



**“True understanding of the Olmstead decision language need not forever be deferred.”  
~ Ann Knighton, VOR President**

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## “Choice and Quality Need Not Forever Be Deferred”

By Ann Knighton, President

[The following are excerpts from Ms. Knighton's President Message to Members at the 2014 VOR Annual Conference on June 8, 2014 in Washington, D.C.]

My involvement with VOR began as a member, and eventually President, of the East Central Georgia Regional Hospital (“Gracewood”) Family Council, a VOR organization member (then and now). As an organization member, the Family Council received VOR’s literature which it shared with its members. I immediately saw the value of VOR and have been an individual member and donor ever since.

It was not until 2007, however, that my involvement in VOR really blossomed, beginning with a phone call inviting me to participate in the Annual Conference and Initiative. I made that journey alone. It was an unforgettable trip and the journey of a lifetime.

Since then, I have attended every Initiative. It takes a lot of effort arranging for time away from daily life and work, but so worth it. I hold VOR in such high esteem. I learn so much each and every year.

I appreciate VOR because VOR advocates for people in all care settings. I attend the Conference and Initiative each year for the benefit of my daughter, Erica, who has given me a cause, and for VOR who has helped me think globally in speaking not just for Erica, but for her

peers in all these United States.

I continue my efforts for VOR because VOR has given me a sense of passion about the issues that impact our family members. I’m proud of VOR’s accomplishments (see articles on pages 8-10).

VOR has been instrumental in my Georgia advocacy. A Department of Justice (DOJ) Settlement is impacting choices and quality in my state. VOR has helped with resources and meetings, including annual meetings with DOJ attorneys. We’ve seen bittersweet progress. Many people have died, resulting in a halt in transfers for now, but some individuals are being displaced from their homes in Central Georgia to relocate to Gracewood. All this allows us some license to say, “I told you so,” but we don’t relish this sort of progress. With VOR’s help we’ll continue working against the odds to reverse the process. That is my dream.

I am indeed grateful to all VOR leaders, members and friends for all their hard work; the journey we have taken together has indeed been long and difficult, but it continues as we have so much more work to do and many more miles to go before we sleep.

I will close with reference to one of Barbara Jordan’s classical speeches that commented that the “American Dream Need Not Forever Be Deferred”:

Choice for persons with intellectual and developmental disabilities (I/DD) need not forever be deferred.

True understanding of the *Olmstead* decision language need not forever be deferred.

The redemption of issues that impact our most vulnerable citizens with I/DD need not, and must not, forever be deferred.

**If not now, when? If not us, who?**



### VOR Is Family

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#### VOR MISSION STATEMENT

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

On the Cover and Page 8: L-R: Bob Anthony, Peter Kinzler, Tamie Hopp, Ann Knighton and David Hart.



Mary and Mary Elizabeth in December 1969, at the beginning of their journey.

## A Tribute to Mary McTernan for 22 Years of Service to VOR

[A special thanks to VOR member George Mavridis who helped write this tribute].

On June 30, 2014, Mary McTernan, VOR Past President, long-time Officer and Board Member, Committee Chair, member and donor, ended her final term on the VOR Board of Directors. Her accomplishments on VOR’s behalf are many and deserve our deepest appreciation.

Mary’s foray into advocacy on behalf of people with intellectual and developmental disabilities (I/DD) began like most of VOR members – the birth of her daughter, Mary Elizabeth. Her advocacy work began in Massachusetts, serving in various leadership positions.

Her service on VOR’s Board of Directors began in the early 1990s and continued for 22 years, including 4 years as President, many years as the Chair and member of the VOR Government Affairs Committee, and Chair and Founder of VOR’s Legislative Committee.

Mary is the architect of the VOR Washington Initiative in its current form (folders, briefings and debriefings), and urged the hiring of VOR Washington Representative, Larry Innis. During her term as President, she expressed her appreciation to Initiative participants by sponsoring breakfast for every Initiative participant for 2-3 years. Mary enlisted the help of attorney William Burke to prepare VOR’s Amicus Brief for the landmark *Olmstead* case, a decision which includes a quote from VOR’s brief. Mary’s friendship with retired U.S. Representative Barney Frank resulted in Rep. Frank introducing class action reform bills in three sessions of Congress, with the addition of the Department of Justice lawsuits in the last version of the bill.

