

From Moron to Manhood
VOR Annual Meeting
H.R. 1225 picks up steam
Golden family - why give?

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25th Anniversary
1983/2008

VOR
*Speaking Out for People
with Mental Retardation*

Reflections from my first year as president

The President's Message By Robin Sims

VOR's fiscal year runs from July to June, so about this time every year we pause to reflect on the past year.

The highlight of my year was my trip to Augusta, Georgia where I attended the Family Day at Gracewood, at the invitation of Ann Knighton. I loved meeting the families and touring Gracewood. I welcome the opportunity to visit other centers!

A special thanks to VOR's entire Board of Directors. On page 4, you will see a list of board members. I want to personally thank these retiring board members for their past service on VOR's Board: Lex Wells, Kathy Spare, Alfred Bennett and Carolyn Cowan.

Government Affairs & Legislative Activities

Both of these committees met their board-approved priorities, including tracking and responding to federal legislation and proposed regulations, educating the new Administration and working to achieve needed reforms to the activities of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) programs."

Most notable is the reintroduction of Rep. Barney Frank's family rights legislation. You can read about the progress of this bill, reintroduced as H.R. 1255 in March 2009, in the legislative section of this newsletter. The legislative committee's efforts resulted in nine "original" cosponsors to the bill including (so far) 58 Democrat and Republican (nearly equal!) cosponsors.

The Government Affairs Committee prepared written comments last Fall (2008) in response to proposed federal regulations relating to Money Follows the Person and the DD Act. According to a June 2009 memo from the White House, all proposed regulations have been withdrawn.

The Government Affairs Committee also addressed VOR's concerns regard-

ing the erosion of guardianship rights across the country in a letter to the American Bar Association (ABA). Although the ABA's initial response was disappointing, a follow up meeting provides us with more hope.

With regard to the DD Act, VOR remains prepared for the Reauthorization, which now is expected (after a decade) to take place by early next year. Examples of DD Act abuses have been shared with Congress and we are working to contribute our perspective to a research effort relating to DD Act program effectiveness.

On a related note, I'm pleased to report that I have just been sworn as the only member of the NJ DD Council representing Developmental Centers and Community by virtue of having two children with developmental disabilities, one in a center and one at home.

VOR has also worked to educate the new administration, beginning with the submission of policy recommendations to the newly-elected president. We have also had two meetings (one by teleconference) with Kareem Dale, who is President Obama's Special Assistant to the President for Disability Policy. While in D.C., VOR leaders met with other representatives of the administration, and we will meet with others as they are appointed.

Legal Developments

There were also many notable legal developments this past year, with some ups and downs. In Massachusetts, the Supreme Court opted not to take the Ricci case, which left standing a disappointing and dangerous federal court decision. In Illinois, however, families 2,500 strong objected to a proposed P&A settlement agreement, prompting the court to reject the agreement and decertify the class. A great outcome!

In New Jersey, families alerted the Department of Justice that the state planned to cut doctors from our centers, relying on a bogus patient/doctor ratio, contrary to federal regulations and a



Robin Sims

DOJ settlement agreement. DOJ is working to restore some of the lost medical services.

Conclusion

Thank all of you for being part of VOR! I look forward to advocating with you throughout the coming year!

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On the Cover: Top left-L-R Doris Gatlin, Walter Gatlin, Rep. Bill Cassidy, Terry LaFleur, Mary Kay Cowen at the Capitol; Center-Donald Vitkus; Bottom right-David Hart.

Effective Advocacy in Changing Times: VOR's 2009 Annual Conference in Washington, D.C.

Conference Presentations

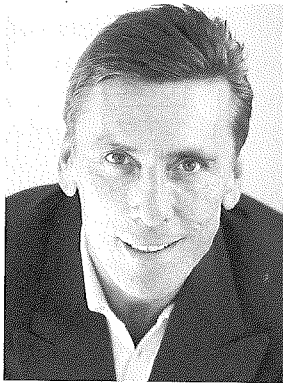
Michael Manganiello

The conference kicked off with an inspiring talk from seasoned grassroots advocate and political strategist, Michael Manganiello, a self-described "underdog."

