VOR is a national non-profit organization advocating for high quality care and human rights for people with intellectual and developmental disabilities.

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- VOR Milestones: 30 Years of Effective Advocacy


- Feature Article Available for Publication: Individuals With Intellectual And Developmental Disabilities, And Their Families, Seek Right of Housing Choice

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- We Are Excited to Tell You About VOR! Mission and Membership Flyer

- VOR National Board of Directors and Professional Staff (2013-2013)
Only VOR speaks up for a full spectrum of residential, vocational, and education options, based individual choice and person-centered needs for people with intellectual and developmental disabilities.

VOR MILESTONES
30 + Years of Effective Advocacy

LEGISLATIVE ADVOCACY MILESTONES

✓ 1993: VOR secures individual and family “primary decision-maker” language in the federal DD Act.
✓ 1997: VOR forms its first Legislative Committee.
✓ 1998: VOR secures the introduction of federal legislation seeking protections for people with intellectual disabilities in Medicaid managed care. VOR receives commendation by the bill’s sponsor in the Congressional Record.
✓ 2000: VOR secures stronger “primary decision-making” language in the DD Act.
✓ 2006: VOR presents oral and written testimony in support of the facility option at U.S. Medicaid Commission hearings.
✓ 2010 - 2011: VOR presents testimony at HHS Listening Sessions, provides testimony at Administration on Intellectual and Developmental Disabilities (AIDD) Listening Sessions and online, and submits federal comments on defining “community” and mixed population community waivers.
✓ 2007-2011: VOR secures the introduction of federal legislation to requiring federally funded lawyers to notify individuals and their guardians prior to filing class action lawsuits, and offer an opportunity opt out of the lawsuit.
✓ 2012: In separate federal comments, VOR points to human abuse and calls for independent oversight and audit of AIDD and the three DD Act programs.
✓ 2012: VOR submits written testimony objecting to additional funding for the Department of Justice’s Civil Rights Division and written testimony for a Senate Olmstead hearing calling for individual choice, as Olmstead requires.
✓ 2013: VOR testifies before the House Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education, and Related Agencies seeking a prohibition of wasteful HHS v. HHS spending.
✓ 2014: VOR canvassed Congress with our Key Principles relating to the rights of all people with disabilities.
LEGAL ADVOCACY MILESTONES

- **1993**: VOR is *Amicus Curiae* in *Heller v. Doe* (U.S. Supreme Court), successfully arguing in support of family participation in placement decisions.

- **1999**: VOR, with 141 organizations, is *Amicus Curiae* in the landmark U.S. Supreme Court case *Olmstead v. L.C.* The Supreme Court cites VOR’s brief.

- **2000**: VOR, with 93 organizations, is *Amicus Curiae* in *Garrett v. University of Alabama*, defending the constitutionality of the Americans with Disabilities Act.

- **2005**: VOR establishes the Burke Legal Support Fund and recruits Martha Dwyer to serve as VOR’s volunteer *Pro Bono* Coordinating Counsel.

- **2010**: VOR’s President serves as an expert witness in a federal lawsuit in support of residential choice.

- **2012**: After long legal battle, VOR helps secure an ICF/ID placement for Virginia Massa. VOR connected Virginia’s stepmother and guardian, Mary Reese, with skilled counsel who secured placement for Virginia who had been suffering in a group home, and whose case resulted in important precedent for other families.

- **2012**: VOR participated as *Amicus Curiae* in support of family interveners in two federal appeals, which resulted in securing family intervention and the overturning of a bad settlement agreement.

- **2006-2014**: VOR secures representation for families, and provides legal advocacy support, in nationally significant cases in Florida, Illinois, Maryland, Pennsylvania, Virginia and New Jersey; and participates as *Amicus Curiae* in cases in Washington State, California, Massachusetts, and Virginia.

MEDIA and EDUCATION ADVOCACY MILESTONES

- **Since 1983 - current**: Editorials, interviews and quotes in newspapers across the country.

- **2003**: VOR’s peer-reviewed cost comparison study is published in a respected professional journal. An update was published in 2009.

- **2004**: VOR’s articles regarding measuring quality care are published.

