



Sierra - Age 7

Expanding VOR's Horizons Through Vision and Mission

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Your Voice Matters

By Sybil Finken and Ann Knighton, VOR co-Presidents

Using our collective voices can be empowering: *"Hear the voice of the people!"* "Voice" can be used to describe a minority position: *"Some segments of society feel they have no voice."* It can be both, and so it is for VOR.

Together the thousands of members that make up VOR have a very powerful voice for persons with intellectual and developmental disabilities (ID/DD). We are also the most relevant, most important voice: the families of people with ID/DD – people who truly have no voice and who require the compassionate advocacy, decision-making, and voices of their dedicated relatives. While this position is unique to VOR as a national advocacy organization, it is well-founded in law. The Supreme Court and federal laws have recognized individuals and their families as the primary decision-makers.

Our voices matter most – if we use them. Here's how:

1. VOR Membership Survey: Tell VOR's Board of Directors what you think.

All VOR members recently received a VOR membership survey by mail or email. This is your opportunity to provide feedback about VOR, its activities, and its overall effectiveness. **Your feedback will help the all-volunteer VOR Board of Directors develop VOR's Strategic Plan which will be the organization's course in coming months and years.** Please return the survey today. Your voice really matters in this process. "Leadership has to come from the bottom of the pyramid, not the top" (*Time Magazine*, "Person of the Year – The Protester," Dec. 2011).

2. Use your VOICE to carry out our collective advocacy for people with ID/DD around the country:

Your voice matters to the politicians you elect. They will listen when you write, call or visit them, or read your views in media. It is not enough that our issues are so morally compelling that anyone, included elected officials, should support the life-sustaining programs that are so critically necessary to your family member with ID/DD. They must hear from YOU, the voters. Family members own the moral high ground, but only if we use our voices – individually and collectively – to write, call, and visit will we be heard. A great opportunity to use your voice is VOR's Annual Conference and Washington Initiative. Please join us. Details are enclosed.

3. Financial donations to VOR are another way of using your voice

When you donate more than your annual \$40 dues, your donation tells us that you support the continuation and expansion of VOR's good works. Many VOR members contribute more than the minimum and we are very grateful for their added support and vote of confidence. Extra financial donations not only matter, but are critical to maintaining our national advocacy. If you support VOR and our advocacy on behalf of people with ID/DD, please voice your support with an additional donation.

Thank you for working with VOR to speak out for people with ID/DD and their families across the country. Together we must succeed. We appreciate all of you!



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Who is VOR?

VOR is the only national advocacy organization supporting the right of individuals with intellectual disabilities and their families to choose from a full array of residential services and supports, including family home, small settings, and licensed facilities.

On The Cover:

Artwork by Sierra, age 7

2012 Annual Conference and Washington Initiative

Agenda and Information

June 9-13, 2012

All VOR meetings will take place at the Liaison on Capitol Hill, 415 New Jersey Ave., NW, Washington, D.C.

Saturday, June 9, 2012

VOR Annual Board Meeting 1 – 3 pm

VOR members welcome to attend. Time will be provided for member comments and questions.

Reports from the States 3:30 – 5:30 pm

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

Networking and Hospitality Room 5:30 pm

Join VOR board members and staff for an informal reception. Light snacks and beverages will be provided.

Sunday, June 10, 2012

VOR 2012 Annual Conference, Legislative Briefing and Dinner Event **Expanding VOR's Horizons through Vision and Mission**

Agenda

12:00 pm: Registration: Network with families from across the country.

1:00 pm:

- President's Address, Ann Knighton
- Installation of Officers and Introduction of Board Members
- Voice Award – Rep. Barney Frank

2:00 pm: Keynote Speaker, Sam Brock, Anchor/Reporter at CBS 6 (WTRV, Richmond, VA): A Journalist's Observations
- Why Virginia is falling short and what can be done to improve coverage of the crisis.

