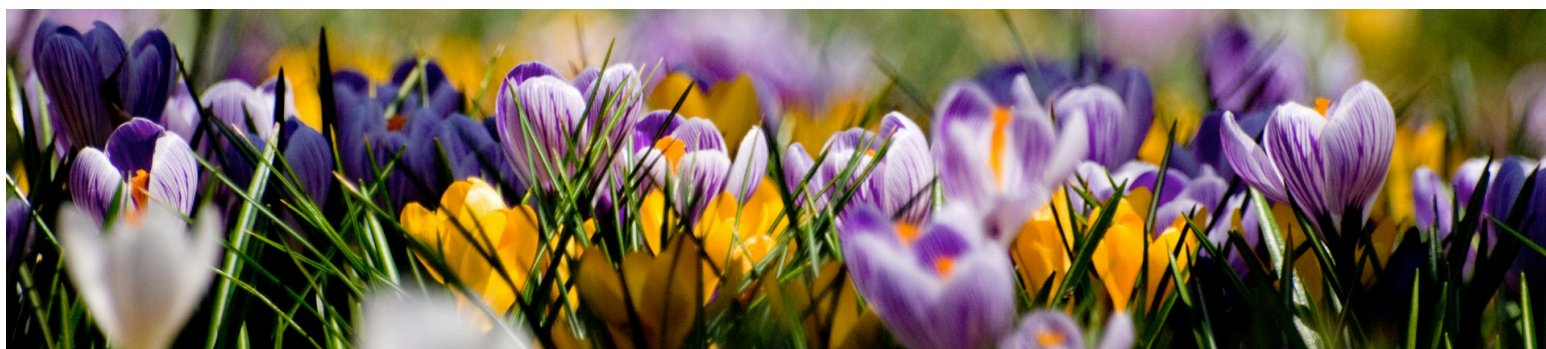


VOR 2016 Annual Conference and Washington Initiative
“Voices for Choice”
June 4 - 8, 2016
Washington, D.C.



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My Sister Rosemary

By Joanne St. Amand

My name is Joanne St. Amand. My brother and I are the guardians for our youngest sister Rosemary, a woman with profound intellectual disabilities. Of her 3 pregnancies, my mother felt the best with Rosemary and the delivery was uneventful, so no one was expecting a problem. My mother however knew something was wrong soon after her birth because Rosemary never cried out and had trouble sucking on a bottle. Doctors tried to persuade my parents to leave Rosemary and not take her home to live. Not willing to do that, Rosemary came home after about a three month stay in the hospital.

Rosemary's disabilities are profound. She is 60 but looks many years younger. She would be about 5 feet but the severe scoliosis and muscle contractures make her look shorter. She has a cognitive age of a 3 month old. She cannot walk or talk but that twinkle in her eye tells me she approves of my actions to advocate for her. She cannot roll over by herself. She won't make eye contact with you for more than a second or two. She has to be lifted and carried from her bed to her wheelchair or to a bathing area. Wherever you place her, she will stay until you move her again. Rosemary needs help with everything. She has to be bathed and dressed. Rosemary cannot chew and is fed pureed food. She suffers from dysphasia and all of her liquids need to be thickened so she does not choke. Rosemary suffers from seizures, which generally have been well controlled by the doctors at the center. She cannot tell you when she is not feeling well and depends on those around her to figure it out.

Rosemary moved to Woodbridge Developmental Center, a state run ICF in NJ when she was 20 and lived there until shortly before it closed in 2014. For those 39 years she received excellent care. Her staff is her family and they love her very much. Although Rosemary cannot express herself, I'm sure the feeling is mutual. In any one day, no less than 10 people will stop by and say hi to her. Rosemary needs this interaction since she would not take the initiative. Rosemary was not expected to live past her teens. The fact that she has done so well is a direct tribute to the well

trained and experience staff in her center.

In 2013, Joanne's family and Save NJ Developmental Centers, Inc. placed a 14' X 48' billboard with Rosemary's picture above the I-95 approach to the New Jersey State House in Trenton, in an effort to get Gov. Christie's attention, in hopes that he might prevent the closure of the Woodbridge Developmental Center.

The Woodbridge Developmental Center Parents Association, Save NJ Developmental Centers, Inc. and VOR fought a courageous battle against the State of NJ to stop closure. Rosemary needs ICF level of care. She was one of the lucky ones. When her center closed, she was able to move to another ICF in NJ where Rosemary continues to receive the highest level of care from the most comprehensive program available through CMS. If it weren't for all the resources available to us from VOR, this story may not have had such a happy ending. VOR was there every step of the way, guiding families on residential options and guardianship, assisting with legal representation, submitting key testimony at several public hearings and filing joint testimony with the other NJ developmental centers about the states transition plan.

