
“VOR exists to speak for the voiceless” **VOR Case Statement for Support**

VOR is a national, 501(c)(3) organization. Our mission is to advocate for high quality care and human rights for people with intellectual and developmental disabilities (I/DD).

Founded in 1983, VOR has championed individual and family decision-making with regard to all care decisions. We view the right of decision-making and the provision of person-centered services a basic human right and central to ensuring high quality care in appropriate settings.

VOR is distinguished from *all* other national advocacy organizations for people with I/DD as the *only* organization advocating in support of a full array of residential options, including home, community-based and large settings. For 30 years, VOR has been the *only* voice for families whose loved ones with profound I/DD require the Medicaid-licensed, specialized care settings that have been the target of deinstitutionalization for decades.

Aaron, Lauren, Roger, Ian, Danny, and their peers count on VOR’s voice

What if seniors in a picturesque retirement community were forced to relocate into scattered homes across a city because advocates successfully closed the retirement community on the grounds that the seniors’ congregate, specialized services and amenities were too “institutional?” Seniors protested, but their voice didn’t matter.

What if parents of elementary school students read in the newspaper that their children were plaintiffs in a lawsuit involving the closing of their school? The parents protested, but their voice didn’t matter.

What if hospitals closed intensive care units (ICU) in favor of home-based health care, despite the fact that medically-fragile people would be isolated from the specialized care they required and health care costs would skyrocket? Patients and their families protested, but their voice didn’t matter.

If these examples were true, citizens would be outraged and come to the support of these seniors, parents, and patients.

Yet, this same scenario, through aggressive “deinstitutionalization,” is impacting individuals with intellectual and developmental disabilities (I/DD), removing these fragile individuals from their homes, without regard to choice, need, or input from them or their families:

“Was there any consideration for what is best for the residents of [the center to be closed]? My daughter is 44 years old and has lived in [the center’s] cottages since she was about 8 years old. She is comfortable there, is used to the hubbub, and loves the staff that care for her. She is non-ambulatory, has a mental age of about 2-3 years old, and has seizures. [The center] is about 53 miles from where I live. I am almost 70 years old and never dreamed that they'd pull the rug out from under my daughter's home. I don't think a group home is right for my daughter and surely hope they don't want to move her to a facility that is 3-4 hours away from me. What to do? I am scared.” (E-Mail to VOR, August 2012).

Parent and family fear is understandable. There are widespread, well- documented tragedies following closures. These tragedies are predictable because needs are remarkably profound:

Aaron is 32 years old, but has the cognitive ability of a 2 month old infant. He receives 24/7, compassionate support in care facility chosen by his parents. In their words: “Aaron was born 8 weeks premature. While he survived the birth, the lifelong effects from subarachnoid and pulmonary hemorrhages are devastating. A large portion of his brain was destroyed with the subarachnoid hemorrhage. His functional abilities are in the 2-3 month range. Seizures, respiratory insufficiency, frequent pneumonias, cortical blindness, spastic tetraplegia with ever increasing spasticity are just a few of the daily challenges for his caregivers.” ~ Aaron’s parents and VOR Wisconsin State Coordinators (2012)

Brian is 42 years old, but has the cognitive ability of a young child. He also experiences dangerous behaviors which are well-managed to keep him and other safe in a care facility chosen by his parent. In his mother’s words: “Brian was expelled from four homes in two states because of dangerous aggression - he was sent HOME where we had little children. He injured everyone in the family except the baby who was locked away from him and broke hundreds of windows (we repaired them every weekend). Finally, in 1990, a state-operated facility for people like Brian in yet another state provided him the care he needs and continues to serve him well. What apartment building would be right for Brian and which McDonald's has an application with his name on it?” ~ Brian’s mother and VOR Illinois State Coordinator (2012)

“**Lauren’s** disabilities and needs are significant. She has severe intellectual disabilities due to corticocerebellar damage and prenatal hyposia, fibrocystic breast disease-bilateral, a seizure disorder, degenerative osteoarthritis of the spine, spastic quadriplegia, and more. Lauren is non-communicative and non-ambulatory. Once, when her bedroom moved from one room to another, she stopped eating.” ~ Lauren’s sister and VOR Member (2011).

Roger is 50 years old, but has the cognitive ability of an infant. He is medically-fragile and receives high quality, specialized supports in a care facility chosen by his mother. In her words: “Roger suffers from brain damage due to an oxygen deficiency at birth,

epilepsy with uncontrolled mixed seizures, profound swallowing problems, brittle bones, optic atrophy with myopia, incontinence, stenosis of his neck and back, peripheral neuropathy and hyper-salivation. Roger is non-verbal and completely non-ambulatory. He gets all nutrition, hydration and medication via a gastrostomy tube.” ~ Roger’s mother and VOR member from Virginia (2012)

“**Danny and Ian** are brothers who live in a group home in Ypsilanti, Michigan. They have severe cerebral palsy and profound intellectual disabilities. Facility care was never offered as an option, but services have been cobbled together by their parents and the local community mental health agency. Still, their parents pay for a day program and a private dentist and monitor care at the group home constantly. Many families are not able or cannot afford to fill in the gaps in services. Now that all the larger facilities for people with developmental disabilities in Michigan have closed, the advocacy groups are trying to close the only licensed facilities left – the group homes.” ~ Danny and Ian’s mother and VOR member from Michigan (2012)

Equally tragic is the fact that more than two hundred thousand (200,000) people are languishing without adequate services across the country. There are so many people waiting for services, we believe, due to deinstitutionalization, which removes people who are receiving services from their homes and adds them to an over-stressed, under capacity system of community-based care, to the direct neglect of those going without services.