Manganiello shared valuable "lessons learned" from his more than 25 years of experience leading grassroots causes to greater visibility and marked successes, including his work with the Christopher and Dana Reeves Foundation on behalf of Americans with paralysis.

Specifically, he stated that, successful advocates:

- Put a human face on issues.
- Speak with one voice - and repeat the message over and over again -
- Use challenging issues don't get fixed overnight - you have to be willing to fight over years."
- Understand that advocacy efforts should not be mutually exclusive - they should be mutually reinforcing
- Implement effective media campaigns.
- Educate the public and Congress.
- Identify Congressional champions.
- Come to Washington.



Michael Manganiello, founding partner, HCM Strategists

In June, nearly 100 advocates from across the country attended VOR's Annual Conference in Washington, D.C.

The conference drew overwhelming praise for the selection of speakers and networking opportunities. One participant remarked, "Thank you for your attention to detail, culminating in a successful gathering of like-minded advocates for our children." Another participant stated, "VOR does a great job of organizing this event. I hope we helped advance the cause."

VOR's annual event fosters a sense of synergy and empowerment that can only be leveraged when so many like-minded advocates convene in one place.

vocacy for people with cognitive versus physical disabilities.

"For what it is worth, you have one convert to your cause standing in front of you today. . . I think H.R. 1255 is a tremendous platform for you to tell your story. You have compelling and heart-breaking arguments. Your movement cannot fail because there are real consequences that will effect not just your lives but all Americans . . . VOR needs



Susan Daniels, Ph.D., Daniels & Associates

to be voice in health care reform under this administration but in your bill you have a very specific vehicle to educate Congress and the American public about your cause and at the same time get yourselves to the table."

Susan Daniels, Nanette Goodman & Simon Goodman

Annual Conference participants also had the opportunity to provide feedback to Susan Daniels, Nanette Goodman and Simon Goodman, who are conducting research on the effectiveness of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) programs.

The research is being funded by the National Council on Disability (NCD), an independent federal agency that provides advice to the president, Congress, and executive branch agencies on disability policy. Dr. Daniels explained that while her team is conducting research and submitting drafts, NCD has final say as to what appears in the final report, including

recommendation, expected in Fall 2009.

Because research is still pending, Dr. Daniels could not share her findings to-date, but she welcomed VOR input. Not surprisingly, VOR members are overwhelmingly dissatisfied with the DD Act programs, citing program bias against individuals whose needs are best served in licensed facility settings. To make this point, VOR members shared examples of litigation, lobbying, advocacy trainings, media quotes and advertisements, and other examples. Some members shared written comments, and VOR shared an overview of DD Act abuses, as compiled by VOR's DD Act Task Force.

The Annual Meeting concluded

VOR Lifetime Achievement Award

In recognition of more than 50 years of advocacy on behalf of their two daughters with developmental disabilities and their peers, VOR presented a *Lifetime Achievement Award* to Warren and Marian Snow. The Snows were honored at the 2009 Annual Meeting in recognition of their generous, caring and deep commitments to improving the lives of citizens with developmental disabilities, noting that each has been pivotal to VOR's success. For more than a decade, beginning in 1990 Warren served as a VOR officer, including nine years as first vice president. Marian was

a founding member of Fairview Families and Friends, an organization dedicated to the residents of Fairview Developmental Center in Southern California. She also served several terms on VOR's legislative committee. VOR extends its sincerest gratitude for the Snows' leadership and sustained contributions to our shared advocacy.



Warren Snow

Officer/Board of Directors Elections

On June 12, the following officers were elected to serve a one-year term, beginning July 1, 2009:

- Robin Sims (NJ), President
- Sybil Finken (IA), First Vice President
- Barbara Cukierski (IL), Treasurer
- Elbirda Haley (KY), Secretary

Mary McTernan remains VOR's immediate past president.