3:30 pm: Legislative Briefing

- Legislative Advocacy, Speaker TBD
- Initiative Issues Panel: Peter Kinzler, Larry Innis, and Tamie Hopp
- Distribution of Leave-Behind Folders

5:30 pm: VOR Reception with cash bar

- Entertainment

6:30 pm: Dinner

- Keynote address: Dr. Terry Kopansky, Executive Director, Mur-Ci Homes (an ICF/MR in Antioch, Tennessee)

The Week of Monday, June 11, 2012

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. Please plan time to cover your state's Congressional Delegation.

Monday and Tuesday, June 11 and 12, 2012

Informal De-briefings 6:30 – 8 pm

Reports by state spokespersons regarding Congressional visits.

For hotel and transportation information, see page 11. To Register for this event, see page 12.

Thoughts on Life with Jordy – A Younger Sister's Perspective

By Marlo Engels

I have often been asked, "What was it like having a sibling who was so profoundly handicapped?"

My answer? It didn't feel like anything unusual. For me it was completely normal. People might think that sounds like an odd answer, but because I was born 3 years after Jordan ("Jordy") I simply accepted that he was, the way he was. He was just Jordy - what did I know?

My brother couldn't talk or walk, eat or drink on his own, he couldn't hold something in his hands and play ... truthfully he could 'do' absolutely nothing, because he only functioned at the level of a 1 month old baby. But Jordy could smile! And make giggling sounds - sometimes. And we loved that. I think Jordy had the sweetest smile

I have ever seen. There is a picture of his smiling face that is taped to my night stand and every night before I go to sleep, I look at him and smile back.

Jordy needed to live where a qualified nursing staff could look after him 24/7. My family and I visited him as often as we could. Sometimes we would put on Elvis Presley music and watch our little guy rock from side to side! When I was a teenager I tried to play whatever current music was popular - NSYNC, Britney Spears, Christina Aguilera... you name it, I tried it, but nothing could get Jordy moving like Elvis... it was amazing to watch.

A couple of times during the year we arranged for Jordy to come home to visit. I loved that. On those mornings I remember waking up, being giddy and ecstatic with anticipation. I paced all around the house and when that got to be too much for everyone, I'd go outside to sit on the sidewalk until I saw the van coming down the street. I wanted to be the first to greet Jordy with lots of hugs and kisses. But my sweetest memories of Jordy are the times when I was just laying down, quietly, beside him. Whether I snuck into his bed or laid down with him on a blanket on the floor, it was rubbing our noses together, snuggling close to his silky, soft skin and holding his delicate hands, that made the memories I will treasure forever.

Shortly after Jordy passed away I told my mother that when the time comes for me to have children, I would like to honor his life by using his initials to name my first born son. My sister gave me a bracelet that bears Jordy's initials. I never take it off.

Jordy was different than most brothers. But being Jordan's sister was my normal. We had a different kind of bond, a different kind of love than most sibs, but it was our normal... and it was precious to me.



Carly, Jordan, and Marlo Engels, 1989.
(Correction: In the last issue of *The Voice*, this picture's caption incorrectly referred to Marlo as Margo. Our apologies).

From a Reader:

"[Bill], I think your work with this organization (and others) on your sister's behalf is wonderful. I thought your article was heartfelt and sincere with a strong message for parents/siblings who are new to the difficulties and heartbreak of mental retardation. I can't begin to imagine the challenges you and your brother face to ensure your sister's continued care and the financial issues you deal with. My 'hat is off' to you both and I wish you and all the other parents and legal guardians success in educating people and gaining support for family members like Joyce."
(Judy to Bill Ryerson)

Virginia Families Ask Federal Judge for a Voice in Court

On March 2, residents of the five Virginia Training Centers which are the target of a Justice Department (DOJ) and Virginia proposed settlement agreement petitioned a federal court to allow for intervention. The Proposed Intervenor argues that they have a “meaningful and concrete interest in their own care” and point to DOJ’s claim that appropriate care can only be provided in small settings and Virginia’s plan to close training centers to meet the terms of the proposed settlement as justification for intervention. “The settlement agreement, if approved, will impair or defeat the rights of the proposed intervenors to choose ICF/MR care,” argue the Proposed Intervenor, citing *Olmstead*.

