

Finding *and keeping* our seat at the table

By Robin Sims, President

Happy New Year to All!

As many of us continue to dig out from the snows of winter it is time to think about the hot days ahead of us in Washington in June.

VOR's Annual Conference and Washington Initiative begins on June 4, 2010. I hope that many, many members – even more than in past years – will take advantage of the opportunity to meet fellow members and feel the power of grassroots advocacy as we go on the Hill. You will find information about VOR's event in 2010 throughout this newsletter.

VOR's annual event has helped increase our credibility as advocates. Our collective participation in the past has helped secure and preserve VOR's "seat at the table," by bringing a message to policymakers that is credible and right.

The VOR presidents who preceded me did an outstanding job securing and preserving VOR's spot at the table. I'm doing everything I can to preserve existing relationships while also identifying many new doors to open. Already this year, VOR has met with DOJ officials, attended a Special Olympics conference, been represented at a Families USA event, presented comment at an HHS Listening Session, and participated in an Office on Disability Stakeholder meeting.

This level of access is amazing for an all-volunteer group like ours, and our Annual Conference and Washington Initiative is a critical

part of our access success. Indeed, it is at this annual event, with all of us in one location speaking with one voice, where we do our most amazing work.

Please Join Us in Washington, D.C.!

I know that coming to Washington is a great commitment of both time and money. Please speak to

Our commitment to openness... means recognizing that government does not have all the answers, and that public officials need to draw on what citizens know.

President Barack Obama, 01/21/2009

your local organizations about sponsoring you or having a fundraiser to ease the financial burden. You are going as their voice and your presence at the table makes a difference. If you cannot go, but have a family member willing to come in your place, get them involved.

VOR makes sure that everyone is well-prepared when they go on Capitol Hill and it is an amazing experience. Those of you who have

done this many times know that access to Members of Congress and their staff makes a difference as issues are brought

forth. They have a great respect for VOR members and know we are coming as true grassroots advocates and not paid advocates. Congress notices our amazing and unquestionable dedication. Your volunteer efforts in maintaining re-

We deal with a lot of myths and we bring the truth to those myths through our advocacy efforts.



Robin Sims

lationships with your local and national representatives are the reason we have the success we do.

We deal with a lot of myths and we bring the truth to those myths through our advocacy efforts. We have earned our place at the table. Let us all gather together in June and bring our unique voice to those who need to hear it. *See you in June!*

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VOR MISSION STATEMENT

The mission of VOR is to unite in advocacy, educate and assist families, organizations, public officials, and individuals concerned with the quality of life and choice for persons with mental retardation within residential options including home, community-based options and facility-based care.

Welcoming *In* 2010!!

at The Liaison on Capitol Hill and the dates are June 4-9, 2010.

This event provides a wonderful opportunity to network with other VOR members. One of the additions we have made to the schedule of events is to provide a VOR Member Forum. This will provide participants with the opportunity to visit directly with the VOR Board of Directors; I know each of them welcome your input.

This edition of *The Voice* includes detailed information on how you can take part in the Annual Conference and Washington Initiative. In addition to registration information (last page), we have also included information regarding individual or organization sponsorship opportunities, and for the first time, VOR is also offering you the opportunity to recognize your organization or business in the VOR Conference Program. You can find information on these opportunities at www.vor.net/events/.

About Your Membership

For 27 years VOR has maintained its annual dues at \$25 for individual memberships, even as mailing costs and the expenses of doing business have dramatically increased. We've opted to keep dues at just \$25 to help ensure our outreach efforts are as inclusive as possible. We do ask and hope that those of you who can afford to help VOR's mission and vision contribute generously and look at the \$25 mem-

bership as only a starting point.

It is the commitment and generosity of our membership that keeps our Voice a crucial part of the national scene advocating for choice in residential options for all of our families. There are many ways to support VOR: Membership, donations, Annual Conference sponsorships and recruiting new members. We welcome your involvement; this is your organization.

Online Giving!

Members and donors can now, online, pay membership dues, donate and register for the 2010 Annual Meeting and Initiative by visiting www.vor.net.

It is clear that each and every one of you is facing issues in your states and you are continuing to work diligently to protect your loved ones' rights. Keep up the good work and know that VOR is here for you. Tamie Hopp, director of government relations and advocacy, does a wonderful job responding and assisting in times of need. I would also like to offer thanks to VOR's president, Robin Sims, for all her loyalty, dedication and hard work on behalf of VOR. She is truly inspiring!!

I have said this numerous times before but we could not accomplish the many things we do if not for you! *THANK YOU* and I look forward to seeing you in June.

