, Aging and Long-Term Care Policy update and expand on its 2006 Report to Congress, "Supply Of Direct Support Professionals Serving Individuals With Intellectual Disabilities And Other Developmental Disabilities,"⁴ to **(a)** study the relationship between key direct staffing issues, such as livable wages, adequate training, turnover, and background checks, to determine the relationship between staffing issues and the quality of care receiving by individuals with I/DD in community-based settings; and **(b)** include recommendations for legislative and regulatory reform.

Deinstitutionalization is advanced by several federal agencies in spite of well-documented tragedies. VOR urges Congress to **hold hearings** to make its own determination **and help advance quality of care across all settings.**

Sincerely,

Ann S. Knighton, VOR President

¹ "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010," University of Minnesota (2012)

² Id.

³ Letter from U.S. Senator Chris Murphy to the Health and Human Services' Inspector General (March 4, 2013)

⁴ [The Supply Of Direct Support Professionals Serving Individuals With Intellectual Disabilities And Other Developmental Disabilities: Report To Congress](#), U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy (January 2006)