1,200 deaths in NY group homes

More than 1,200 deaths in the past decade have been attributed to either “unnatural or unknown” causes, according to data obtained by *The New York Times*. New York has made little effort to track or thoroughly investigate the deaths to look for troubling trends, resulting in the same kinds of errors and preventable deaths due to choking, falling, eloping, drowning and other preventable causes, over and over, revealing disturbing patterns (Nov. 6, 2011). In March 2011, *The Times* also revealed that the State’s far-flung network of small group homes operates with scant oversight and few consequences for abusive employees. There has been little or no response to these reports by the federal agencies charged with protecting vulnerable citizens.

Arkansas gets limited suit repayment from DOJ

In 2009, the Justice Department (DOJ) sued Arkansas alleging that Conway ICF/MR violated residents’ federal rights by not offering community options. DOJ lost the lawsuit in 2011. The ruling, pointed to strong support of families for Conway’s care of their profoundly disabled family members as one factor for dismissing the lawsuit. With its solid victory, the State sought reimbursement from DOJ for \$4.3 million in legal fees. Though the Judge found DOJ’s claims “troubling,” they were not “frivolous,” court costs for \$150,585, however, were reimbursable. “[At least] he agreed families in Arkansas have a right to choose which setting their loved ones should get care in, and that is so important,” said an Arkansas spokesperson.

With their Motion to Intervene, residents also filed a Motion to Dismiss the case, arguing that DOJ does not have standing. “DOJ received limited authority from Congress” to enforce existing federal rights, but the case must be filed under the Civil Rights for Institutionalized Persons Act (CRIPA). Because DOJ only alleges violations of the Americans with Disabilities Act, DOJ lacks standing argued the residents.

VOR, which has called the DOJ and Virginia settlement an “alarming and likely dangerous prospect for Virginia’s most fragile citizens,” applauds the families’ action. A detailed summary, press release and the families’ court filings are available at vor.net/get-help/legal-resources.

Georgia/ DOJ settlement, deaths spark protest and family concerns

Advocates are decrying at least four patient deaths among those moved from Georgia institutions into the community, including two residents from the Gracewood ICF/MR. A DOJ Settlement from October 2011 requires that at least 150 residents with ID/DD be moved out each year. Families, who were not party to the settlement, have been speaking out about their concerns. They are not surprised to hear that people have died and predict more tragedy. “We keep trying to explain to them, over and over, that these places cannot attend to our children like they should because they don’t have the resources and they don’t have the skills to do it,” said Theresa Senior, an officer of the Gracewood family association. An independent reviewer hired to oversee the settlement’s implementation confirms concerns. While finding compliance with the “no admission” and discharge requirements, the reviewer’s report also cited “unsafe practices,” concerns about self-medication, and the use of psychotropic medication without adequate consent, in a sample of individuals who had transitioned from facility settings. With forced community placements, these concerns are “tragically predictable.” (Source: *Augusta Chronicle*, Jan. 20, 2012).

VOR and 92 families file Amicus Brief in Pennsylvania case; ask court to overturn settlement

VOR and 92 individuals filed an *Amicus Curiae* brief in support of nine appellants (families of Pennsylvania’s ICFs/MR), seeking to overturn a class action settlement initiated by five named plaintiffs (represented by Protection & Advocacy) and the State of Pennsylvania (*Benjamin v. Pennsylvania Department of Welfare*). The named plaintiffs in this action seek to transition from ICFs/MR.