- **2005 - current**: VOR publishes the Grassroots Organization and Advocacy Toolkit (updated and expanded in 2013) and hosts its first member training. Since then there have been regular Toolkit updates and additional training for families and professionals.

- **Ongoing**: VOR speaks and exhibits at family and professional association conference. Additionally, VOR’s Annual Conference offers it membership and others nationally-significant speakers who provide timely presentations aimed at empowering family advocates in support of residential choice.

- **2013**: VOR hosts its first Webinar for State Coordinators and unveiled its updated and expanded “VOR Advocacy Manual and Toolkit,” an extensive advocacy resource for advocates. State Coordinator Webinars will be offered quarterly. Upcoming Webinars will feature social media “how-tos” and lessons learned by State Coordinators, who will host these Webinars.

- **2013**: *EP Magazine* featured VOR in several editions, including Annual Conference information and article submissions.

- **2011-2014**: VOR’s Board supports and pursues a public relations initiative through the work of its Marketing and Communications Committee. This Committee makes leveraging the potential of social media, reaching the press, and local awareness opportunities as VOR priorities.
The world of disability advocacy boasts its own language, for better or worse. In some instances for the better, hurtful labels to describe a type of disability have been replaced by words that do not yet have a pejorative connotation.

In other cases, however, terms of common usage, such as “choice,” “inclusion,” “integration” and “community,” have been incorrectly redefined to mean only certain choices or certain places according to the user’s ideology. In these instances, some individuals with disabilities have suffered due to a lack of individualized care in favor of ideology.

Consider the situation facing residents of Apache ASL Trails, an apartment complex serving seniors with hearing impairments. “ASL” is in reference to American Sign Language and Apache ASL Trails boasts architectural features designed to meet the unique needs of its residents, such as flashing lights instead of doorbell or phone sounds, and wiring in common areas that pipe announcements directly to residents’ hearing aids. Beyond architectural conveniences, the complex features a sense of community among similarly-disabled residents who are able to communicate and socialize.

If this scenario involved college students or non-disabled seniors, there would be no argument from advocates or the federal government about the community and cost efficiencies fostered when similarly-situated individuals live together.

Yet, the U.S. Department of Housing and Urban Development (HUD) has filed a discrimination complaint against the developers of Apache ASL Trails, the construction of which was supported in part by federal funds. HUD alleged that the complex is engaging in housing discrimination because most residents are hearing impaired and thus are not “integrated” enough with the general population.

According to representatives for Apache ASL Trails, “HUD did not interview one single deaf tenant at Apache [or] consult with any experts from the deaf community.” In other words, HUD found discrimination on behalf of a group of citizens who, quite to the contrary, are happy and “not lonely anymore.” HUD incorrectly cites Olmstead, a landmark Supreme Court decision, to justify its findings, yet Olmstead actually embraces individual choice.

Regrettably, this is not an isolated example of a misguided ideology empowered by a misinterpretation of Olmstead. Rather than support “inclusion” and “integration,” these actions imposing limitations that can
lead to isolation and, at times, risk.

Compare the experiences of Brian and Mark. Brian, who is intellectually disabled, experiences dangerous behaviors. When living with his family, he injured every family member and they replaced hundreds of windows. Brian has been expelled from four community homes in two states and now lives comfortably and safely in a Medicaid-funded facility for people with I/DD.

Mark, who has multiple disabilities, wanders out of his home, has little sense of danger, and is prone to outbursts. To keep Mark safe, his mother keeps very loud alarms around her home to alert her and others if he wanders from the home. “If Mark goes out of the door, then we and God and everyone else can hear it because it is so loud,” she said. “But it is exhausting. It is intensely stressful and it’s very exhausting.”

According to current federal policy (embraced by the U.S. Department of Justice, Centers for Medicare and Medicaid Services, HUD, and the National Council on Disability), Brian is safe, but considered isolated and segregated because he lives on a campus setting with more than three other individuals with disabilities. Mark is isolated and in a potentially unsafe situation, but considered integrated because he lives with his family in the “community.” Underpinning this policy is, again, a misinterpretation of Olmstead.