Ms. Cukierski was elected to replace VOR's David Swain, who opted to retire after serving many years as VOR's treasurer. "David has brought us forward as an organization," remarked President Robin Sims. To ensure continuity, David agreed to serve another three-year term as a member of VOR's board of directors, and also as chair of VOR's finance committee.

In addition to the VOR officers listed above, the following individuals serve on VOR's board. A special welcome and thank you to the three new board members (in bold), and sincere thank you to the remaining board members for their continued service to VOR:

- Jill Barker (MI)
- Brian Boxall (CA)**
- Marty Dwyer, Esq. (NY)
- Catherine Gover (MA)
- Carlton Horbelt, DDS (TN)**
- Ann Knighton (GA)
- Mary O'Riordan (CA)
- Maxine Richey (CA)
- William Ryerson (NC)**
- David Swain (NV)

VOR says THANK YOU and farewell to retiring board members, Alfred Bennett (NM), Carolyn Cowans (TN), Kathy Spare (PA), and Lex Wells (CA). Thank you for serving VOR!

The 2009 Voice Award

In recognition of his contribution of skill and untold volunteer hours in the area of legislative advocacy, Peter Kinzler, chairman of VOR's legislative committee was the 2009 recipient of VOR's *Voice Award*.

Before forming a legislative consulting firm, Peter's career spanned more than 25 years working on Capitol Hill in both Senate and House offices. His career joined with advocacy when the Chafee legislation was successfully defeated in the early 80s. Since then, Peter has participated in countless debates, formal and informal, on and off Capitol Hill, on VOR's behalf and to our collective benefit. For many years, Peter has served on VOR's legislative committee, most recently as its chairperson. VOR is most grateful to Peter for his leadership, patience and attentive guidance through the many mazes of government for so many years.



Peter Kinzler

Capitol Hill expert meets with VOR

Diego Sanchez, senior policy adviser to Rep. Barney Frank, gave an empowering address at VOR's annual legislative briefing, which prepares Initiative participants for the week to come. Seeing it as his role to demystify Capitol Hill and "rekindle the fire that brought you here," he encouraged VOR participants to recognize their role as the voices for their children noting that grassroots advocates are the "voice and vision that brings light to the legislature."

State Reports from VOR's Annual Meeting More reports can be found at: www.vor.net/StateReports2009.h

GEORGIA

By Ann Knighton VOR Board Member & State Coordinator

In 2008, the Family Council of Gracewood hosted its annual fall picnic which included a tour of the Gracewood and was described as "time filled with good food, attendance of our family members and legislators, state senators, county commissioners, VOR members, Congressman John Barrow, and VOR President Robin Sims, who so graciously gave an excellent and inspiring delivery on the urgency of the ICFs/MR providing the critical and special care for persons who are developmentally disabled." In 2009, the families plan to hold a legislative rally to show support for Gracewood.

With regard to Olmstead, Gov. Sonny Perdue, in settlement with the U.S. Department of Health and Human Service's Office of Civil Rights (OCR) made the decision to close the ICFs/MR. Families were not consulted regarding the settlement and applications to serve on an implementation committee were not accepted. Instead, outside "experts" are trying to establish "consent" to transition ICF/MR residents to community settings. Ann Knighton, president of the Family Council and a VOR Board Member, filed a complaint with OCR raising objection to the complete lack of family consultation.

MASSACHUSETTS

By David Hart President, COFAR

Massachusetts officials announced that they plan to close four of the six ICFs/MR, with the first closure (Fernald) planned for 2010. Health and Human Services are also facing severe cuts. The "Groton 43," families of 40 severely disabled individuals living

Continued on page 5

Continued from page 4

pediatric nursing homes, continue their fight to avoid transfer required by the Rolland class action settlement. In response to closure plans and budget cuts, the statewide advocacy group, COFAR, in coalition with two unions and the nurses formulated a plan of action that focused on the legislature. The 10-step plan includes a 50,000 piece mail drop, a media campaign, calls to legislators and more.

