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To: Members of Congress

October 23, 2013

VOR is a national non-profit, non-provider organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD).

With this letter, we present our “*Key Principles in Support of the Rights and Opportunities for All People with Disabilities: Respecting Individual Choice*” (VOR, September 2013).

As you will read, VOR is distinguished from *all* other national advocacy organizations in our support for a *full array* of residential and support options. We expressly support community-based care for individuals who choose that level of support, and expressly reject the closure of specialized congregate care settings (“deinstitutionalization”) for people who choose and need that level of care.

Our principles embrace the reality that people with disabilities are individuals with unique and varying needs. VOR rejects a “broad brush” approach to policies and rights which help most people with disabilities, but not others who experience profound I/DD or other serious I/DD and medical and/or behavioral disabilities. **Civil and legal rights should *not* be spliced, applying to some, but not all, individuals with intellectual and developmental disabilities.**

Fortunately and rationally, law and policy agree – including the Americans with Disabilities Act (ADA), as interpreted by the U.S. Supreme Court in its *Olmstead* decision, Medicaid, the Developmental Disabilities Assistance and Bill of Rights Act, and related Congressional intent. Each of these authorities recognizes that, although community integration is preferred for *most* individuals, some individuals have needs that are so great that they are best served in specialized congregate care settings where they can receive comprehensive support and services. The ultimate decision whether to leave a facility resides with the individual and his/her family/legal guardian, not with “professionals.” Justice Ginsburg said it best in the *Olmstead* decision:

“As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk . . .

“For [some] individuals, no placement outside the institution may ever be appropriate. See Brief for the American Psychiatric Association, et al (‘Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times – perhaps in the short run, perhaps in the long run – for the risks and exposure of the less protective environment of community settings; for these persons, ‘institutional settings are needed and must remain available.’) . . .

‘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**’ [quoting VOR’s *Amici Curiae* brief].” (emphasis added).

Deliberate misinterpretation and misapplication of the *Olmstead* decision by other advocacy organizations and some federally-funded agencies has resulted in forced deinstitutionalization of individuals. Blind ideology in support of integration, without regard to choice and needs, has resulted in harm and tragedy.

Representing primarily families of individuals with intellectual and developmental disabilities, VOR’s only stake in this advocacy is the well-being of our constituents. VOR does not provide direct care services, is supported 100% by private donations, and is governed by an all-volunteer, national Board of Directors.

Thank you in advance for taking the time to review VOR’s “*Key Principles in Support of the Rights and Opportunities for All People with Disabilities: Respecting Individual Choice*.” We hope these Principles will help guide your work on behalf of Americans with disabilities.

Sincerely,

Ann S. Knighton
President

cc:
David Hart, Chair, Legislative Committee
VOR Board of Directors



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Key Principles in Support of the Rights and Opportunities for All People with Disabilities: Respecting Individual Choice

Key Principles

General Principles

- “Individuals with disabilities” describes a widely diverse group of people, ranging from people with mild physical and/or intellectual disabilities to those with profound or other severe intellectual disabilities, along with medical or behavioral disabilities.
- “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.” DD Act, 42 U.S.C. 15001(c)(3)(2000).
- Most individuals with disabilities are capable of living just like people without disabilities and should have the opportunity to do so. These individuals with disabilities should have control over their own day, including which job or educational or leisure activities they pursue, and where and how they live, with any necessary supports.
- Support for full community integration of most individuals with disabilities should not be interpreted to deprive individuals with profound intellectual and developmental disabilities (I/DD) or other serious I/DD and medical and/or behavioral disabilities from assurances of proper care of their health and safety needs, and individuals with disabilities should not be forced to accept services or participate in activities they do not wish to accept. As Justice Ginsburg wrote in the *Olmstead* decision, “Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing that, **on a case by case basis**, that setting may be in an institution.” (**emphasis added**)

Choice

- Individuals with disabilities and, where appointed by a court, their legal guardians, should have the opportunity to make informed choices among all legally available options. They must have full and accurate information about their options, including what services and financial supports are available.

Employment

- Most individuals with disabilities should have the opportunity to be employed in regular workplaces. Most individuals with disabilities can be employed and earn the same wages as people without disabilities. When needed, individuals with disabilities should have access to supported or sheltered employment, or other day activities, to ensure fulfilling and productive experiences.

Housing

- Individuals with disabilities have the right to choose where to live from an array of residential options.
- Most individuals with disabilities can live in their own homes with supports and they should get to decide where they live, with whom they live, when and what they eat, who visits and when, etc.
- These choices for most individuals with disabilities should not deprive individuals with profound I/DD or other serious I/DD and medical and/or behavioral disabilities from the right to live in congregate arrangements, multi-unit buildings or complexes that cater to specific needs, according to individual choice and need.

Public Funding

- Government funding for services should support implementation of these principles to assure a full array of residential and service options to accommodate the diverse needs and preferences of the disabled population. Financing for long-term services and supports must be responsive to the needs of *all individuals* with disabilities, recognizing that the cost to care for individuals must necessarily vary and be responsive to varying needs.

For more information about VOR, visit www.vor.net.

VOR’s Policies and Positions Statement, which reinforce VOR’s Key Principles, are found at
www.vor.net/images/VORPolicyandPositionStatements.pdf