Mary is driven by a work ethic best described by Harry S. Truman: “It is amazing what you can accomplish if you do not care who gets the credit.” She held herself and those around her to strict standards, but never sought credit and was always motivated by the best interest of our shared advocacy on behalf of people with I/DD.

Like so many tributes for VOR leaders, this is a tribute and not a farewell. Although she may be leaving the Board of Directors, Mary remains supportive and involved in VOR’s advocacy – and that is to our collective benefit. **For our more detailed tribute to Mary, visit VOR’s website at [vor.net/contact-us/board-of-directors](http://vor.net/contact-us/board-of-directors).**

## VOR Announces the Election of its 2014-2015 Officers

On Saturday, June 7, 2014, the VOR Board of Directors elected VOR’s Officers (see above) for the fiscal year beginning July 1, 2014. These officers were installed at the Annual Conference on June 8, 2014. VOR is grateful to these leaders for the extra time and commitment they offer to VOR as Officers.

## In Their Own Words: Why VOR Matters to Me

Several VOR Board Members provided short video testimonials speaking on why VOR matters so much to them. You can watch these videos on VOR’s YouTube Channel at [youtube.com/VOR4Choice](http://youtube.com/VOR4Choice).

## VOR Board and Officers July 1, 2014 – June 30, 2015

### Officers

- Ann Knighton (GA), President
- Geoffrey Dubrowsky (NJ), First Vice President
- Jill Barker (MI), Second Vice President
- Jill Goldstein (NY), Treasurer
- Sybil Finken (IA), Immediate Past President and Secretary

### Board Members

- Cindy Bartman (NJ)
- Mary Kay Cowen (LA)
- Gil Fonger (IL)
- David Hart (MA)
- Terry Kopansky (TN)
- Mary O’Riordan (CA)
- Terry Lafleur (LA)
- Linda Lotzi (PA)
- Mary Reese (MD)
- Joanne St. Amand (NJ)
- Mary Vitale (MO)



VOR Board Members receive Certificates of Appreciation and flower seed packets in appreciation for their leadership and helping VOR grow.



Top, L-R: John Sullivan, Laura (sister), Colleen Lutkevich. Bottom, L-R: Gladys Sullivan, Jean (sister), Joyce (sister)

## My Sister Jean

By Colleen Lutkevich, Executive Director, Massachusetts Coalition of Families and Advocates (COFAR.org)

My mother was nine months pregnant with me when my older sister, Jean, six years old, was placed at what was then called the Wrentham State School. My other sister was twelve, and my younger sister was born two years after me.

This is the story I grew up with, and it was not a happy one.

At that time, Wrentham Developmental Center (WDC) was a place of last resort. There were really no other options for individuals with intellectual disabilities. From the beginning, my parents were actively involved in the parents association at WDC, and my younger sister and I grew up coloring in the back of the room while they attended monthly meetings. Jean came home with us every Sunday, and that was our routine.

As time went on, conditions at WDC deteriorated greatly. My parents along with several other activist families filed a federal class action lawsuit (*Ricci v. Okin*), resulting in a consent decree that was the beginning of great improvements not only at the newly named WDC, but across Massachusetts. I was a high school student by this time, and the beginning of my advocacy was driving a carload of my friends across a picket line at WDC during a strike in order to provide care for residents when many staff walked off the job.

Under Judge Joseph Tauro conditions improved over the years to the point where staffing and care at WDC is second to none, and my sister resides in her own room in a beautiful cottage on the grounds. All residents at Wrentham now have these excellent living conditions. More importantly, the medical, nursing, and supportive services are excellent, resulting in a quality of life for the residents that could not have been imagined in the 1960's.