Our family will be forever indebted to VOR and will remain always, loyal members.

Joanne St. Amand

Member of the VOR Board of Directors



VOR's Annual Meeting and Washington Initiative

“Voices For Choice”

By Hugo Dwyer, VOR Executive Director



“Voices for Choice” is the theme for VOR’s 2016 Annual Meeting and Washington Initiative, to be held at the Hyatt Regency Capitol Hill in Washington, DC, June 4-8, 2016.

As you know, VOR has undergone many changes in the past year. We urge you to attend this year’s meeting, to renew your connection with VOR and with advocates from across the country. This is your opportunity to redefine VOR, and to help us forge a new direction and to plan for the years to come.. We need your ideas, your energy, your commitment, and your voices.

This is your VOR.

As always, our annual meeting will focus on our steadfast commitment to choice, empowering families and guardians to make their own choices, in order to better protect the rights, safety, and care of their loved ones with Intellectual and Developmental Disabilities (I/DD).

This year, however, our speakers will come from our own ranks. Our goal is to further empower our members to become stronger advocates by hearing the experiences of others and sharing ideas and strategies that have proven successful for like-minded advocates from other states. Members of our Legislative Committee will outline their current and long-term goals. The Issues/Oversight Committee will lead a forum on Guardianship and explain the new laws that are being proposed that would take away some of your rights as a guardian. The Marketing Committee will demonstrate how VOR’s Salsa platform can be used to help you initiate an advocacy campaign in your state. We will help you to better use social media, and to understand its importance in bringing our message to legislators and its ability to help you to expand your advocacy network.

This is an important year for us on Capitol Hill. It’s an election year, and representatives tend to listen a little more closely during election years. Next year, we will have a new President, a new House, and a new Senate. The first six months of any presidential term are the ones in which a new agenda is set. We hope that your meetings in congress this year will help to set the tone for next year, and the terms that will follow.

I look forward to seeing you in Washington this year. For further information, please contact me at hdwyer@vor.net or call me at 646-387-2267.

A handwritten signature in black ink that reads "Hugo Dwyer". The signature is written in a cursive, flowing style.

Hugo Dwyer
Executive Director

Olmstead Protects Individual Choice and Recognizes the Need for Higher Levels of Care

By Caroline A. Lahrmann

Individuals with intellectual and developmental disabilities (I/DD) are far too frequently finding life-sustaining services pulled out from under them by agencies charged with the duty to protect them – namely state departments of developmental disabilities and protection and advocacy organizations. They attempt to use the law as a weapon against the community of people with disabilities instead of the tonic it is meant to be.

These agencies tell the public and lawmakers, wrongly, that the Americans with Disabilities Act (ADA) and the U.S. Supreme Court *Olmstead* decision require “de-institutionalization” and “community integration,” regardless of individual need and choice. We are told that “least restrictive environment” in all cases means small community settings, even when many individuals with I/DD cannot be safely served in such settings **and/or** they choose the higher level of care provided in large facilities, such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), facility-based day programs and sheltered workshops.

Don’t be fooled by this deception, and don’t let your elected representatives be fooled either. *Olmstead’s* majority and concurring opinions take great care to stress that “institutions” such as ICFs/IID are a critical part of a range of services that a state must provide to meet the needs of the diverse community of people with mental disabilities. *Olmstead* recognizes that there are individuals who desire and require a higher level of care for whom “institutions” must remain available. *Olmstead* also states that the wishes of individuals are paramount in determining residential placement.

The importance of individual choice, including for some the choice of “institutional care,” is repeated throughout *Olmstead’s* majority opinion as follows:

*“Such action (community placement) is in order when the State’s treatment professionals have determined that community placement is appropriate, **the transfer from institutional care to a less restrictive setting is not opposed by the affected individual**, and the placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities.”*
(Emphasis added.)

“But we recognize, as well, the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand.”

“We emphasize 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.”

“As already observed...the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk...Nor is it the ADA’s mission to drive States to move institutionalized patients into an inappropriate setting...”

“For other individuals, no placement outside the institution may ever be appropriate...for these persons, institutional settings are needed and must remain available.”

*“For these reasons stated, we conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, **the affected persons do not oppose such treatment**, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”*
(Emphasis added.)

In his concurring opinion to *Olmstead*, Justice Anthony Kennedy warned against its misinterpretation, specifically pointing to state agencies. Kennedy states in Part I of his concurring opinion, which Justice Stephen Breyer joined, that:

“It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.”