“**VOR exists to speak for the voiceless**” (VOR Membership Survey, 2012). For 30 years, VOR has been the only national voice for affected individuals. For nearly 3 decades, VOR’s advocacy has helped connect countless families to the services their profoundly disabled loved ones require, no matter the setting they choose, and provided many more with advocacy support in an effort to prevent the closure of specialized homes.

It is a classic David and Goliath struggle. It is VOR up against the seemingly unlimited resources of the United States Department of Justice, other federally-funded entities, and many State governments. Their actions are driven by ideology – a blind belief that people are better served in smaller, home-like settings – and by cost-conscious public officials who believe money will be saved. Both notions – increased quality and cost savings – have been shown time-and-time again to be false notions, but ideologues and budget hawks persist.

The stories of abuse, suffering and unexplained deaths among those sent to homes for the disabled in New York State are horrifying. A worker sits on an autistic boy and crushes him to death. Another worker sexually abuses a 54-year-old disabled woman. A quadriplegic drowns as an aide leaves him in a tub of water. As reported in *The Times* over the last year, there have been numerous cases of abuse and at least 1,200 deaths attributed to unnatural or unknown causes in publicly financed homes for the disabled in the last decade. Many cases have barely been investigated, with incompetent workers often being moved to a different facility, without being prosecuted. (“Monitoring Care for the Disabled,” *New York Times*, May 8, 2012).

If not for VOR, the individual and family voice would be missing from all these actions.

Through our current national programs – Legislative/Government Affairs, Legal, Family, State Coordinator, Awareness and Outreach, and Annual Conference programs – VOR has combatted deinstitutionalization and embraced true choice with success.

Solutions: VOR Goals

According to the U.S. Census, about 1.2 million adults and 1.7 million children have an intellectual disability. Another 944,000 adults have other developmental disabilities, including autism and cerebral palsy. Other sources estimate that 3% (about 87,000) of all citizens with intellectual disabilities have severe or profound intellectual disabilities. These individuals are most at risk due to the prevailing ideology in support of aggressive deinstitutionalization which eliminates access to specialized care and health care services, as well as constant pressure in many states to limit or eliminate specialized services in the community.

Without VOR, there would be no effective voice for these individuals.

VOR's voice must be loud and effective for these citizens. To this end, VOR is launching a public awareness campaign designed to educate the general public regarding the tragic injustice befalling individuals with I/DD around the country, especially in those areas where a center is threatened (see section on Marketing and Public Relations).

- Increase our membership and donor base so that we can remain a leader in the voice for choice in each state across the nation. Growth in all areas is projected; new sibling members will be one target audience.
- Continue our long-standing Legislative/Government Affairs, Legal, State Coordinator, and Family Advocacy national programs.
- Continue our support for guardianship relationships when in the best interest of the individual, as determined by a court of a law. Counter attacks on guardianship.
- Expand the effectiveness of our Legislative/Government Affairs program by adding an e-advocacy component to allow for enhanced grassroots participation.
- Expand the effectiveness of our State Coordinator program to assist in regionally-targeted membership and financial growth objectives.
- Expand outreach to families whose disabled family members live in community settings without adequate services. Support efforts to assure a full range of community and institutional options appropriate to the individual needs of all people with severe and profound I/DD.

- In 2013, VOR will launch an initiative to identify and pursue uniform, humane quality standards in community settings across all states, with an emphasis on staff competency and access to specialized health care and supports. Although proponents of deinstitutionalization promise a better life in the “community,” the promise is far from well-documented reality, resulting in tragedy for thousands of impacted citizens.

Why You Should Care and Invest in VOR

VOR has the good fortune of having families of individuals with I/DD as our leaders, members and donors. The family connection results in an understandably unmatched commitment to our advocacy. As one reporter observed:

"Seeing Terry and Glenda and how they are with Jamie, I also feel a sense of gratitude for people like the LaFleurs. I cannot remember the last time I met people so kind, selfless and genuinely good. Jamie is a beautiful spirit - an 'angel,' as Terry calls her - who still has that sense of wonder that we all, at some time or another, wish we still had. She may not have wings, but Jamie, like her mother and father, are all angels of the same feather." ~ "Angels of a Feather," by Nancy Duplechain (*Bonnes Nouvelles Evangeline*, July 2012, featuring Terry LaFleur, VOR Board Member, and daughter Jamie).

Thanks to VOR, the LaFleurs and families like theirs across the country do not have to advocate alone. VOR has always been there for individuals with I/DD and their families, no matter where they reside. With VOR's help and its expansion goals, many more families will gain awareness and appreciation for VOR, including the general public. "VOR is the *only* organization that truly listens." (Membership Survey, 2012).

Whether you are a family member of an individual with I/DD, a friend, advocate or average citizen, we should all care about the least of our brethren.

Thank you for your support.

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