Jean is now 61 years old. She is nonverbal, with autism, extremely low intellectual functioning, and many other difficulties. It is my sincere hope that she will be able to live out her life in the comfort and security of Wrentham Developmental Center, among staff and friends who know and love her. I know if her way of life is threatened, this time it will be my sisters and me on the picket line.

## VOR Announces the 2014 Jordy Engels Award Recipients

VOR joins with our Florida affiliate, DSI (Developmental Services Institutions) Supporters ([dsisupporters.org](http://dsisupporters.org)); Ed and Virginia Carraway, VOR Florida State Coordinators; and David and Leni Engels, long-time VOR members, in proudly announcing the recipients of the annual 2014 Jordy Engels Award:

**Mike Fasano**, Tax Collector of Pasco County and retired Florida Senator and Representative; **Greg Giordano**, current communications director and former legislative chief of staff to Mr. Fasano; and **John Stokesberry** who, for more than 40 years, has served people, including people with disabilities, including intellectual disabilities, and the elderly.

Warm congratulations to Mr. Fasano, Mr. Giordano, and Mr. Stokesberry, and sincere gratitude for their many contributions to the field of intellectual disabilities and advocacy. For more information about each of these deserving recipients, visit [vor.net/news/25](http://vor.net/news/25).

## Does VOR have your email address?

Don't miss out on important information. Send your email address to [info@vor.net](mailto:info@vor.net) to receive our weekly e-news publication and action alerts.

# We all can tell the stories and help VOR GROW!!

By Julie Huso, VOR Executive Director

Each and every one of us could write a story about the battles, disappointments and disbelief we have experienced in life. We even could add all the joy, love and the moments that have taken our breath away.

Cherish these joys. It takes only a few moments to sit back, enjoy and be grateful for these times in our lives.

Too often parents, families and advocates struggle to recall or enjoy the successes of our daily battles for our loved ones and their peers each day. We fight together for their safety and well-being, even as we **hear of the many tragedies about abuse, neglect and deaths in Georgia, New York and far too many other states.**

For VOR advocates – you – these outcomes are just not acceptable. That is why VOR is now urging Congress **to mandate a national background checks program** for direct care workers for all Medicaid long-term care homes, while continuing to pursue quality and honor individual and family choice. **Congress must build on existing models and good intentions!**

## TO BE SUCCESSFUL, VOR MUST GROW!

**VOR MUST grow in membership and support!** We **MUST** ask our family members, our neighbors, co-workers and the facilities your loved ones live in to support and join VOR.

For VOR to continue to help the sister in Illinois, or the parents Georgia, or the families in Virginia, or the friends in California, or advocates in your state, **we MUST GROW!!**

Recently, a member stated, “She felt honored that a VOR board member picked up the phone and let her know how important she was to the work we do.” Another member recently stated, “It is so nice to know that you are only a phone call away.”

**VOR is here for you. No other organization is saying or doing what we are!**

**But, we absolutely need your help for a strong and viable future!** Please **spread the word of VOR today and help VOR grow.**

Please consider making a monthly donation to VOR (see form on page 11) and know how much your investment will help.

**Let’s work together and spread the word, stop the abuse and neglect, and support VOR!** We are the only national advocacy organization that is speaking out loudly to protect and ensure quality of care for all people with intellectual and developmental disabilities.

**You, along with every member, are writing the story for VOR.**

**Each and every one of you are standing up for what is right!**

**Thank you for your involvement, commitment, and investment.**



### VOR Monthly Giving Opportunities!

**Monthly giving** helps you make a larger gift over time and it's a safe and reliable way to give!

**Monthly giving** helps VOR to enhance and continue the good work we do protecting all people with I/DD.

**Signing up is easy!!** Just fill out the form found on page 11 of this newsletter and mail, fax or email it to us.

# VOR's 2014 Annual Conference and Washington Initiative: Making it Happen- Reforming Policy and Law in Support of Person-Centered Quality and Choice

VOR's Annual Conference and Washington Initiative, June 7 – 11, 2014, brought together nearly 70 advocates from around the country, bringing them inspiring and informative presentations and providing them the tools to bring our mission and message to each Congressional office.