Justice Kennedy then quotes from the majority opinion,

*“Justice Ginsburg’s opinion takes account of this background. It is careful, and quite correct, to say that **it is not “the ADA’s mission to drive States to move institutionalized patients into an inappropriate setting...”**” (Emphasis added.)*

Justice Kennedy concludes,

*“In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, **States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.**” (Emphasis added.)*

Justice Kennedy’s warning has sadly proven prophetic for developmentally disabled citizens around the country who have been forced out of their chosen ICF/IID homes, facility-based day programs and sheltered workshops because of real or perceived threats of litigation, oftentimes from federally-funded protection and advocacy agencies set up to protect our most vulnerable citizens.

Olmstead is not a decision to be feared by individuals seeking specialized services for their unique needs connected to their intellectual and developmental disabilities. Congress demonstrated this fact when it recognized the importance of considering individual choice based on need in ADA (*Olmstead*) enforcement activities in this December 2014 Report language to accompany the Consolidated and Further Continuing Appropriations Act of 2014:

“Deinstitutionalization.-There is a nationwide trend towards deinstitutionalization of patients with intellectual or developmental disabilities in favor of community-based settings. The Department [of Justice] is strongly urged to continue to factor the needs and desires of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Americans with Disabilities Act.” [Conference Report to accompany the Consolidated and Further Continuing Appropriations Act, 2014(for Commerce, Justice, Science, and Related Agencies, p. 17) (December 2014)].

Olmstead embraces options. Its careful and responsible findings respect the diversity inherent in the community of people with mental disabilities and seek to ensure that all people receive safe, appropriate, and individually-driven services.

Caroline A. Lahrman
VOR State Coordinator Ohio
Disability Advocacy Alliance, Co-Founder

HELP US TO HELP YOU

VOR is forming working groups to research, formulate policies, and submit position papers on:

- Sheltered Workshops
- State and Federal Background Checks
- Quality of Care Standards for Individuals with I/DD

Each of these groups will work via email in coordination with VOR staff and the Legislative Committee. Please contact Hugo Dwyer at hdwyer@vor.net or call 646-387-2267 for further information or to sign up for one of these working groups.

VOR 2016 Annual Conference and Washington Initiative June 4 - 8, 2016

All VOR meetings will take place at the Hyatt Regency Capitol Hill, 400 New Jersey Ave., NW, Washington, D.C.

Saturday, June 4, 2016

VOR Board Report to Membership **1:00 pm**

Time will be provided for member questions and comments

Reports from the States **3:30 pm**

Participants report on news from their states. Session is moderated by VOR Board Members

Networking and Hospitality Reception **5:30 pm**

Join VOR board members and staff for an informal reception. Due to an overwhelming response in past years and hotel limitations, only certain participants will be invited to bring food. Everyone is welcome to attend.

Folders for Congressional visits will be available at this time.

Sunday, June 5, 2016

VOR 2016 Annual Conference and Legislative Briefing “Voices for Choice”

Legislative Committee Meeting **10:00 am**

Registration: Network with families from across the country **12 Noon**

Welcoming Messages to Conference Attendees **1:00 pm**

Ann Knighton, President and Hugo Dwyer, Executive Director

Speeches and Presentations **1:30 pm**

VOR Committee Chairs update members on recent activities and coming goals

VOR Members share their personal stories about the ongoing struggle to keep their facilities open

Speakers To Be Announced

VOR Annual Raffle

Legislative Briefing **4:00 pm**

Panel Discussion and Issue Briefing. Folders for Congressional visits will be distributed.

Installation of VOR 2016-2017 Officers and Introduction of Board Members **5:30 pm**

Monday, June 6 – Thursday, June 8, 2016

The Washington Initiative

Visits to Capitol Hill - Personal meetings with Members and Congress and their staff are the most effective way to educate and influence federal lawmakers. Join choice advocates from around the country as we work together to convey the importance of residential choice and family decision-making directly to Members of Congress. Plan time to cover your state's Congressional Delegation.

Monday, June 6 **Informal De-briefing** **6:30 - 8:00 pm**

Tuesday, June 7 **Informal De-briefing** **6:30 - 8:00 pm**

Reports by state spokespersons regarding Congressional visits.

HOTEL INFORMATION Reservations due by May 9, 2016

Hyatt Regency Capitol Hill

Washington, D.C. 20001

400 New Jersey Ave., NW

All Conference, Dinner and VOR Meetings held at Hyatt Regency Washington on Capitol Hill.

Roommates will be arranged, if possible, upon request.

To make your reservations: Online <https://resweb.passkey.com/go/AnnualVORConference>

If you do not have internet access, call 1-800-233-1234 and mention “VOR’s Annual Conference” when making the reservation.

