



VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: (877) 399-4867
<http://www.vor.net>

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
(646) 387-2267
hdwyer@vor.net

President
Caroline Lahrmann
2359 Coventry Road
Columbus OH 43221
(614) 359-9323
calnwal@aol.com

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012
(410) 757-1867
LarryInnis@aol.com

The Importance of Medicaid For Our Loved Ones with I/DD

VOR is a national nonprofit organization that advocates for high quality care and the human rights of all people with intellectual and developmental disabilities (I/DD).

VOR is concerned that our vulnerable family members, people with intellectual and developmental disabilities, including people on the severe and profound end of the I/DD continuum, may be unduly and inadvertently harmed in a Medicaid per capita spending cap or block grant system due to the small size of their population and their inability to verbalize concerns and travel to meet with legislators.

Background

Of the 69 million Americans enrolled in Medicaid, approximately 5 million people with intellectual and developmental disabilities (I/DD) are supported through state Medicaid programs, only 7% of the Medicaid population.

Severe and profound intellectual disabilities (ID) occurs in only 3-4% and 1-2%, respectively, of the population of individuals with ID. Individuals on the profound end function at the level of an infant. **Therefore, Medicaid recipients operating at the severe to profound end of the I/DD continuum are only about 250,000 people nationwide, representing only 0.36% of all people accessing Medicaid.**

Medicaid recipients with I/DD require crucial services and supports to address their disabilities and function in their daily lives. For the 0.36% of Medicaid recipients with severe and profound I/DD, their intellectual, behavioral, physical and medical conditions are such that they require total care and 24 hour supervision, including for many, around the clock nursing services and access to specialized therapists and physicians to address conditions before they get out of hand.

What We Know

VOR members understand the intensive needs of our family members, how quickly their conditions can spiral out of control when their needs are not appropriately met, and how vulnerable they are to harm from individuals who are ignorant or dismissive of their disabilities or are prone to deviant behavior.

Many of our members have experienced attacks on the chosen way of life of their family members who need and choose Medicaid licensed residential facilities (such as Intermediate Care Facilities for Individuals with Intellectual Disabilities, ICFs/IID) for life-sustaining nursing and supervision, behavioral supports and community integration. **Their choice aligns with Medicaid and other federal law including the Supreme Court's *Olmstead* decision.** For many, these facilities are the most integrated setting appropriate to their individual needs. Many individuals who have been dislocated from these homes against their choice, have found themselves in community settings that are woefully inadequate to handle their complex needs.

For disabled citizens with I/DD, no matter where they reside, Medicaid plays a far more comprehensive role than simply health coverage alone – it is the means by which all aspects of daily living are provided and the lifeline to the day and night nursing, therapy and medical supports that sustain them.

To protect health and safety for Medicaid recipients, we urge that any reform be implemented incrementally and with great care.