## Overview of Conference Presentations

### How to Use Olmstead as a Sword, Not a Shield Presented by attorney Bill Choslovsky

For his presentation, Bill drew on his experience as counsel for Misericordia, a private Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) in Illinois, in the *Ligas* lawsuit, a Protection & Advocacy (P&A) class action lawsuit that threatened to close large private ICFs/IID. In that case, he and co-counsel Scott Mendel prevailed, preserving residential choice for thousands of Illinoisans with intellectual and developmental disabilities (I/DD), due to a successful legal and advocacy strategy.

Throughout the *Ligas* litigation, Bill was motivated by the principle that “real choice is a two-way street, not superimposed from above,” a theme he argued is also prevalent in the *Olmstead* decision. Quoting Jack Dempsey, Bill told participants that the “best defense is a good offense,” pointing to legislation, education, popular opinion, and litigation as tools that advocates can use to take the offense in support of choice. *Olmstead* in particular supports the right of every ICF/IID resident to move to a small setting. But every resident also has the right to stay in their ICF/IID home. The real lesson of the *Ligas* victory, said Bill, “is that the real power actually resides with the families and ICF providers.” See Bill’s entire presentation on VOR’s website at [vor.net/images/BillC\\_ICF-Olmstead\\_Presentation.pdf](http://vor.net/images/BillC_ICF-Olmstead_Presentation.pdf)

### Thank you Linda Colley

Kathleen Brown, RN, BA, CDDN, was all set to present at VOR’s Conference when a family emergency prevented her attendance. Linda Colley, RN, CDDN, Secretary-Elect for the Developmental Disabilities Nurses Association (DDNA), answered the call. With very short notice she gave a very informative presentation on the rewards and challenges of serving a patient population with cognitive disabilities, and how residential setting can play a role in delivering nursing care.

### “Is 50 Nifty with 3 Special Needs Children?”

Presented by Kim Stagliano, nationally recognized autism advocate, speaker, author and mom



As our dinner keynote speaker, Kim used milestones in her own life and the lives of her three daughters with autism, to take attendees on a journey of highs, lows and everything in between. Her life is one of extremes – three daughters with autism, each with unique abilities and disabilities, abuse at the hands of a caregiver, times of prosperity and poverty, and through it all a happy marriage. Still, her growth as a full-time advocate, motivated by the individualized and unique needs of each of her daughters, is really no different, she pointed out, than each of VOR’s members and advocates.

Likewise, her concern for the future in a world that seems intent on watering down or eliminating services and expecting families to be perpetual caregivers long after what is reasonable or safe, matches the concerns of VOR families.

There is a silver lining: Families and advocates working together will make the world a more accepting and accommodating place. Advocates for I/DD, autism and other disabilities share the same challenges. We must work together.

“Thank you, VOR! The time in Washington was really valuable to me. I hope to be able to attend next year.” ~ 2014 VOR Conference Participant

### Nursing Study Update

At the request of VOR, the Developmental Disabilities Nurses Association continues its work on a nursing study, looking at health risks to individuals with individuals and developmental disabilities (I/DD) in various settings. Sarah Ailey, PhD, APHN, Community Health Nurse Specialist, who serves as an Associate Professor in the Department of Community Systems and Mental Health Nursing in the Rush University College of Nursing, is leading the effort. Methodology is being considered with a focus on the Health Risks Screening tool (HRST) and how it can be used to gather data associated with level of disability, risks, and care settings.



Kim’s family celebrating her 50th Birthday.

## Panel Discussion: The Future of Our Advocacy in a Changing World



L-R: Gil Fonger, David Hart, Jill Barker, and Peter Kinzler

VOR Board Member Gil Fonger moderated this panel discussion featuring panelists David Hart (Chair, VOR's Legislative Committee), Peter Kinzler and Jill Barker. David focused on the importance of the VOR "brand" and the role every VOR member plays in VOR Awareness, with an emphasis on consistency – using our name and mission properly and consistently. Jill spoke on the continued push beyond "deinstitutionalization" to de-centralizing and de-specializing services and supports— closing anything "congregate" - for people with I/DD, even in states with no "institutions." The future of our advocacy must include focus beyond only "deinstitutionalization" but also respond to an overall attack on anything "congregate" (e.g., community groups homes) and "segregated" (residential communities, sheltered and supported employment, guardianship). Peter spoke on his experience with DOJ in their state and strategies including the effectiveness of unique coalitions.