See 92 Families and VOR on page 10



VOR Calls on Congress; urges moratorium of closure lawsuits

VOR has urged Congressional members in several states to call for a moratorium of federally-funded deinstitutionalization lawsuits. VOR's call for a moratorium was prompted by ongoing reports by the *New York Times* of 'unnatural or unknown' deaths, abuse, neglect, and financial fraud perpetrated on New York's most vulnerable citizens with intellectual and developmental disabilities. Citing the "enormity of the human tragedies taking place in New York and other states," VOR has urged Members of Congress to respond by calling on these federal agencies to halt closure lawsuits until Congress has had time to investigate how these problems occurred, determine what changes in federal policies are necessary to protect the lives of people with ID/DD who reside in the community, and decide if changes are needed in federal policy to guarantee residential choice to the residents of facilities for people with ID/DD. "Reports of people with profound disabilities experiencing harm and death after being displaced from specialized settings are frighteningly predictable," said Tamie Hopp of VOR, citing a bibliography of similar reports from around the country (see, vor.net/abuse-and-neglect). VOR will continue to press for Congressional action.

H.R. 2032: Update and Action Needed

If passed, H.R. 2032 will help restore the decision-making authority of ICF/MR residents and their legal representatives (usually close relatives) in certain lawsuits which threaten to close their ICF/MR homes. As it stands now, the federally-funded lawyers filing these lawsuits do not consult the affected residents or their legally appointed representatives and who, upon learning of the lawsuit, strongly object. These federally-funded lawsuits have closed specialized homes, displacing thousands of fragile citizens with ID/DD, and causing harm and even death to many.

H.R. 2032 now has 67 cosponsors and has never been closer to House Judiciary Committee consideration. **Here is how you can help.** If your U.S. Representative is not already a cosponsor, seek his/her support. In addition, ask your Representative (whether or not a cosponsor) to contact Judiciary Committee Chairman Lamar Smith (R-TX) and Holt Lackey, Counsel to Chairman Smith, in support of Judiciary Committee action on H.R. 2032. For more information, including a list of current cosponsors, position papers, contact information for Congress and more, contact Tamie Hopp at thopp@vor.net or 877-399-4867, or visit vor.net/legislative-voice/action-alerts.

VOR Calls for Objective Evaluation of DD Act Programs

In a federal comment submitted in January, VOR strongly urged against self-reporting performance evaluations that have been ineffective in revealing widespread DD Act grantee abuses. Comments were sought by the Administration for Children and Families, which includes the Administration on Developmental Disabilities' (ADD) grant programs such as Protection and Advocacy and DD Councils.

VOR noted that existing "self-audits" have not addressed the difficult question of whether small settings are prepared to safely care for all individuals with profound ID/DD. DD Act grantees proceed to push for ICF/MR closures regardless of outcome and irrespective of individual choice and need, and without regard to family input. VOR's comment is available at vor.net/images/VORCommentDDActEvaluationJan2012.pdf.

See Legislative Update continued on page 10

Join VOR advocates from around the country in Washington, D.C.
June 9-13, 2012

Join us to help secure Congressional support for federal lawsuit reform (H.R. 2032) and DD Act program reform. Details about VOR's Annual Conference and Washington Initiative are enclosed. A registration form is on page 12.

If not us, who?

**Invest in Choice.
Invest in VOR.**

- ✓ VOR issues action alerts and hosts an annual Initiative to connect family voices with Congress and other key officials.
- ✓ VOR calls for a moratorium on lawsuits and Congressional investigation.
- ✓ VOR's DD Act Advocacy project seeks Congressional reform and oversight; speaks out against ineffective self-reporting by DD Act programs.
- ✓ VOR pushes to pass H.R. 2032 to restore individual and family/guardianship decision-making in federal DOJ and P&A actions to close ICFs/MR.
- ✓ VOR files amicus briefs in support of choice in federal court.

**Invest in choice.
Invest in VOR.**

Grass-tops and Grassroots Advocacy: It takes both

By Tamie Hopp, VOR Director of Government Relations & Advocacy
thopp@vor.net * 877-399-4867

VOR epitomizes the definition of a *grassroots* organization. Our greatest strength comes from the collective voices of our dedicated volunteer members. VOR also employs “grass-tops” advocacy to maximize our impact. “Grass-tops” advocacy is the mobilization of people with a close personal connection to the decision-maker, usually an elected official.

