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VOR Statement on the U.S. Department of Justice Investigation of Nursing Homes in South Dakota

For more than 30 years, VOR has represented families of individuals with Intellectual and Developmental Disabilities (I/DD), whose loved-ones for the most part have severe and profound cognitive disabilities, multiple physical disabilities, and are medically fragile or experience dangerous behaviors.

VOR supports a system of services that is responsive and respectful of individual needs and preferences. We recognize the need for a broad continuum of services and residential and employment options that match the broad spectrum of abilities, needs, and preferences within the I/DD population.

In South Dakota, a recent U.S. Department of Justice (DOJ) <u>investigation</u>¹ found serious problems resulting in unwanted and unnecessary nursing home placements for many of the more than 3,400 Medicaid-funded patients living in nursing homes. About 190 of the 3,400 are people with I/DD, and DOJ found that many of them expressed a desire to receive services in the community. The DOJ investigation found many barriers that make community living difficult to obtain, including: a lack of information on the availability of community services; limits on services that would allow more people to live in their own or their family's home; a lack of resources and assistance, especially in Native American and rural communities; and nursing home placement offered as the only option for receiving necessary care and treatment.

Disability law supports DOJ's position in South Dakota that the wishes of individuals and their families regarding the services they receive and where those services are delivered should be paramount in correcting the problems documented by the DOJ investigation. VOR also supports this position.

VOR's quarrel with DOJ is not with the situation as described by DOJ in South Dakota, where DOJ supports the expressed residential choices of people with I/DD. What VOR objects to are actions by DOJ in other states to override the wishes of individuals with I/DD and their guardians when those wishes are to continue to reside in congregate settings. VOR and disability law support individual choice, whether that choice be to receive supports in the community or in a congregate setting.

Individual choice, not DOJ choice, is a key underpinning of the ADA and 1999 U.S. Supreme Court <u>Olmstead</u>² decision. Unfortunately, DOJ and others have <u>misinterpreted</u>³ Olmstead as a mandate for community placement *only*. VOR's support for a full continuum of residential options, including facility-based care, has often been misconstrued as advocacy by VOR for "institutional" care *above all other options*. This could not be further from the truth. See VOR Policy Statement, "Respecting Individual Choice: The Rights of All People with Disabilities", 4 9/2013 ("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".)

It is also essential to address quality in the community system. Too often, deinstitutionalization efforts by DOJ and other federally-funded programs have resulted in tragic outcomes. The most recent examples of this are in Georgia and Virginia, two states that are implementing *Olmstead* settlement agreements with DOJ. In Georgia, DOJ found that 79 of the 503 individuals with I/DD who moved from state facilities to community settings have died. In Virginia, the death rate of those individuals with I/DD who have transferred from facility care is double that of individuals who remained in facility care.

In the spirit and language of the Americans with Disabilities Act and the *Olmstead* decision, VOR continues to support consideration of individual needs and choice in determining the services that people with I/DD receive in settings *appropriate to their needs*.