## Congratulations Sybil Finken and Rebecca Underwood! VOR's 2014 Voice and Advocacy Award Recipients



Sybil Finken and Tamie Hopp

At the 2014 Conference, VOR presented its annual Voice and Advocacy Awards. The 2014 Voice Award recipient is **Sybil Finken**, VOR's Immediate Past President, Secretary, State Coordinator, Committee Chair, and long-time Board Member. Sybil was recognized for her decades of advocacy on behalf of individuals with intellectual and developmental disabilities in Iowa, including her son, Seth, and his peers across the country. For most of her volunteer advocacy career, she has been involved in VOR as a member and leader. She is best known for her no-nonsense approach to our advocacy and her leadership, as well as her wit. VOR is very grateful to Sybil her outstanding leadership over so many years on behalf of people with intellectual and developmental disabilities.

The 2014 Advocacy Award was presented to **Rebecca Underwood**, VOR's Wisconsin State Coordinator, long-time member and volunteer. Rebecca is a strong advocate who is savvy about her own state's process, policy and politics, as well as our federal challenges. She spends a significant amount of her own time and dime attending meetings and conferences to give her son a voice - and that has been to the benefit of our collective advocacy on behalf of all people with intellectual and developmental disabilities. VOR appreciates very much Rebecca's advocacy contributions in Wisconsin and nationally, on behalf of her son, Aaron, and his peers around the country.



Rebecca, Kevin and Aaron Underwood.

## Thank You Annual Conference and Initiative Sponsors! We couldn't have done it without you!

VOR expresses sincere gratitude to our generous 2014 Annual Conference and Initiative Sponsors. Many organizations, individuals and businesses sponsored our event. Without these generous sponsors, our annual event would not be possible. Please take a moment to check out our sponsor list on our website at [vor.net/images/THANKYOUVORSponsors2014.pdf](http://vor.net/images/THANKYOUVORSponsors2014.pdf), **visit their websites and say thanks with words and patronage!**

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Mark Engberg (MD) - In Memory of my sister Mary Beth Engberg  
Bob and Jane Anthony (VA)

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Conway Human Developmental Center Volunteer Council (AR)  
East Central Georgia Family Council (GA)  
Families and Friends of North Lake Supports & Services Association (LA)  
Fairview Family and Friends (CA)  
Friends of Fircrest (WA)  
Massachusetts Coalition of Families and Advocates for the Retarded  
Mt. St. Joseph Association (IL)  
Parents and Friends of Ludeman Center (IL)  
Parents and Relatives of Oakwood Facility (KY)  
Pinecrest Parent Family Association (LA)  
Wisconsin Parents Association for the Retarded

*"Thanks for such an excellent conference. The time and energy spent in organizing this event is much appreciated. All the presentations were relevant, educational, and useful." ~ 2014 VOR Conference Participant*

**The U.S. House of Representatives urges the Department of Justice to factor in choice and individual need in Olmstead actions**

On May 15, 2014, the House passed H.R. 4660, the Commerce, Justice and Science, and Related Agencies Appropriations bill for FY 2015 (the Senate has not yet acted). House Report 113-448 to accompany H.R. 4660 included this language, requiring DOJ to adhere to the *Olmstead* decision when enforcing *Olmstead*:

“*Deinstitutionalization* - The Committee notes the nationwide trend towards deinstitutionalization of patients with intellectual or developmental disabilities in favor of community-based settings. The Committee also notes that in *Olmstead v.*

*L.C.* (1999), a majority of the Supreme Court held that the Americans with Disabilities Act does not condone or require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting, and that Federal law does not require the imposition of community-based treatment on patients who do not desire it. The Committee strongly urges the Department to factor the needs and desires of patients, their families, and caregivers, and the importance of affording patients the proper setting for their care, into its enforcement of the Americans with Disabilities Act.”