“The more familiar grassroots approach identifies a large group and urges them to blast decision-makers with a message demonstrating popular support for an issue. Grass-tops, however, stealthily seek out influential local community leaders or personal friends . . . to make the case directly. As both attempts become more sophisticated, the lines between the two are increasingly blurred, making it difficult to tell where one approach ends and the other begins. They’re rarely used in isolation.” (*Politico*, June 28, 2007)

In sum, quantity and quality counts. VOR relies on our *grassroots* to speak out in one voice, with one message of choice. We issue action alerts that contain talking points, templates and contact information. We host our Annual Washington Initiative so that individuals can bring our shared message to Congress.

VOR also leverages our *grass-tops* potential by enlisting constituents or state leaders (or, ideally, both) to share their personal stories with target lawmakers. Credible “emotion moves politics,” and if you can combine that with a personal contact or constituent, “that’s what moves the needle.” (*Bonner & Associates*, 2007).

Just as VOR has always preached, relationship building (grass-tops) is a valuable investment of time that will pay dividends with patience and persistence, just as demonstrating popular support for an issue does (grassroots).

“Sometimes that means a letter-writing effort involving our entire membership. Other times that means quietly leveraging the relationships we have cultivated over time” (*The Voice*, Spring 2011).

Myth Busting: Nonprofits CAN Lobby!

The IRS expressly allows 501(c)(3)s to lobby up to a certain dollar limit each year. The limit on lobbying expenditures relates to the size of the organization and most 501(c)(3)s, including VOR, file a simple 501(h) form which indicates they will stick to the limit and report annually how much they have spent on lobbying.

“Getting involved in the legislative process and having a say in policy discussions is not just an appropriate role for non-profits; it is vital.” (American Bar Association, April 2009).

Grassroots, Grass-Tops and the VOR Annual Conference and Washington Initiative

The VOR Annual Conference and Washington Initiative is our pinnacle event that combines grassroots and grass-tops advocacy with proven success. It brings together our grassroots volunteers and provides them with the tools to bring our shared advocacy message to every Congressional office. Coordinated with contact from constituents back home, the Initiative packs both a grassroots and grass-tops punch.

Our overall success depends on the participation of our members, both in D.C. and back home.

Please consider attending VOR’s Annual Conference and Initiative. **Numbers really do count.** We need “all hands on deck” in Washington, D.C. to maintain the relationships we have worked hard to build over the years. We need many volunteers to help carry out our grassroots event with success. **Please consider attending.** All details are included this newsletter. **Register today (see p. 12)!** And, if you can’t make it, consider sponsoring another participant from your state.

See you in D.C.!



ATTENTION GRASSROOTS! Does VOR have your current e-mail address?

If you do not receive the VOR Weekly News Update publication, then chances are we do not have your current e-mail address.

Help us update our email records by emailing your current email address to info@vor.net.

THANK YOU!

VOR and You!

By Julie Huso, Executive Director

One of VOR's most important assets is each of you - a group of individuals that unite together to protect the rights of your family members' with intellectual disabilities. Together we fight for the right to choice and the right to have our voices heard to make a difference.

VOR is nothing without each of you. Recently, members received a survey asking for input and opinions. If you have not already, please take the time to complete this survey. The volunteer VOR Board of Directors truly care about your opinions and will work together to prepare a strategic plan for VOR.