EMPLOYMENT INCLUSION

Advocacy and policies around the employment rights of individuals have marched down a similar path.

Competitive employment – adults with disabilities having the right to work full time and receive at least minimum wage in regular workplaces – is the ideal for many individuals with disabilities, but not all. Some individuals with more serious disabilities require reduced hours, more training, and additional assistance. For these individuals, sheltered and supported employment options allow for a meaningful and productive day that may otherwise be out of reach.

Recognizing the need for a continuum of employment options, the New Jersey Legislature recently voted to save its sheltered employment for its citizens with disabilities:

“Supporters contend that even the work and the paychecks are just part of a larger program that also focuses on helping individuals reach goals, including increasing attention span, motor and interpersonal skills, and socialization. Many said a competitive workplace, even with support, was not a realistic goal, noting that those who can move into those workplaces do so.” (Burlington County Times, July 29, 2013)

In other states, disabled employees who count on sheltered employment options may not be so lucky. Like other areas of disability advocacy, “choice” and “inclusion” have come to mean only competitive employment. Federal funding cuts and advocacy are pushing states to drop their sheltered employment options to provide disabled individuals the “right” to receive competitive employment. However, this could well be an empty “right.” Even in robust economic times, unemployment rates for individuals with disabilities remain very high. Historically, employers have not had the time or funds to train, supervise and support someone with a disability. Sheltered employment offers alternatives for disabled workers, but if such options are discontinued, the few jobs for people with more profound disabilities will disappear along with their sense of self and accomplishment.

“For those who are not capable of working in community settings but are still capable of work, and want to work, and enjoy the company of their colleagues and the staff at a sheltered workshop, this can be a meaningful alternative – and one vastly superior to spending their days in less productive (or nonproductive) activities at their residences.” (Testimony of Linda Blumkin, VOR member, before a New York Office for Persons with Developmental Disabilities Town Hall Meeting, September 13, 2013).

Full inclusion / competitive employment advocates claim to be protecting rights, yet they may actually be limiting rights by limiting choices.

“I think people deserve a choice,” said
Donna Saskowski, Executive Director of Genesee Arc in New York, which is facing closure due to lost funding. “If they choose to be out in the community, that’s their choice. If they choose to be in the work center, I think they should also have that opportunity. If we eliminate the workshop, they no longer have a choice. Why can’t they have both?”

**A NEW VISION FOR PEOPLE WITH DISABILITIES: RESPECTING DIVERSITY AND CHOICE**

In an effort to correct for past sins, the disability community has over-corrected. Just as there was nothing person-centered about policies which support forcing all individuals to accept services and supports in small, “community-based” settings.

Both extremes neglect the need for person-centered supports in an unreasonable, and potentially dangerous, quest for “sameness.” The human condition is not that convenient. Equitable – providing individualized care and employment options – does not mean equal. People with disabilities have vastly different needs, requiring vastly different supports across the continuum. Choices will be different. The provision of care and related costs of care must necessarily vary and be responsive to varying needs.

People with disabilities should not have to endure a different standard of community than other populations and society in general. Rights should be individualized, respectful of diverse conditions, and inclusive of the entire disability population.

In this spirit, VOR presents the following “Key Principles in Support of Ensuring the Rights and Opportunities for All People with Disabilities”. We call on the broader community of advocates to support and promote these principles.

Embrace diversity. Embrace choice. •

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**KEY PRINCIPLES IN SUPPORT OF ENSURING THE RIGHTS AND OPPORTUNITIES FOR ALL PEOPLE WITH DISABILITIES**

**GENERAL PRINCIPLES**
- “Individuals with disabilities” describes a widely diverse group of people, ranging from people with mild physical and/or intellectual disabilities to those with profound and/or severe intellectual disabilities, along with medical or behavioral disabilities.
- “Individuals with developmental disabilities and their families are the primary decision-makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision-making roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(2000).
- Most individuals with disabilities are capable of living just like people without disabilities and should have the opportunity to do so. These individuals with disabilities should have control over their own day, including which job or educational or leisure activities they pursue, and where and how they live, with any necessary supports.
- Support for full community integration of most individuals with disabilities should not be interpreted to deprive individuals with profound intellectual and developmental disabilities (I/DD) or other serious I/DD and medical and/or behavioral disabilities from assurances of proper care of their health and safety needs, and individuals with disabilities should not be forced to accept services or participate in activities they do not wish to accept. As Justice Ginsburg wrote in the Olmstead decision, “Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing that, on a case by case basis, that setting may be in an institution.” (emphasis added)

**CHOICE**
- 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. They must have full and accurate information about their options, including what services and financial supports are available.