**VOR Calls for Direct Care Worker Background Checks to Ensure Safe, Competent Care in all Medicaid Long Term Care Settings**

As part of its 2014 Congressional Initiative, VOR volunteers called on Congress to support direct care worker mandatory national background checks to better ensure a safe and qualified direct care workforce across all long-term care settings and across all states.



The Centers for Medicare and Medicaid Services (CMS) currently offers a voluntary grant program for states to implement background checks. In support, CMS noted that “long term care (LTC) patient abuse, neglect and misappropriation of funds have been identified as a widespread problem for millions of Americans receiving LTC services.”

In the past, Congress has signaled support for added protections. The 2003 Medicare Modernization Act (Section 307) provided for a demonstration program, and the Affordable Care Act’s national background check grant program was even more robust. According to CMS, “both actions point in the direction of potential national applicability.” VOR’s position and additional resources are available at [vor.net/legislative-voice/legislation](http://vor.net/legislative-voice/legislation).

**Senator Tom Harkin introduces bill to expand community-based services**

S. 2515, the Community Integration Act would, introduced by U.S. Senator Tom Harkin (D-IA), would require that states allow individuals who are eligible for “institutional” care (ICFs/IID or nursing facilities) also be eligible to receive home and community-based supports. S. 2515 would also prohibit states from making people ineligible for services in the community based on their particular disability. Senator Harkin will retire at the end of 2014..

**Workforce Innovation Act Passes: Workshop eligibility limited, National Council on Disability changed**

The new federal law will prohibit individuals with disabilities age 24 and younger from working in jobs paying less than the federal minimum of \$7.25 per hour unless they first try vocational rehabilitation services, among other requirements. There are exceptions for those already working in sheltered employment and in cases where individuals are deemed ineligible for vocational rehabilitation. In addition, the law calls for a smaller National Council on Disability (NCD) and a new appointment process that takes sole discretion away from the President and puts some in the hands of Congressional leadership. VOR has been critical of NCD and its bias against individual choice in housing and employment options for people with intellectual and developmental disabilities.



## **New Jersey: In Debate Over Choice, Residents Rarely Heard**

In spite of her severe cerebral palsy, Wendy English can make her own legal, medical and financial decisions, vote in local and national elections, and communicate with the help of a specially programmed iPad. But she can't control the thing she deems most important to her life: the decision to remain in her longtime home.

English, 51, one of about 1,000 people with developmental impacted, doesn't want to move from the Woodbridge Developmental Center, her home for the past 18 years.

Though haltingly delivered, her words offer a rare personal insight in a debate that has been dominated by state officials, advocacy groups, and caretakers who say they know what's best. English had a tumultuous early life, moving 17 times before she was placed at Woodbridge, when she was 33. Her memories of most of those places are grim. Her caregivers often tied her down. She refused to eat. A psychiatric hospital where she spent several years often neglected to bathe her.

"I'm so sorry this closure is happening to her and turning her life upside down after 18 years," said Joanne St. Amand, the president of the Woodbridge Developmental Center Parents Association and VOR Board Member. She has become one of English's closest friends and staunchest advocates. "The anxiety for Wendy of not knowing what was going to happen was unbearable for her." (Disability Scoop, July 16, 2014)

## **Massachusetts: Sheltered workshops for the disabled win big reprieve**

Advocates of employment choice succeeded in securing state support for sheltered workshop opportunities which they say provide invaluable skills and activities for their loved ones with intellectual disabilities. Language in the State's Fiscal Year 2015 budget, signed by Governor Deval Patrick, says that the state must not "reduce the availability or decrease funding for sheltered workshops serving persons with disabilities who voluntarily seek or wish to retain such employment services." The administration had planned to close all remaining sheltered workshops as early as next June. (COFAR Blog, June 14, 2014).