MICHIGAN

By Jill Barker
VOR Board Member & State Coordinator

In February 2009, the Governor announced that the Michigan Department of Community Health (MDCH) planned to close Mt. Pleasant Center, the last remaining ICFs/MR in Michigan, by October 2009 as a cost-saving measure. An explanation of alleged savings was requested, but the response did not include an assessment of costs associated with displaced state workers, costs transferred to other entities in the state, such to community mental health agencies (CMHs) for medical services, which have already been asked by MDCH to serve more people for less money. The MDCH estimates that about 30 residents of Mt. Pleasant Center will be relocated to Caro Psychiatric Hospital, another state run facility, in a separate unit that will be ICF/MR certified.

IOWA

By Sybil Finken
VOR First VP

Iowa still has two facilities, Glenwood and Woodward. Both have waiting lists. The Arc-IA and P&A are working together (in the same office), and P&A has called for Glenwood closure. The DOJ has been investigating Glenwood since 2004. Recently, DOJ gave the center marks, moving it one step closer to substantial compliance.

Choice advocates win big in Illinois

More than 2,500 residents and families of Illinois' private ICFs/DD facilities registered their opposition to a proposed settlement agreement, which would have threatened the future viability of their homes.

The settlement agreement, forged between the state and Illinois' P&A agency, sought the reduction of ICF/DD capacity and an assessment process that worried residents and residents who are pleased with their present ICF/DD homes.

Responding to 2,500 written objections and more than 250 people present at the hearing to consider the settlement agreement, the judge noted the diversity of class members' needs and reversed an earlier order certifying the class.

The Ligas decision, especially as it relates to class certification is nationally significant. For a copy of the three-page decision contact Tamie at Tamie327@hotmail.com or 877-399-4VOR.

"The decision recognizes that the disabled are too varied to be shoe-horned into a settlement against their will that might help only some at the expense of others," remarked Bill Choslovsky, who represented families reside at Misericordia, a private ICF/DD.

In decertifying the class, the judge also cited Olmstead, noting that "the class definition fails to restrict the class to developmentally disabled individuals that are eligible for, *and desire*, community placement" (*emphasis added*).

"The decision demonstrates that what is lacking most in Illinois is not choice, but rather funding for all the existing choices, be they for small homes (CILAs), large homes (ICF-DDs), or something in between," Choslovsky said, referring to the severe budget challenges facing the state.

The Ligas decision, especially as it relates to class certification is nationally significant. For a copy of the three-page decision contact Tamie at Tamie327@hotmail.com or 877.399.4VOR.

Families to file federal lawsuit alleging discrimination against Fernald Center residents

In April 2009, families and guardians of residents of the Fernald Developmental Center announced that they will file a new federal lawsuit, alleging that the Patrick administration is discriminating against residents by allowing dramatic declines in care and conditions at the facility in recent months. The lawsuit will mark the second case brought in federal court by the Fernald families and guardians since the 1970s. The first case, Ricci v. Patrick, which was originally filed in 1974, came to an end earlier this year when the U.S. Supreme Court declined to consider an appeal to keep the facility open as an option to its current residents. Fernald is the first of four facilities for persons with mental retardation in Massachusetts that the Patrick administration has marked for closure.

Supreme Court rules public must pay for private special education

On June 22, the Supreme Court held that federal law (IDEA) requires public schools to pay private school tuition if the public school does not appropriately identify and provide services to eligible students.

Pennsylvania P&A files lawsuit seeking the community integration

P&A has filed a class action lawsuit alleging that the rights of over 1,200 Pennsylvanians with mental retardation who reside in state operated ICFs/MR have been violated because they have, allegedly, not been "offered the opportunity to move to appropriate community living arrangements." Families disagree. One plaintiff's mother was unaware that her son would be a plaintiff in this lawsuit. **H.R. 1255 is needed!** (see p. 8).

Memories of a "Moron" By Ed

"Hello, my name is Donald Vitkus. I am a former moron."

That's how one man introduced himself to VOR members from across the country, gathered at our 2009 Annual Meeting and Washington Initiative held in Washington, D.C. this June.

Donald, who is now vice-president of Advocacy Network, Inc., an affiliate of the Massachusetts Coalition of Families and Advocates, grew up in the former Belchertown State School in Western Massachusetts, under what was then the Department of Mental Health.