**EMPLOYMENT**
- Most individuals with disabilities should have the opportunity to be employed in regular workplaces. Most individuals with disabilities can be employed and earn the same wages as people without disabilities. When needed, individuals with disabilities should have access to supported or sheltered employment, or other day activities, to ensure fulfilling and productive experiences.

**HOUSING**
- Individuals with disabilities have the right to choose where to live from an array of residential options.
- Most individuals with disabilities can live in their own homes with supports and they should get to decide where they live, with whom they live, when and what they eat, who visits and when, etc.
- These choices for most individuals with disabilities should not deprive individuals with profound I/DD or other serious I/DD and medical and/or behavioral disabilities from the right to live in congregate arrangements, multi-unit buildings or complexes that cater to specific needs, according to individual choice and need.

**PUBLIC FUNDING**
- Government funding for services should support implementation of these principles to assure a full array of residential and service options to accommodate the diverse needs and preferences of the disabled population. Financing for long-term services and supports must be responsive to the needs of all individuals with disabilities, recognizing that the cost to care for individuals must necessarily vary and be responsive to varying needs.

**TELL US WHAT YOU THINK!**
Do you support these principles? VOR welcomes your comments.

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Individuals With Intellectual And Developmental Disabilities, And Their Families Seek Right of Choice

Some families of individuals with profound intellectual and developmental disabilities (I/DD) are fighting for a right that most of take for granted: Choice.

Across the country, “deinstitutionalization” – a decades-old 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.

“History is both a lesson and curse for families like mine who family members require highly specialized care in licensed facilities,” said Ann Knighton, President of VOR, a national organization that has been advocating for high quality care and human rights for people with I/DD for 30 years. It's the only national 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.

“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. Unfortunately, the old image still sticks with people,” 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.”

Knighton’s daughter, Erika, has profound intellectual disabilities and a host of medical issues, making daily survival something to celebrate.

Erika is one of more than a 100 residents of the East Central Georgia Regional Hospital in Augusta, Georgia. Also known as Gracewood, the hospital is federally-licensed and provides highly specialized, compassionate care to its residents.

Across the country, about 160 state-operated homes like Gracewood, and several hundred private centers, serve medically fragile or behaviorally dangerous individuals who also have profound intellectual disabilities. Stringent federal requirements are reviewed annually to ensure consistent high quality care in areas relating to staffing, onsite health care, nutrition, and “active treatment” - programming designed to help individuals gain new skills.

Big still considered bad

These very facilities, designed to serve the most disabled, however, continue to be targeted by closure advocates. However, unlike the early decades of this movement when less disabled people were inappropriately placed and conditions of care were a concern, today closure is motivated by integration – the ability for disabled people to interact with nondisabled people.
Yet, families whose loved ones receive care at facility homes will argue that their lives are far more integrated on their expansive and open campuses than they could ever hope to achieve in a four person home on a busy street.

“I visited some smaller residential settings that were being pitched as an alternative to my brother’s home,” said Mary Vitale, whose brother resides at Bellefontaine Center in St. Louis, Missouri. “Some of the homes had no exterior devices to assist disabled residents and several were located in high crime areas with collapsing buildings and abandoned properties. The promise of ‘community integration’ was far from reality.”

One federally funded agency, the National Council on Disabilities (NCD), is so fervent in its desire to close all federally-licensed residential homes that it 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.”

“Families whose individuals will lose their homes if states act on NCD’s recommendations were not consulted,” remarked Julie Huso, VOR’s Executive Director. “Their voices should matter most, but they were completely ignored. NCD is not alleging that these programs are bad, only that they are too big. Remarkably, NCD feels that four people in a home is too “institutional.”