Questions for Julie? Contact her directly at 605-370-4652; or husoj@sio.midco.net.



Julie M. Huso

As the calendar year for 2009 came to a close it was clear that VOR members remembered us as one of their choices for year-end giving. In today's society there are many good causes that need our help; **thank you** very much for making VOR one of your choices.

VOR Annual Conference & Initiative

VOR is now busy making plans for our 2010 VOR Annual Meeting and Initiative. We will once again be

VOR Board of Directors

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Executive Director's Message February 2010

H.R. 1255 Update

H.R. 1255 continues to garner impressive support in Congress. To date, 75 U.S. Representatives have cosponsored H.R. 1255 (34 Democrats; 41 Republicans).

If passed, H.R. 1255 will restore individual and guardian decision-making rights in class action lawsuits filed by federally funded lawyer organizations (such as P&A) against federally licensed ICFs/MR.

To see a list of current cosponsors and learn more about this important bill, visit VOR's website at: www.vor.net/legislative-voice/legislation/.

VOR raises concerns about DOJ "Olmstead enforcement"

On January 15, 2010, VOR President Robin Sims sent a letter to Kareem Dale, Special Assistant to the President for Disability Policy, expressing "serious concerns about statements and actions by the United States Department of Justice (DOJ) Civil Rights Division with regard to its positions and initiatives relating to 'Olmstead enforcement.'"

VOR's letter was prompted in response to DOJ pronouncements that "Olmstead enforcement" initiatives to achieve community integration would be intensified. In VOR's letter, Ms. Sims expressed VOR's grave concern that DOJ was "motivated by an ideology against federally-licensed Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) that is not in the best interests of the residents, is not supported by the residents' family members and guardians and is not supported by law, including *Olmstead*."

In conjunction with the letter, VOR also arranged to meet with Tom Perez, who heads up DOJ's Civil Rights Divi-

sion. At the January 29 meeting, Ms. Sims and Peter Kinzler, chairperson of VOR's Legislative Committee, expressed again VOR's concern that *Olmstead* was being incorrectly used as a sword to displace residents from ICFs/MR and questioned whether DOJ could help address well-documented quality of care concerns in community-based settings.

DOJ officials stated that it was not the Department's intent to close all facilities, noting that they object to displacing residents from licensed care to inappropriate or nonexistent community alternatives. They noted that the Civil Rights Division is charged with addressing ADA (Americans with Disabilities Act) violations, including, they believe, quality of care concerns in the community. VOR also received assurances that we would be included in future DOJ stakeholder meetings.

VOR addresses proposal to change "mental retardation" to "intellectual disabilities"

In response to S. 2781, legislation which proposes to change references to "mental retardation" to "intellectual disabilities," in federal law, VOR's Government Affairs Committee prepared a statement which supports the spirit of the legislation, but urges caution:

"We are concerned because the sources used to define 'mental retardation' in current law and practice are varied and in flux, and there is some question whether S. 2781 reaches all federal laws and regulations, and their interpretations. The unintended consequences of S. 2781 could cause people in need to fall through the cracks due to a very well-intentioned stroke of a pen."

To address this concern, VOR proposes a greatly expanded Rule of Construction to ensure consistent application of the new terminology across all federal laws for greater protection for beneficiaries now and in the future.

VOR will participate in HHS Listening Sessions

On June 22, 2009, the 10th Anniversary of *Olmstead*, President Barack Obama launched "The Year of Community Living" initiative. In response, the U.S. Department of Health and Human Services (HHS), with other agencies, is working to identify ways to improve access to housing and other community supports for individuals with disabilities.

As part of this effort, HHS recently launched the first several HHS "Listening Sessions," to be held around the country. VOR Board Member Mary O'Riordan represented the organization at the first session in San Diego in late February. VOR members Lex Wells, Warren Snow, and Brad Whitehead also took part as representatives of their local organizations. VOR plans to participate at each Listening Session, focusing on promotion for the Community Resource Center (CRC) model.

CRC allows non-residents to access critical health care and other services readily available at existing ICFs/MR.

Entitlement Commission proposed

President Obama is expected to announce the creation of a bipartisan Entitlement Commission to explore revenue and entitlement policy, including consideration of Medicaid, Medicare and Social Security. This idea, aimed at finding ways to reduce the deficit (which could translate into cuts to some vital programs for people with disabilities) also has the support of some in Congress.