Unable or unwilling to care for him, Donald's unwed mother had given him up to the state when he was just 27 days old. At age six, after being tossed from foster home to foster home, Donald ended up at Belchertown. There he was immediately labeled a "moron" with an IQ of 41.

Donald would spend his entire youth at Belchertown from 1949 to 1961, a time when that institution, like many others of the period, was rife with decay, neglect, and abuse.

At age 66, he now holds an associate's degree, and is a direct care worker for persons with mental retardation.

"I was called a 'retard' when I was at Belchertown," Donald told VOR members, "so I thought I must be one. In my experience, a lot of people set low standards for personal goals in the lives of people with mental retardation."

Donald told the audience he wants people to know what conditions in the institution were once like, so that we never return to those days.

"One day a group of state legislators came to tour our facilities," Donald said. "After they left the building, I saw some of them throw up on the sidewalk outside, because of what they had seen, heard, and smelled."

Donald said what happened in his twelve years at Belchertown has had lasting impact. For example, he

want yet another negative label like "moron" or "retard," and he was successful.

I was called a 'retard' when at Belchertown, so I thought I must be one. In my experience, a lot of people set low standards for personal goals in the lives of people with mental retardation.

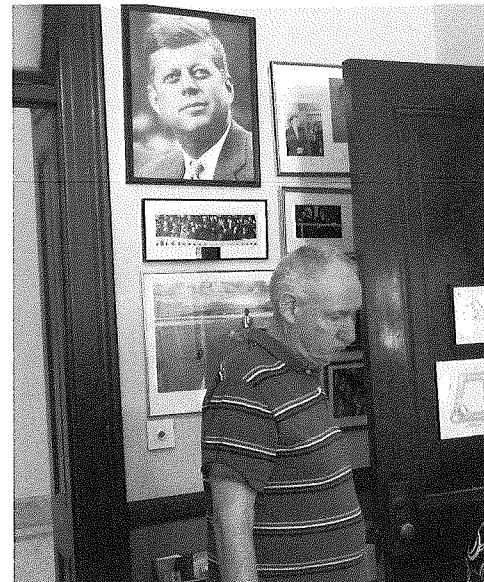
ful in getting his classification changed. Consequently, he was drafted into the U.S. Army and served a year in Vietnam. Ironically, when Donald later returned to his hometown and applied for a gun permit, the chief of police denied him because he had been institutionalized.



Donald Vitkus expresses a point during a VOR Annual Meeting session.

started brushing his teeth just three years ago, because patients never had toothpaste or brushes. He still sleeps with his head under the covers, a habit he acquired for protection. And because toilet seats were non-existent, he sometimes still lifts the seat and sits directly on the porcelain.

At age 18, Donald registered with the Selective Service, at the height of the Vietnam War. Because of his record at Belchertown, he was classified "4-F," mentally unfit to serve. But he didn't



One of Donald Vitkus's stops on Capitol Hill was the office of Massachusetts Senator Ted Kennedy.



Donald Vitkus meets Lorena Barrios (L), at a break at the Annual Meeting in Washington, D.C.

At VOR's annual meeting, Donald participated in a panel discussion about the "R" word, including society's derogatory usage of the word "retard," and the trend away from the use of "mental retardation" and "retarded" in advocacy and laws.

Members were visibly moved by Donald's account, and inspired by his

Orzechowski

to overcome adversity. He had a similarly profound impact on legislative aides when he lobbied Congressional offices on behalf of VOR during our annual Washington Initiative.

It was clear that Donald's life experience, both as former "moron" and now as caregiver, provides a unique

perspective to express the needs that many of our loved ones cannot themselves articulate.

He is a passionate advocate—a "Voice of the Retarded."



OR members, Ritter (R), during a meeting



Donald Vitkus (left) and Ed Orzechowski listen during a panel discussion about "The R Word" at VOR's 2009 Annual Meeting in Washington.