NCD is not the only threat. Family advocates find themselves up against a veritable Goliath as they desperately defend their choice of care for their loved ones. The U.S. Department of Justice, federal advocacy agencies, and some State Governments all seek closure of larger programs, arguing people can be served cheaper and better in the smaller settings.

Families Strongly Disagree

“You get what you pay for,” said Knighton. “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. Predictable tragedies are widespread and well-documented.”

Sam Bagenstos, a former Principle Deputy Assistant Attorney General for the Department of Justice, then considered the point man on Olmstead enforcement, also acknowledged in a law review article that mistakes have been made. Although he remains a strong proponent of deinstitutionalization, he points to an alliance between closure advocates and fiscal conservatives as the main reason why community services are not always well-equipped to serve people with significant disabilities safely. Fiscal conservatives expected to save money by closing facilities; they were not then keen on investing in robust community supports.

“It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services,” stated Bagenstos, who also acknowledged that the perceived cost savings for community services would evaporate if such programs were adequately funded.

Forgotten Families

Linda Lotzi is her sister, Lauren’s, primary advocate. As her legal guardian, she found herself challenging a lawsuit by a federally –funded agency to close Lauren’s home at White Haven Center in Pennsylvania.

“They filed this lawsuit claiming to represent Lauren. They had never met Lauren, yet these attorneys decided that Lauren would be happier and better
served in a new home,” said Lotzi. “White Haven has been her home for 40 years. Once, when she moved just from bedroom to another, she stopped eating. I have no idea why the attorneys didn’t consult with me.”

Families like Lotzi are fighting back with the help of attorneys referred to them by VOR. A grateful Lotzi now serves on VOR’s national Board of Directors.

“VOR listens – really listens – to the families,” says Lotzi. “My involvement with VOR has enabled me to with families all across the country who are facing similar threats. This is truly a national crisis.”

Knighton agrees. “In Georgia, we are facing the closure of all specialized residential services due to a federal Justice Department Settlement,” said Knighton. “Erika could lose her home, yet the court appointed monitor who is keeping track of how things are going now acknowledges serious problems with community-based care for people with developmental disabilities. We take little comfort in saying ‘I told you so,’ when we learn of abuses and even deaths.”

Knighton has also been outspoken about the lack of family input in developing, approving and implementing the settlement agreement.

“Shouldn’t our voices matter most?,” asks Knighton. “It’s our children who are most directly affected by this lawsuit. All we want is a voice and a choice. It’s our right as parents.”

“Fortunately, federal law, which appropriately that the voices who matter most are the residents and their families, 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 a peace of mind that their family members will continue to be well cared for and that their choices will be respected.”

-End-

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.
Dear Mr. Valenzano and Mr. Rader,

Thank you for welcoming a response from Dr. Alison Lozano, the Executive Director of the New Jersey Council on Developmental Disabilities, to VOR’s “When Equitable Does Not Mean Equal: Respecting Diversity and Choice” (October 2013), and allowing my reply. On behalf of VOR, I am grateful for this opportunity.

I wear many hats.

I am a VOR Board Member and also a member of the New Jersey DD Council. More important than these titles, however, are my roles as dad and uncle.

My son, Danny, has severe autism. At age 18, he still lives with me and his mother, but will require community-based services in the future.

My nephew, Benny, has Fragile X syndrome. He also lives with his father, but is involved in vocational and recreation programs and will someday need community-based residential supports.

My niece, Heather, has a profound, regressive form of autism, meaning her disability is more pronounced with each passing year. She calls Hunterdon Developmental Center home, in every sense of the word. She has a job she loves, has good friends, and receives the exceptional care and support she needs to survive. She’s hardly “isolated” or “segregated,” as Dr. Lozano claims. Her quality of life and care is typical of New Jersey Developmental Center residents. It’s simply a myth born in past, corrected history that these individuals are somehow shut away from society.

Dr. Lozano’s reply to VOR’s article begins with a claim that VOR does not believe in choice, diversity or equality. She points to a name – not VOR’s name – as justification for her claim. VOR has never been called “Voices of the Retarded,” and several years ago we changed our name to VOR from “Voice of the Retarded.” Just as the Association for Retarded Citizens (now called The Arc) did, VOR opted to move away from “anti- quated language that does not reflect respect for people with developmental and intellectual disabilities.” On this point, Dr. Lozano and I agree.