## **New York: Safeguards Must Be in Place Before Closure of Center, Lawmakers Say**

Lawmakers came to a compromise that will slow down the closure of the Broome Developmental Center to make sure safeguards are in place. "We're concerned it's happening too fast and people are transitioning into potentially unsafe settings where workers aren't as trained as we would like. So we've been able to slow up the process, get more oversight, to have greater involvement from our mental health commissioner, and others," said New York Assemblywoman Donna Lupardo (TWC News, June 23, 2014). Lupardo also indicated her intent to encourage federal representatives to back down its urging to slash the number of facility capacity in New York from 700 to 150 individuals, a number she says is "clearly inadequate to serve the needs of the entire state of New York." (WICZ, June 24, 2014).

## **Texas: Uncertain Future at Institutions for Disabled Texans**

A State Sunset Advisory Commission has recommended the closure of 6 of Texas' 13 state-supported living centers, drawing fire from families and some state lawmakers. Supporters of the centers argue that community-based care does not work for everyone — especially people with profound medical and behavioral disabilities. They say closures would be hugely disruptive to the people living there, to their families and to the employees of the facilities, which are often located in remote communities. The State cannot close any of the centers without a legislative directive, so the commission's recommendation will be considered by the Legislature. One lawmaker, State Rep. Lois Kolkhorst, Chairwoman of the House Committee on Public Health, slammed the closure recommendation, calling the Commission's report "inaccurate" and "slanted." In a letter to the Commission, she criticized its report's faulty financial assumptions and the fact it ignored "the systemic and under-reported failures" in group homes. (Texas Tribune, June 3 and July 1, 2014).

### **Tribute**

Thank you to all individuals who requested or gave donations in honor of someone special, or in memory of a loved one. For those who have lost someone special, please accept our deepest sympathy.

#### **IN MEMORY**

Delores Cannon  
Sarah Deffendall  
Edward Dubrowsky  
Mary Wilkes Hedenquist  
Bertha Rose Lambremont  
Lynette Lang  
Jean Ann Loncrini  
Lawrence and Rose Lotzi  
Erin Mahoney  
Ruby O'Donnell  
Mildred Pelan  
Doreen Randall

#### **IN HONOR**

Orian Ruth Adams  
Seth Finken  
Vincent A. Gallaccio  
Julie Huso  
Jolie Jourde  
Paul Keipert  
Frank David Selman  
John F. Spellman

### **State News online:**

Reports from the June 7, 2014 VOR State Report Forum are available at [vor.net/events](http://vor.net/events).

## Georgia: Upon implementing Justice Department settlement, State struggles with care for disabled in community

Since 2010, when the Department of Justice and the State agreed to close all facilities, about three-fourths of the group homes receiving displaced facility residents have been cited for violating standards of care or investigated over patient deaths, abuse or neglect. Forty people died after moving into group homes. At least 30 of those deaths had not been expected. Officials have documented 76 reports of physical or psychological abuse, 48 of neglect, and 60 accidental injuries. In 93 other cases, group home residents allegedly assaulted one another, their caregivers or others. For now, these outcomes have led to a suspension of transfers from state ICFs/IID. About 350 disabled people remain in state hospitals, and many of them have profound medical needs that will complicate efforts to find acceptable homes. (Atlanta Journal-Constitution, June 21, 2014)

## Supreme Court Strikes Down Law Setting Strict I.Q. Limit for Execution

The U.S. Supreme Court has struck down a law used by Florida and other states that set a strict cut-off, based on IQ test scores, to determine eligibility for the death penalty. Justice Anthony Kennedy, who wrote the court's opinion, said the experts who design, give and interpret IQ tests say they reveal only a range — that a person's IQ may be five points above or below the score. For that reason, the court held, defendants must be allowed to present evidence of intellectual disability, beyond IQ, including deficits in functioning over his lifetime.

## VOR's Awareness and Outreach Initiatives Reach Thousands of Families

Over a year ago, VOR formed its Marketing & Communications Committee which has led the organization's efforts to get the word out about VOR's important and unique mission to many more families, advocates, professionals, and public officials.

Hugo Dwyer, Chairman of the Committee, has done a fabulous job steering this effort, emphasizing the expanded and effective use of social media tools, with Cristy Dwyer's help.