Throughout this edition of *The Voice* you will be informed of the importance of attending the VOR Annual Meeting and Initiative, June 9-13, 2012 in Washington, DC. Collectively we can make a difference while in our nation's capital. You may notice a slight increase in this year's registration fee. We recognized that the cost to travel is expensive and also that the number attending every year has declined a little bit. With that in mind we opted to hold our Annual Conference on Sunday to eliminate one night hotel stay, which will save participants about \$240 at the Liaison. In the past we have also had a "networking" dinner on Saturday night at various locations at a cost of \$40 to \$50 which most participants attended. This year, that cost is rolled into the conference registration fee because the conference includes a dinner with a keynote speaker. We will also arrange this year's dinner so that a board member will be present at each table to provide all attendees an opportunity to maximize networking with VOR leaders and other attendees.

Thank you for your generous support!

I would like to thank each of you who continue to support VOR financially above and beyond your membership dues! A good example of this generosity is the recent gift from Bob and Jane Anthony in recognition of the hard work VOR is doing and continues to do in Virginia in preparing the fight against DOJ! Please, take a moment and consider what extra financial support you could offer so VOR is positioned to continue to assist you and your loved ones!

See you in Washington, DC!



"Thank you VOR for helping Virginia families in our fight against DOJ and Virginia. Here's a donation to show our appreciation."
~ Jane and Bob Anthony

TRIBUTES

Thank you to all of the 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

Anne Golden
Apolonia Amador
Martin, Ellen, & Nancy Pratt
Robin Sims
Mary Constance Poritsky
Les Abbot
Edward Dubrowsky
Bill McGuire
Amelia "Molly" Thomas
Tony Loiercino
Paul Heckt
Joanne Bezubka
Harold D. Hubbart
Mary Louise Myers

In Honor

Judith & Duane Dyer
Seth Finken
Sybil Finken
Anthony Pederzani
Timothy Callahan
Tamie Hopp
Bill Burke
Beth Milley
June Davis
Jackson Finken

In Appreciation

To VOR for all VOR's hard work in Virginia
in response to the VA/DOJ settlement

VOR Board of Directors

Ann Knighton (GA), Co-President
Sybil Finken (IA), Co-President
Bill Ryerson (NC), First Vice President
Barbara Cukierski (IL), Treasurer
David Swain (NV), Secretary
Jill Barker (MI)
Brian Boxall (CA)
Patricia Crawford (NE)
Mary Kay Cowen (LA)
Geoff Dubrowsky (NJ)
Elbirda Haley (KY)
Steve Johnson (CA)
Mary McTernan (MA)
Mary O'Riordan (CA)
Marilyn Straw (IA)

2012 Annual Conference and Washington Initiative

Sponsorship Opportunities

June 9-13, 2012

All Sponsors and Vendors will receive recognition in VOR's Website, Newsletter and Weekly E-Mail Update

Vendor Opportunities

Fee:

\$350 – if payment is received by March 1, 2012

\$400 – if payment is received after March 1, 2012 (no information listed in program if received after May 1)

Vendor Sponsor Benefits and Recognition: Each Vendor Sponsor will be listed as an exhibitor with organization contact information in a conference program and applicable signage at event. Vendor sponsors will also be able to promote their businesses **via an email alert will that reach thousands of advocates and organizations**, in addition to being listed on VOR's website and being recognized in a VOR Weekly E-mail Update.

Sponsorship Opportunities

Platinum Sponsor - \$10,000 and Above

- Full-page ad in conference program and signage recognition
- Opportunity to address conference attendees
- Will receive 6 guest passes

Gold Sponsor - \$7,500

- Half-page ad in conference program & signage recognition
- Will receive 4 guest passes

Capitol Hill Reception Sponsor - \$5,000

- Half-page ad in conference program & signage recognition
- Will receive 3 guest passes

Silver Sponsor - \$3,500

- Quarter page ad in conference program & signage recognition
- Will receive 2 guest passes

Bronze Sponsor - \$2,500

- Recognition in conference program and signage recognition
- Will receive 2 guest passes

Equipment Sponsor - \$1,500

- Recognition in conference program and signage recognition
- Will receive 1 guest pass

Dinner Table Sponsors - \$500 (Need 10 Sponsors)

- Recognition in conference program and signage on tables
- Will receive one lunch voucher