The VOR Group rate is \$269 for single or double, plus tax, per night. Larger rooms and suites are also available.

TRANSPORTATION INFORMATION

Taxis and “Super Shuttle” vans are available at Reagan International Airport, the closest airport to the Hyatt. “Super Shuttle” is \$14 per person (\$10 each additional passenger), one way. At airport, follow signs to “Ground Transportation.” Reservations are only required from the hotel to the airport (800-258-3826 or supershuttle.com). Union Train Station is just 3 blocks from the hotel.

NEED A ROOMMATE AT THE HYATT FOR THE INITIATIVE?

If you would like to share a room to defray costs during your stay in Washington, please contact us at info@vor.net and we will try to match people up for a night or two or three.

Annual Conference & Legislative Briefing (Saturday & Sunday, June 4 - 5, 2016)

Registration Form – Return to VOR

836 S. Arlington Heights Rd., #351 • Elk Grove Village, IL 60007

Fax: 877-866-8377 • hdwyer@vor.net • Phone: 877-399-4867 (toll free) or 646-387-2267

Register online at vor.net/events

Name(s) _____

Address _____

City, St, _____ Zip _____

Home Phone _____

Work Phone _____

Email _____

Sponsoring Organization: _____

INITIATIVE REGISTRATION

_____/We will attend the Washington Initiative and will be able to make Congressional visits through _____ [specify date(s)]

ADDITIONAL DONATIONS APPRECIATED

An Additional donation of \$ _____ is enclosed.

ANNUAL CONFERENCE REGISTRATION

Fee includes all Sunday, June 7 events including conference registration and materials.

VOR Members:

_____ \$75 per member if paid by **April 8, 2016.**

_____ \$90 per member if paid by **May 9, 2016.**

_____ \$110 per member if paid after **May 9, 2016.**

Non-VOR Members:

_____ \$100 per person for non-member if paid by **May 9, 2016.** Fee includes 1 year membership.

_____ \$135 per person for non-member if paid after **May 9, 2016.** Fee includes 1 year membership

Amount to Charge: _____

Charge card: MC Visa Discover

Expiration date: _____

Credit Card Number: _____

3-Digit Security Code (back of card) _____

Signature _____

Optional Dinner at the Dubliner

\$36 per person

Includes Salad, Entrée, Dessert & Non-Alcoholic Beverage

Tax & Tip Included

Reserve Here For _____ Persons

(no payment required at this time)

Thank You for Supporting VOR!

According to the Foundation Center, there are 1.5 million nonprofit (501(c)(3)) organizations. With so many choices, we are grateful you chose VOR.

VOR is different than all the rest. VOR is the ONLY national 501(c)(3) advocacy organization for people with disabilities that supports a full array of residential, employment and education options for people with intellectual and developmental disabilities.

Only VOR expressly OPPOSES “deinstitutionalization”: the downsizing, reduction and elimination of specialized residential facility care, workshop employment, and education options without regard to individual need, demand and choice.

Only VOR expressly SUPPORTS CHOICE and the expansion of high QUALITY residential, employment and education options in small and large settings to accommodate the vast continuum of individualized need.

Thank you for your support! Donations to VOR are tax deductible.



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 www.vor.net

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*A national, non-profit 501(c)(3) volunteer association
 speaking out for people with intellectual and developmental disabilities*



www.vor.net



/VOR



info@vor.net



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Membership/Contribution Form

VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007
 Fax: 877-866-8377 or donate online @ <http://www.vor.net/get-involved>

Thank you for your dues and contributions!

I would like to give a gift membership to:

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____ Fax _____

Email _____

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____ Fax _____

Email _____

MY CONTACT INFORMATION HAS CHANGED

I WOULD LIKE TO MAKE A TRIBUTE GIFT:
 IN MEMORY OF: IN HONOR OF:

- \$40 per year per individual;
- \$200 per year per family organization
- \$250 per year per provider/professional org.

Send acknowledgement to: _____

- I would like to make monthly donations to VOR. Please charge my credit card each month for: \$ _____
- I would like to make an additional donation to support VOR. An additional gift is enclosed for:
 \$5,000 \$2,500 \$1,000 \$500 \$250 \$100 \$50 Other \$ _____

Make checks payable to VOR, or use your credit card: Visa MasterCard Discover

Card Number: _____ Expires: ____/____/____ CVC (3-digit security) Code _____

Signature: _____

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is our best interest that you receive VOR's information, so please call if \$40 per year poses a financial hardship. If you have included VOR in your estate planning, please let us know. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.