The VOR Board also assisted in its approval of a complimentary subscription program — which has resulted in more than 1,000 new advocates receiving VOR's information each and every week — publishing privileges in *Age of Autism* and the use of Salsa, an online advocacy tool, both of which have enabled VOR to engage hundreds more family advocates. Additional awareness opportunities include several articles in *EP Magazine*, regular press releases, a new VOR Press Kit (at [vor.net/about-vor](http://vor.net/about-vor)), an article in the *Nonprofit Quarterly*, and several presentations by VOR Board Members and Julie Huso at meetings and conferences. Awareness, of course, leads to more advocates making our advocacy response that much

more effective. In short, numbers count!

## George Mavridis shares memoir with Conference participants

As we shared in the Winter 2014 issue of *The Voice*, George Mavridis, long-time VOR member, published a memoir of his cousin. "Joanna, God's Special Child," is his thank you to his cousin for bringing out the brother, father and advocate in him for the past 45 years.

George shared his book at the 2014 VOR Conference, even donating a copy for the annual VOR raffle. George has attended VOR's Annual Conference and Washington Initiative for the past decade, often carrying with him a letter "from" Joanna — written by George in Joanna's voice to help Members of Congress and their staff recognize that their work impacts real people with real needs. "Joanna, God's Special Child" is available on Amazon.



## On the web: People as Pendulums

An article by VOR was published in *Nonprofit Quarterly*.

"Pendulums and People:

Deinstitutionalization and People with Intellectual and Developmental Disabilities," explores the history of deinstitutionalization, which initially unified advocates, but as harm and tragedy became apparent, has divided advocates.

You can read the article at [nonprofitquarterly.org](http://nonprofitquarterly.org) or on VOR's website at [vor.net/get-involved/vor-advocacy-letters](http://vor.net/get-involved/vor-advocacy-letters).



Hugo and Cristy Dwyer

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## Membership/Contribution Form: VOR, 836 S. Arlington Heights Rd., #351 Elk Grove Village, IL 60007; by fax 605-271-0445 or donate online @ <http://www.vor.net/online-membership-form>

### Thank you for your dues and contributions!

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Telephone number(s) \_\_\_\_\_  
Fax \_\_\_\_\_ E-mail \_\_\_\_\_

Referred by (if applicable): \_\_\_\_\_

### My contact information has changed.

#### Membership Categories

Individual --- \$40  
Family/Parents' Association --- \$200  
Professional Assoc./Corp. --- \$250

**I would like to make an additional donation to support future efforts of VOR. An additional gift is enclosed for:**

\_\_\_ \$5,000 \_\_\_ \$1,000 \_\_\_ \$500 \_\_\_ \$250 \_\_\_ \$100 \_\_\_ \$ \_\_\_ Other

Checks made payable to VOR, or by credit card:  Visa  MasterCard  Discover

Card Number: \_\_\_\_\_

Amount to charge: \$ \_\_\_\_\_ 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). If 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 Julie Huso at VOR, 605-370-4652 or [jhuso@vor.net](mailto:jhuso@vor.net).

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### I would like to give the gift of a VOR membership to:

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

### **VOR Monthly Giving Opportunities!**

**Monthly giving** helps you make a larger gift over time and it's a safe and reliable way to give!

**Monthly giving** helps VOR to enhance and continue the good work we do protecting all people with I/DD.

**Signing up is easy!!** Just fill out the form found on page 11 of this newsletter and mail, fax or email it to us.

### **Help Increase VOR Awareness!**

In celebration of 30 years, VOR is offering **complimentary, electronic subscriptions** to its *Weekly E-News Update* and *The Voice*, its tri-annual newsletter, through June 30, 2015. To extend this offer to those on your email list, please send the names and email addresses (never sold or shared) to [jhuso@vor.net](mailto:jhuso@vor.net). In addition, we are always excited about opportunities to **present VOR information and issues at conferences and meetings**. Contact Julie Huso at 605-370-4652 or [jhuso@vor.net](mailto:jhuso@vor.net) for more information.