Georgia: MCG to run clinical services at state hospital

In October 2009, the Medical College of Georgia (MCG) took charge of certain administrative and clinical services at the East Central Georgia Regional Hospital, including its Gracewood campus for people with developmental disabilities. The public sector partnership will bring to the hospital additional staff and the benefit of academic-caliber forensic and mental health services. East Central had in the past been considered a candidate for closure or privatization. With the new partnership in place, the facility will instead be a centerpiece of the state's efforts to improve the quality of care in its facilities statewide.

State officials expect that the partnership will bring stability and quality to the clinical work-

force, as well as provide MCG students the opportunity to experience the challenges



VOR Board Member Ann Knighton with Rep. Patrick Kennedy during his Jan. 2010 tour of Gracewood ICF/MR.

and rewards of working in the public behavioral health system. The agreement calls for residencies, fellowships, nurses, and students practicing and learning at East Central. There is the expectation that more MCG students will, as a result, choose careers in the public sector.

Current center employees, including at Gracewood, will continue on staff to provide direct care and support services; only a handful of administrators have seen their roles change.

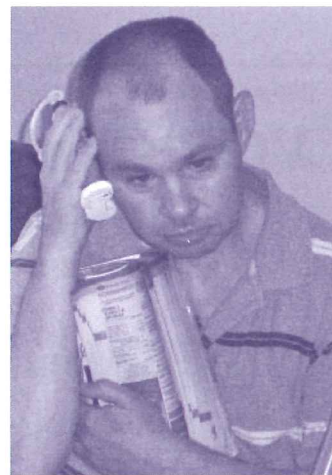
The initial agreement between MCG and the state is expected to last three to five years, with monthly progress reports and annual reviews to determine whether it will continue. In addition to providing key personnel, MCG will also provide assistance in carrying out the State's settlement agreement with the U.S. Department of Justice, to perform an analysis

State News continued on page 8

A Sibling's Perspective

By Mary Kay Cowen, Chair, VOR Membership Committee

My brother, Thomas Waldo (Tommy) has lived at the North Lake Supports and Services Center in Hammond, Louisiana for 45 years. He is profoundly mentally retarded, with an I.Q. of eight months and motor skills of 18 months. He is very mobile and loves to be outside. North Lake provides the sanctuary he requires to allow all the freedom he seeks under the watchful and loving eyes of his "other family" – the direct care staff.



Thomas "Tommy" Waldo

My father, Harry Waldo, was very much involved with the care and issues connected with Tommy. He stayed active in the Parents Association (now called Families and Friends) and got involved in the politics connected with the developmental centers from the time Tommy moved to North Lake at the age of 6 until the day he died – 47 years later.

During those years, Daddy allowed the rest of us (Tommy's siblings) to develop our own lives and families. He would send us information every year about Tommy's annual meeting, but did not keep us informed on other activities. My youngest brother, Bobby, was the first to realize we needed to get involved when he moved in with Dad during his college years. By the time he graduated, he had convinced me to begin attending the parents meetings with them.

Daddy died April 9, 2005. By then, both Bobby and I were very involved with the Families and Friends Association and I had gotten involved with Daddy on a statewide level through the Alliance of the Families and Friends Associations of Louisiana (now called the Coalition). Since my children had "grown and gone" and Bobby's family had several issues that would take years to contend with, I became Tommy's guardian.

My siblings have thanked me for keeping them informed about what's going on with Tommy and also politically. Two live in Texas and one in Florida, but there are areas they have been able to get involved – even if it is in small ways.

I encourage them to visit Tommy at least once a year (preferably more), and highlight the months I will not be able to see him. I also make sure they are aware of special activities (Family Day, Christmas Party) occurring at Tommy's home. The goal is



Perspective continued on page 10

Arc of VA case dismissed: Choice upheld

A federal judge has dismissed a lawsuit brought by The Arc of Virginia against the State of Virginia challenging a state plan to renovate and resize the Southeastern Virginia Training Center (SEVTC). Judge Robert Payne held that The Arc failed to establish a "case or controversy" ripe for judicial review and, thus, the court lacked jurisdiction to hear the case. The Virginia Office of Protection & Advocacy represented the Arc. The U.S. Department of Justice participated as *Amicus* ("Friend of the Court") in support of the plaintiffs.

Noting that deinstitutionalization was the plaintiff's central motivation in this case, Judge Payne held that, in this situation, the State has indicated that no one will reside at the new SEVTC who doesn't want to be there.

"Here, there is evidence that shows that many individuals will choose to live in the new facility. In fact, at least 84 of the 155 legal representatives of the current SEVTC residents have made formal pleas to permit their loved one to remain in the new facility rather than be placed in community housing (citation omitted). Thus, the argument made by Arc and the United States regarding the risk of institutionalization fails to account for a key principle in the *Olmstead* decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it."