I strongly disagree, however, with Dr. Lozano’s characterization of VOR as supporting only institutional (“developmental center”) care. I would not support VOR if that were the case. As noted, I have two family members who will someday want and need community-based supports, just as Heather requires more specialized care for her survival.

And, that is exactly the point: People with disabilities do not have the same needs or wants. As clearly stated in our article:

“Equitable – providing individualized care and employment options – does not mean equal [the same]. People with disabilities have vastly different needs, requiring vastly different supports across the continuum.”

As a New Jersey DD Council member, my views with regard to the provision of services based on individual need and choice are well known. I have openly challenged the Council’s public relations and legislative advocacy campaign in support of the State’s decision to close developmental centers. As a publicly-funded entity, I believe strongly that the Council should not “take sides” in support of some individual care decisions, but not others. By vast majority, the individuals being served in developmental centers have profound intellectual disabilities. They have the cognitive abilities of infants and young children. They require the help of their families to make care decisions, just as young children do. I don’t agree that it is the Council’s place to question caring families who, by vast majority, are supportive of the care received in our developmental centers.

Dr. Lozano also suggests that VOR has misrepresented federal law, yet nowhere in the ADA, in the Supreme Court’s Olmstead decision, or in the Developmental Disabilities Act is there a mandate to close all “institutions.” These laws encourage community integration where possible, but leave the final decision to individuals and their families. The Supreme Court in Olmstead goes further, requiring individual choice and emphasizing that “nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”

VOR’s support for an array of service options, from own home, family home, community-based supports and facility-based options, based on individual choice and need, sounds a whole lot more like choice than Dr. Lozano’s position that everyone must live alongside everyone else in a regular neighborhood, enjoying their community to their fullest extent.”

Living in “regular neighborhoods” is a nice image, but what’s “regular?” Some of us live in homes in the suburbs or in the hearts of cities; others live in condominiums, apartment complexes or college dormitories; and others choose to live in retirement or gated communities. Like all of us, people with intellectual and developmental disabilities will choose and need different living arrangements. They should not be relegated to someone else’s notion of what is “regular.”

My own family represents the continuum of need and I’m grateful for real choice.

Thank you again for this opportunity.

Respectfully,
Geoff Dubrowsky
Dad to Danny
Uncle to Benny and Heather
VOR Officer and Board Member
New Jersey Council on Developmental Disabilities, Member
Our mission is to advocate for high quality care and human rights for individuals with intellectual and developmental disabilities.

We are excited to tell you about VOR!

VOR is a national organization that advocates for all individuals and families 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 matters involving care and housing. 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 voice for families who have loved ones with profound I/DD.

VOR is 100% privately funded and receives more than 95% of its financial support from families of individuals with I/DD.

We recognize and champion the right of individuals and their families to be the primary decision-makers regarding care and policy decisions.

VOR has launched its “Quality in the Community” initiative to proactively address the negative outcomes associated with unprepared community settings for people with I/DD.

The need for VOR’s Quality in the Community Initiative is urgent. Deinstitutionalization – the closure of federally-licensed specialized settings – continues in earnest. As a result, individuals with profound I/DD, multiple disabilities, serious medical problems, and behavior challenges are removed from specialized settings to “community-based” settings often with poorly trained staff and inadequate health and safety measures in place. Predictable tragedies are well-documented and widespread. VOR believes the safety of the individual should be regarded above all other concerns.

Our objective is to identify best practices and promote high-quality, person-centered community-based services for individuals with I/DD whose needs can be met in community settings and to ensure through advocacy and legislation uniform and humane quality standards in across all states.
To join VOR, please enclose dues payment:

- Individual $40
- Family Organization $200
- Professional Assn. $250

An extra donation is enclosed:

- $1000
- $500
- $100
- $50
- Other

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Street Address ____________________ Work Phone __________________________
City, State, Zip ___________________
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Facility/Organization Affiliation ___________________________ Title: ___________
Please Charge My: □ MC □ Visa □ Discover Card Number: ____________________
Expiration Date: ___________ Three Digit Security Code: __________________
Signature: ________________________
Location your loved one calls home: ___________________________ State: __________

Thank you for supporting VOR. Gifts to VOR are tax-deductible to the fullest extent of the law, as no goods or services are provided in consideration of a gift.