Break Sponsors - \$350 (Need 5 Sponsors)

- Recognition in conference program and signage on tables
- Will receive one lunch voucher

Session Sponsors - \$250 (Need 9 Sponsors)

- Recognition in conference program and signage on tables
- Will receive one lunch voucher

Participant Sponsor – This cost is variable and assists those who wish to attend with additional funding to help cover costs

- Recognition in conference program and signage on tables

Deadline for sponsor listing is May 1, 2012

Please email camera ready ad to
Julie Huso
jhuso@vor.net
Or call 605-370-4652

Name of Organization: _____

Contact: _____

Mailing Address: _____

Telephone: _____

E-Mail: _____

Name(s) of Additional Person(s) Attending (Name & Title):

VOR cost rebuttal resources available to counter claims that closure will save money

In Alabama, advocates lost Partlow Developmental Center despite efforts to save it. The closure was pursued by the Governor, in part, due to state budget shortages. In Illinois, Governor Quinn has called for the displacement of 600 people from state-run ICFs/MR in just 2.5 years, with the first closure proposed as early as October, citing facility upgrade costs and expected cost savings. In Oklahoma, New Jersey, and Missouri state officials and lawmakers are considering proposals to close one or more state-run ICF/MR, with hoped for cost savings being central to these discussions. Yet, research and experience shows that closing specialized care settings for people with intellectual disabilities will not save money and will result in lost revenue, unless the health and welfare of the displaced residents are also compromised. Family advocates are fighting back in states, working to arm officials with accurate cost comparison information. Through family and legislature “toolkits,” available on VOR’s website, advocates and policymakers are armed with credible and compelling information, including research and lessons learned. For more information visit www.vor.net, or contact Tamie at thopp@vor.net or 877-399-4867.

Missouri: Families oppose closure study bill and call for reversal of “no admission” policy

“We are extremely alarmed at the relentless efforts to close habilitation centers [ICFs/MR],” Mary Vitale, president of the Bellefontaine family association and VOR State Coordinator, testified in opposition to a bill that would transfer residents to smaller settings. “The very specialized care and services my brother receives at the Bellefontaine Habilitation Center has allowed him to attain and maintain his highest God-given abilities. The only reason he is alive today is this specialized care.” Vitale also took issue with alleged cost savings, noting that State’s community cost of living estimates are incomplete. Dental, medical, therapies, transportation costs, room and board, and day programming costs are included in calculating habilitation costs, but not in community costs. Earlier this year, families also challenged the state’s “no admission” policy which worsens the state’s large waiting list, artificially increased costs, and reduced federal funding.

From a Reader:

“Ann Knighton’s ‘Excerpts from a Diary’ brought back [memories]. Your diary entries so closely echoed so many of my thoughts and feelings during that time [I placed my daughter]. I am very thankful for your life of dedication to the people with ID/DD. I’m sure that there are thousands who are better because of your advocacy. I am very grateful for your life.” (Eadie, TX)

Oklahoma: Families and workers present proposal to save centers

To avoid closure, a 20-year bond, excess land sale funds, private donations, and federal and state funding are part of the broader plan proposed by families to gradually phase out all current, aging structures and replace them with eight-resident housing units over a period of years. This gradual upgrade is financially sustainable and would maintain the residents’ long time homes and specialized care at Southern and Northern Resource Centers, Oklahoma’s ICFs/MR. For complete details, visit the Toolkit for Families section on VOR’s website.

Legal Briefs, continued from page 5

92 Families and VOR

Appellants and VOR oppose the plaintiffs’ attempt to impose their choices on appellants through an overly-broad class of plaintiffs that includes all residents with profound ID/DD and a settlement which could render closure inevitable. Even the District Court expressed concern about the problematic provisions which interpret silence as consent. “The solution is not to move everyone from one type of facility to another,” argued VOR. “This is not only in direct contravention of *Olmstead*, but will cause unspeakable harm to those in need of ICF/MR care.”