Plaintiffs have appealed.

Illinois: New settlement proposed in litigation impacting private ICFs/DD

Parties have proposed a second settlement agreement in *Ligas v. Maram*, a lawsuit which targets Illinois policy with regard to community integration opportunities for residents of private ICFs/MR. The parties' first effort to settle this case failed after more than 2,500

class members filed objections. The significant objections prompted the judge to deny the settlement and decertify the class shortly after a required Fairness Hearing in July 2009.

The Second Proposed Settlement Agreement, filed in January 2010, suggests a more narrow class definition – only individuals who affirmatively seek community-based services. Objectors to the first settlement agreement have been included in settlement talks, but concerns remain over certain provisions, such as the impact that funding for class member services will have on future funding for private ICFs/MR and other services in Illinois.

VOR has provided much support to the Objectors, which include the "Golden Interventions," led by Sam Golden on behalf of his daughter, Anne. In mid-February, the Objector group filed a request for Intervention.

Connecticut: Parties seek dismissal of 23 year old lawsuit

The U.S. DOJ and the State of Connecticut agree that the state has met all its obligations to safeguard the care of residents at Southbury Training School. In late-October, they filed a joint motion seeing to dismiss the decades old consent decree.

South Carolina: Suit alleges funds for disabled transferred

A group of disabled residents has asked the South Carolina Supreme Court to stop a deep round of cuts to in-home care. At issue is the state's decision to put federal stimulus funds in a "rainy day" reserve that could be used to stave off in-home service cuts to thousands of families. Plaintiffs allege, in part, that failure to provide these in-home supports which they choose and are serving them well, could result in unjustified institutionalization in violation of *Olmstead*. (Source: *Post and Courier*, Dec. 29, 2009).

Pennsylvania: Families await decision on request to intervene

Families await the court's response to their Motion for Intervention in *Benjamin v. Department of Public Welfare (DPW)*, a class action lawsuit filed by Pennsylvania's P&A. The lawsuit alleges that the civil rights of people who live in state centers were violated because the state did not offer and provide community-based services to non-objecting residents. Intervening families point to P&A's fundamental hostility against state centers and DPW's unwillingness to preserve the center option as justification for intervention. VOR helped secure counsel for the families.

In Memoriam

VOR mourns the loss of **Carlton Horbelt**, *VOR board member*, who passed away unexpectedly in November 2009. Dr. Horbelt was an accomplished dentist of 28 years, specializing in *special care dentistry*, dedicating his time to advancing research and care for people with disabilities. At the time of his passing, he was the director of Dental Services at Arlington Developmental Center (TN). AADMD has established a scholarship in his name. Visit www.aadmd.org, for more details.

In recent months, VOR also said goodbye to **Les Abbott** a friend, member and donor; and to **Skip Landen**, retired *VOR board member*. Memorial contributions are being accepted in memory of both. Visit, www.vor.net for details.



Perspective

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to make sure Tommy is visited by one of us each month.

Asking not just my siblings but other interested relatives to contact their legislators, I send information from VOR, the Coalition, and the Families and Friends Association of North Lake concerning what is going on politically.

At first, they responded by visiting Tommy twice a year and responded to my requests for action. As time passes, they have adjusted to visiting Tommy once a year and respond to my requests for action after a little extra prodding. This was expected and has not discouraged me from keeping them informed.



Mary Kay Cowen

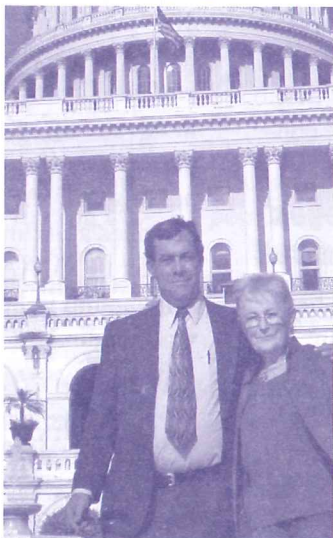
I am thankful I began to participate in "Tommy's stuff" while Daddy was alive and able to guide me through the emotions that one experiences when they first get involved. It enabled me to entwine the necessary activities into my life at a pace that prevented the total upheaval I have seen other siblings experience. Hopefully, by

keeping my siblings and other family members informed, they too will find a way to work "Tommy's stuff" into their lives.

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Likewise, the Annual Washington Initiative – which is credited for building VOR's credibility in Congress, one year at a time – is a critical exercise in grass-roots advocacy. The more participants we have, the more effective we are.

