VOR
Speaking out for people with intellectual & developmental disabilities

Toll free
877-399-4867

www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
Jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tamie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
Thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 Voice/Fax
LarryInnis@aol.com

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For More Information
Julie Huso, Executive Director
605-370-4652 direct
605-399-4867 toll free
jhuso@vor.net

VOR Working for Choice – Not “Deinstitutionalization” - this Holiday Season

While most families across the country prepare for a festive holiday season with worries set aside, some families of individuals with profound intellectual and developmental disabilities (I/DD) seek a gift that can’t be wrapped. Simply, choice.

Across the country, “deinstitutionalization” – a decades-long movement that since 1960 has resulted in the closure of 200 state-operated “institutions” – continues in earnest. With visions of sterile halls and segregated living, many Americans assume that this once well-intentioned movement is a good thing. VOR is the only national non-profit organization of its kind that supports the now reformed specialized “institutions” for people with profound intellectual disabilities, while also supporting the expansion and improvement of smaller residential settings.

“History is both a lesson and curse for families like mine whose family members require highly specialized care in licensed facilities,” said Ann Knighton, President of VOR, a national organization advocating for high quality care and human rights for people with intellectual and developmental disabilities.

“Many family advocates were on the front lines decades ago successfully transforming the institutions of old to the federally licensed, highly specialized homes they are today,” said Knighton. “Family advocates are now working hard to champion choice by fighting to save residential centers while also advocating for much higher quality standards in community programs.”

Across the country, VOR is working to support individuals with intellectual and developmental disabilities and their families in being able to choose from about 160 federally-licensed, state-operated residential programs, and several hundred private centers, serve medically fragile or behaviorally dangerous individuals who also have profound intellectual disabilities. Stringent federal requirements are reviewed annually ensuring consistently high quality care in areas relating to staffing, onsite health care, nutrition, and “active treatment” - programming designed to help individuals gain new skills.

Today, however, these reformed facilities face “deinstitutionalization,” an extension of the movement which began a half century ago.

“What began with altruistic motives – namely, better and more appropriate care for disabled people – has spawned into something very different,” remarked Julie Huso, VOR’s Executive Director. “Today, very fragile people are being forced from their homes under the belief that money will be saved and quality of life will improve.”

Families of facility residents will argue that their family members’ lives are integrated on their expansive and open campuses. In contrast, very disabled people can feel isolated in small homes with limited staff and transportation

“Over and over again, news investigations and state audits show that these very fragile individuals need comprehensive, skilled care. They are the ICU residents of the disability community. Scattering them in homes around a community only separates them from qualified staff, life-sustaining health care, oversight, and friends,” said Knighton.

Family advocates find themselves up against a veritable Goliath defending choice of care for loved ones. One federal agency, the National Council on Disabilities (NCD), recently published a 300 page policy document and toolkit arguing the “unfinished business of closing state-run institutions and other public and private institutional settings . . . should be a top public policy priority in every state where such institutions exist.”

In addition to NCD, families must also respond to legal threats by the U.S. Department of Justice, other federal advocacy agencies, and some State Governments.

“Individual and family choice should matter most,” remarked Julie Huso, VOR’s Executive Director. “These programs are providing high quality care. These battles are not about bad care. Yet, choice is routinely ignored.”

The concern about lack of family involvement in legal actions that seek to close licensed homes has received Congressional attention. A federal bill, with broad bipartisan support, would address this very concern. It would not prevent lawsuits, but would require that federal attorneys only file suits on behalf of informed and willing individuals. Such a change, argues VOR, would help ensure that existing federal laws requiring residential choice, are more consistently enforced.

“The law is on our side,” said Huso. “Families need help enforcing it. Help from attorneys, help from Congress, help from state. All these families seek is respect – respect for the informed choices they have made for their family members with intellectual and developmental disabilities.” To join VOR and become an advocate of choice for people with disabilities or to donate to this non-profit, please visit the VOR’s website at www.vor.net today.

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About VOR: VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. Offering community, legal, medical and educational resources for families of individuals with special needs, VOR is committed to providing help for people with disabilities. Standing up for long term care facilities and community disability programs, VOR is dedicated to maintaining family choice for people with intellectual and developmental disabilities. For more information about VOR, please visit us at www.vor.net.