VOR Contact Information

Executive Director

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Director of Govt. Relations/Advocacy

Tamie Hopp
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Rapid City, SD 57709
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Washington, DC

Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 phone/fax
LarryInnis@aol.com

Membership/Contribution Form or donate online @ www.vor.net/online-membership-form

Please send dues to: VOR, 836 S. Arlington Heights Rd., #351 • Elk Grove Village, IL 60007 • FAX 605-271-0445

Thank you for your dues and additional contributions!

I would like to give a VOR membership to:

Name _____	Name _____
Address _____	Address _____
City _____ State _____ Zip _____	City _____ State _____ Zip _____
Telephone number(s) _____	Telephone number(s) _____

E-mail _____

E-mail _____

☐ My contact information has changed.

I would like to make a gift in ☐ honor ☐ memory of:

Membership Categories

☐ Individual --- \$40

☐ Family/Parents' Association --- \$200

☐ Professional Assoc./Corp. --- \$250

Name _____

Address _____

City _____ State _____ Zip _____

Checks made payable to VOR, or by credit card:

☐ Visa ☐ MasterCard ☐ Discover

Card Number: _____ Expires: _____ CVC (3-digit Security) Code: _____

Amount to charge: \$ _____ Signature: _____

I would like to make an additional gift to support future efforts of VOR.

☐ \$5,000 ☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 Other \$ _____

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information, so please call if \$40 per year poses a financial hardship. Feb12NL

2012 Annual Conference and Washington Initiative

HOTEL INFORMATION

The Liaison on Capitol Hill

415 New Jersey Ave., N.W. Washington, D.C. 20001

Reservations due by **May 11, 2012**

All Conference, Dinner and VOR Meetings held at the Liaison on Capitol Hill

Roommates, if possible, upon request

Reservations -

by Phone: **866-233-4642**

by E-Mail: reservations@affinia.com

Online: <https://gc.synxis.com/rez.aspx?Hotel=19828&Chain=5158&group=VOIR12>

Group rate is \$199 for single or double, plus tax, per night. To receive group rate, mention VOR or provide this **Reservation ID: VOIR12**.

TRANSPORTATION INFORMATION

Taxis and "Super Shuttle" vans are available at Reagan International Airport, the closest airport to the Liaison. "Super Shuttle" is \$15 per person (\$11 each additional passenger). At the airport follow signs to "Ground Transportation." Super Shuttle reservations are required only from the hotel to the airport (800-258-3826). Union Train Station is just 3 blocks from the hotel.

For more information please contact Tamie Hopp at 605-399-1624 or thopp@vor.net.



836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
877-399-4867 toll free
605-271-0445 fax
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*

Annual Conference, Legislative Briefing & Dinner (Sunday, June 10, 2012)

Registration Form – Return to VOR

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

Fax: 605-399-1631 • thopp@vor.net • Phone: 877-399-4867 (toll free) or 605-399-1624

Name(s) _____
Address _____
City, St, Zip _____
Home Phone _____
Work Phone _____
Email _____
Sponsoring Organization: _____

ANNUAL CONFERENCE REGISTRATION

Fee includes all Sunday, June 10 events including conference registration, plated dinner, evening speaker and entertainment.

VOR Members:

- _____ \$100 per member if paid by **April 1, 2012.**
- _____ \$110 per member if paid by **May 1, 2012.**
- _____ \$125 per member if paid after **May 1, 2012.**

Non-VOR Members:

- _____ \$125 per person for **non-member** if paid by **May 1, 2012.** Fee includes 1 year membership.
- _____ \$150 per person for **non-member** if paid **after May 1, 2012.** Fee includes 1 year membership

INITIATIVE REGISTRATION

_____ I/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.

Amount to Charge: _____

Charge card: ☐ MC ☐ Visa ☐ Discover

Expiration date: _____
Credit Card Number: _____
3-Digit Security Code (back of card) _____
Signature _____