I'm so grateful to the many VOR volunteers who have made the trip to Washington, D.C. every year for so many years. I look forward to seeing



Board member Brian Boxall with Enid Emde at a past Washington Initiative.

these participants again, and hope to welcome many new participants.

Please plan to join us in Washington, D.C. this June. Bring a friend. Numbers count.

Thanks for all you do.

VOR Conference & Initiative Lodging

The Liaison on Capitol Hill
866-AFFINIA (233-4642)

Special VOR Rate:
\$189/night

(single or double)

Deadline: May 3, 2010

Continued from page 7

Annual Conference Overview

Saturday, June 5, 2010

Featured Presentations

Robin Sims

A Message from VOR's President

Julie Huso

Executive Director's Address

Obama Administration Representative (pending)

Tom York, Esq.

York Legal Group

DOJ, States and You:

Opportunities for advocates in CRIPA litigation

Paul Heckt, Esq.

Heckt & Associates

Medical Assistance

and Supplemental Needs Trusts

Direct from Capitol Hill

Speaker on Disability Policy,

including the DD Act Reauthorization

Register now

for early-bird rates

(fees include breakfast & lunch on June 5!)

***Members, \$40, by April 1**

***Non-members, \$75, by April 1**
(includes 1 yr membership)

To register:

A registration form can be found on page 12 of this newsletter, or online at: www.vor.net/events/

President:
Robin Sims
Editor:
Rochelle Hagel

VOR

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IMPORTANT INFORMATION

- ★ Your MAILING LABEL now includes your membership expiration date. Please take a look!
- ★ Leadership changes? When your family association elects new leaders, please let VOR know so we can update our records. This ensures VOR's information gets to the right people.
- ★ Email changes? Let us know so we can update our records and you can continue receiving the VOR Weekly E-Mail Update and important alerts.

Membership/Contribution Form: Please send dues to—

VOR 836 S. Arlington Heights Rd., #351, Elk Grove Village, IL 60007; 605-271-0445 fax or donate online @ www.vor.net.

Name _____			Membership Categories: Individual --- \$25 Parents' Association --- \$150 Professional Assoc./Corp. --- \$200 An additional gift/pledge is enclosed for: ___ \$1,000___ \$500 ___\$250___\$100___ Other
Address _____			
City _____	State _____	Zip _____	
Telephone _____			
Email Address _____			
Please check as appropriate:			<input type="checkbox"/> A check made payable to VOR is enclosed. Or please charge to my <input type="checkbox"/> VISA <input type="checkbox"/> Mastercard <input type="checkbox"/> Discover
<input type="checkbox"/> I am a new member			Card Number: _____
<input type="checkbox"/> I am a current member and my records need to be updated (i.e. new address, name, phone, etc.). I have circled the changes needed on this form.			Expires: _____
<input type="checkbox"/> No changes are needed.			Amount to charge: _____
			Signature: _____
If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4VOR). It is in our best interest that you receive VOR's information, so please call if \$25 per year poses a financial hardship. Mar.10NL			



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*A national, non-profit 501(c)(3) volunteer association
 of individuals and families working for persons with mental retardation*

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 *****AUTO**MIXED AADC 601
 Member Expiration Date 11/30/2010 6
 Tamie Hopp 9
 PO Box 1208
 Rapid City SD 57709-1208

Annual Conference and Initiative Registration Form

Return form to VOR * 836 S. Arlington Heights Rd., #351 * Elk Grove Village, IL 60007
 Fax: 605-399-1631 * Tamie327@hotmail.com * Phone: 877-399-4867 (toll free) or 605-399-1624; a 501(c)(3) org.

To register online, visit www.vor.net/events.

ANNUAL CONFERENCE REGISTRATION:

Name(s) _____
 Address _____
 City, State, Zip _____
 Home Phone _____
 Work Phone _____
 Email _____
 Sponsoring organization _____

VOR Members:

- ___ \$40 per member if paid by April 1, 2010.
- ___ \$50 per member if paid by May 1, 2010.
- ___ \$75 per member if paid after May 1, 2010.

Non-VOR Members:

- ___ \$75 per person for non-member if paid by May 1, 2010. Fee includes 1 year membership.
- ___ \$100 per person for non-member if paid after May 1, 2010. Fee includes 1 year membership

INITIATIVE REGISTRATION:(No add'l fee):

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

Additional Donations Appreciated

___ A donation of \$_____ is enclosed

Charge card: MC Visa Discover

Expiration date _____

Credit card number _____

Signature _____