

VOR's Quality in the Community Initiative

Together we will promote high-quality, person-centered, community-based services for all individuals with I/DD through advocacy and legislation to ensure uniform, humane quality standards in community settings across all states.

[ARTICLE PROVIDED BY VOR]

If there is one thing that advocates for people with intellectual and developmental disabilities can agree on, it is that quality matters – in all settings, and in all places, serving people with intellectual and developmental disabilities (I/DD).

In June 2012, with this unifying vision in mind and a desire to address a growing need, the VOR Board of Directors adopted assuring quality in community settings as a strategic initiative for the organization.

“VOR represents many families of individuals who receive quality facility-based care,” said Ann Knighton, VOR President. “These families take comfort in the federal regulations and oversight that dictate a certain, consistent, level of care.”

While many VOR members are advocates for residents of Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFs/ID), a growing number of members have sons, daughters, sisters and brothers with I/DD and autism receiving community-based services. Expanding the organization's priorities to better respond to the needs of individuals with I/DD receiving community-based services is a natural step after 30 years of advocating for this population.

“An initiative focused on quality in the community is timely and appropriate for VOR. We've always been advocates for high quality of care and human rights for all people with intellectual and developmental disabilities and autism, no matter where they are served,” remarked Knighton.

“We'll continue to advocate for residential choice,” said Julie Huso, VOR's Executive Director. “VOR has long been distinguished as the only national organization that supports both facility-based and community-based care for people with I/DD and that won't

change. By addressing quality in the community along with our traditional advocacy, we are broadening our 'choice advocacy' by working to expand the quality options available for individuals.”

Quality in the Community: An Urgent Need

VOR feels strongly that the need to address quality in the community is urgent.

Law and policy in a vast majority of states continues to favor provider flexibility and privatization in small homes with few residents. As a result, deinstitutionalization, a trend that began more than four decades ago, continues in earnest.

According to the University of Minnesota's annual report on residential trends, between 1977 and 2010, the number of people with I/DD receiving residential services in homes of one to six residents grew from 20,400 to an astounding 353,195 people, representing 75.7% of all people with I/DD receiving residential services from mostly (97.1%) private providers. In March 1993, U.S. Rep. (now Senator) Ron Wyden concluded a year-long investigation of small private providers of care for people with I/DD, finding that “growth in

this industry has out-stripped the ability of many state agencies to adequately oversee conditions in these facilities.”

In the two decades since the Wyden Report, little has changed; growth in the number of small settings serving this population has continued to explode, while the number of larger, state-operated facilities has steadily declined. Just last March, U.S. Senator Chris Murphy called for a federal investigation, noting that “[w]hile many private providers are providing excellent care there are too many examples of bad actors. Concerns about staffing, training



VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.

and state oversight of privately run group homes have been raised repeatedly over the last decade. Furthermore, the State of Connecticut has increasingly relied on private group homes as they have moved away from state-run facilities.”

Unlikely Alliances

Although deep division remains around the appropriateness of deinstitutionalization, advocates are united around the right of individuals to receive quality care. Sam Bagenstos, a well-known attorney and advocate in support of deinstitutionaliza-

tion, noted in a recent paper, “Deinstitutionalization advocates are focused to a greater extent than ever on the goal of building up a robust community-based treatment system.” (Bagenstos, S., *The Past and Future of Deinstitutionalization Litigation*, Cardozo Law Review, Vol. 34:1, 6 (Jan. 2013)). Consistently, federal law recognizes that individuals with developmental disabilities have a right to the provision of care that is “free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population,” receive “appropriate and sufficient medical and dental services,” and be free from unnecessary and punitive physical restraint and seclusion (*Developmental Disabilities Assistance and Bill of Rights Act*, 42 U.S.C. 15009(a)(3)(B) (2000)).

Justice Statistics, U.S. Department of Justice (December 2012)). According to the National Council on Disability, 49 states do not have Medicaid coverage for routine dental care and many health care providers are unwilling to accept Medicaid reimbursement limiting access to health care (*Deinstitutionalization: Unfinished Business*, NCD, October 2012). The immediate future is not any brighter, given the current fiscal constraints faced by states which are resulting in service cuts which compounds the challenge of developing and maintaining a strong community-based service system when it is needed most (*Id.*; see also, *supra*, Bagenstos). The result is an increasingly fragmented system of services across states, with significant gaps in critical health and support services and long waiting lists.

The Solution

Amid this grim backdrop there is hope. There is no need to invent the wheel. There are good providers and best practices. Identifying and promoting good providers and their best practices are at the heart of VOR’s Quality in the Community Initiative. Best practices include training and retaining quality direct care staff and supervisors, weeding out the “bad apples” through background checks and regular, consistent oversight to ensure best practices are followed and improved upon at least annually. While there is some aspect of “you know it when you see it,” when it comes to good quality care by competent, compassionate providers, quality programs will also be able to point to empirical (objective) outcomes, such as access to health care, involvement in regular employment and recreation activities, 9-1-1 calls, daily hygiene, and other easy to quantify outcomes (good and bad) that speak to overall quality of care and individual happiness.

VOR is only at the beginning of this initiative, which begins with a national conversation among individuals, families, other stakeholders, and federal and state lawmakers. Together we will promote high-quality, person-centered, community-based services for all individuals with I/DD through advocacy and legislation to ensure uniform, humane quality standards in community settings across all states. •



AVOIDING PREDICTIBLE TRAGEDIES VOR’s Quality in the Community Initiative aims to develop and promote community care standards.

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Yet, unquestionably, people are suffering. A recent U.S. Department of Justice report shows a disturbing rising trend of rape, robbery, aggravated assault and serious violent crimes against those with multiple disabilities from 2009 to 2011, far out pacing the crimes affecting the general population (*Crime against Persons with Disabilities, 2009 - 2011 – Statistical Tables*, Bureau of