Tangible Benefits to Members:

- VOR's Weekly E-Mail Update, that provides members with “real time” national news.
- VOR's print newsletter, The Voice, that includes legislative, legal and state news, along with VOR organizational updates and sibling news published three times per year.
- Regular Action Alerts enabling members with one click access to background information, template messages and contact information enabling members to respond to legislative and other policy proposals impacting people with intellectual and developmental disabilities.
- Annual VOR Conference and other events in Washington, D.C. which feature prominent speakers and timely topics.
- Individual advocacy assistance via access to VOR's Board Members, State Coordinators, staff and key leaders.
- A vibrant Legislative Advocacy program, including an annual Washington Initiative and a year-round Washington Representative who attends legislative meetings, hearings, and conferences on VOR's behalf, ensuring a regular presence in our nation's capitol.
- A vibrant Legal Advocacy program which includes legal advocacy and, when available, pro bono legal representation for nationally significant litigation.
- An informative website (www.vor.net) which some members regard as a “one-stop advocacy shop.”
- Access to VOR speakers and grassroots training opportunities.
- The right to select VOR's Board of Directors through an annual vote.

Intangible Benefits to Members:

- VOR speaks up for families and gets involved when results of legal precedents in other states will affect their loved ones.
- VOR speaks up for individuals to make sure that the quality of care in all settings meets the individual needs of each resident.
- VOR speaks up for the right of families and individuals to choose from a spectrum of residential choices, including large, small, state, private, or home.
- VOR speaks up for families on federal issues that affect funding and quality of life for people with I/DD, like Olmstead, DD Act reform and Medicaid.

Supporting VOR is a good investment!
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VOR’s mission is to advocate for high quality care and human rights for people with intellectual and developmental disabilities.

### Officers

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<th>Name</th>
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<tr>
<td>Ann Knighton, President</td>
<td></td>
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</tr>
<tr>
<td>Jill Barker, First Vice President</td>
<td></td>
<td>2620 Hickory Rd., Ann Arbor, MI 48103 734-996-5561 <a href="mailto:jillrbarker@sbcglobal.net">jillrbarker@sbcglobal.net</a> (Board term ends 6/15)</td>
</tr>
<tr>
<td>Jill Goldstein, Second Vice President</td>
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</tr>
<tr>
<td>Geoffrey Dubrowsky, Treasurer</td>
<td></td>
<td>356 Jarome St., Brick, NJ 08724 201-264-8654 cell <a href="mailto:trotts19@mac.com">trotts19@mac.com</a> (board term ends 6/14)</td>
</tr>
<tr>
<td>Sybil Finken, Immediate Past President / Secretary</td>
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<td>401 Louise Ave., Glenwood, IA 51534 712-527-3250 * <a href="mailto:finkensrc@aol.com">finkensrc@aol.com</a> (Board term ends 6/15)</td>
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### Board Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Contact Information</th>
</tr>
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<tbody>
<tr>
<td>Cindy Bartman</td>
<td></td>
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<tr>
<td>Gil Fonger, CEO</td>
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<tr>
<td>David Hart</td>
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</tr>
<tr>
<td>Terry Kopansky, Executive Director</td>
<td></td>
<td>(term ends 6/15) Mur-Ci Homes, Inc., 2984 Baby Ruth Lane, Antioch, TN 37013 615-641-6446 office * 615-641-2416 fax <a href="mailto:tkopansky@murci.org">tkopansky@murci.org</a>; <a href="mailto:drterrykopansky@bellsouth.net">drterrykopansky@bellsouth.net</a></td>
</tr>
<tr>
<td>Terry Lafleur</td>
<td></td>
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</tr>
<tr>
<td>Linda Lotzi</td>
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VOR also has a network of State Coordinators. Contact information is available on our website at http://vor.net/contact-us/state-coordinators