About the Author

Ed Orzechowski is a freelance writer. He and his wife Gail are VOR members, and board members of Advocacy Network, Inc. and the Massachusetts Coalition of Families and Advocates.

Author's Note:

Donald Vitkus is my friend. He spent his youth in the custody of the Massachusetts Department of Mental Retardation (now the Department of Developmental Services). As patient #23-3394 at the former Belchertown State School, Don-

acquired behaviors that would shape and scar his adult life. Numerous entries in his file state: "Receives no mail, has no visitors, and does not go out on vacations."

Donald is also a Vietnam veteran.

For three decades, he was treated for flashbacks—not to Vietnam, but to Belchertown.

He has been married three times and has two children. A ten-year search led him to his mother's graveside in South Carolina, and a reunion with his three siblings.

He has endured brain surgery, possibly related to childhood head-banging. When the company where he worked for

30 years moved to Mexico, he completed high school, earned an associate's degree in human services, and is now a caregiver in the system that once "imprisoned" him.

When I met Donald a few years ago, he was looking for someone to help him write his story. A passionate advocate, his mission is to tell what life in the institution once was, how he adapted to the real world, and his burning desire that we never return to the way things once were. Our working title is *From Moron to Manhood*. When Donald's book is published, a portion of the proceeds will be donated to advocacy for persons with mental retardation. —Ed Orzechowski

Panel Discussion - The "R" Word: Form or Function?

Donald Vitkus, whose life is the focus of *From Moron to Manhood*, an upcoming book by Ed Orzechowski and Vitkus, participated in a panel discussion at VOR's Annual Meeting. The panel was moderated by Jill Goldstein, a public relations professional who recently helped VOR secure a spot on the national broadcast *Geraldo at Large*.



Panelists, from left: Donald Vitkus, Ed Orzechowski, David Hart, and Sybil Finken. Standing: Jill Goldstein, moderator of a panel discussion relating to the national trend to do away with the word "retarded" and even "mental retardation."

In her introductory remarks, Goldstein noted that "Advocates and policymakers agree that the pejorative use of the word 'retarded' is unacceptable under any circumstances. More and more, however, states are removing 'mental retardation' in agency names and state laws," citing recent actions in Kentucky, Rhode Island, Tennessee, Georgia, New York, Ohio, Alabama, Mississippi, Virginia, Washington State, Texas, Missouri and others.

Panelists and audience members agreed that the use of "retarded" in a derogatory way was unacceptable and must be challenged whenever heard. Likewise, there was strong consensus that "mental retardation" was an important diagnosis that tied closely to eligibility for life-sustaining services and provided clarity to our advocacy on behalf of a very specific population.

**H.R. 1255 Cosponsors
(as of July 7, 2009)**

Sponsor:

Rep. Barney Frank (D-MA)
COSPONSORS

Democrats

Rep. James Moran (D-VA)*
Rep. Steve Cohen (D-TN)*
Rep. Paul Kanjorski (D-PA)*
Rep. Debbie Wasserman Schultz (D-FL)*
Rep. Michael Capuano (D-MA)
Rep. John Olver (D-MA)
Rep. John Barrow (D-GA)
Rep. Luis Gutierrez (D-IL)
Rep. John Larson (D-CT)
Rep. James McGovern (D-MA)
Rep. Pete Stark (D-CA)
Rep. Charles Gonzalez (D-TX)
Rep. John Lewis (D-GA)
Rep. Lynn Woolsey (D-CA)
Rep. Niki Tsongas (D-MA)
Rep. Bobby Rush (D-IL)
Rep. Sheila Jackson Lee (D-TX)
Rep. Sam Farr (D-CA)
Rep. John Sarbanes (D-MD)
Rep. Gwen Moore (D-WI)
Rep. Richard Neal (D-MA)
Rep. Mike Quigley (D-IL)
Rep. Al Green (D-TX)
Rep. Lacy Clay (D-MO)
Rep. Russ Carnahan (D-MO)
Rep. Charlie Melancon (D-LA)
Rep. Marion Berry (D-AR)
Rep. Bob Filner (D-CA)

Republicans

Rep. Ted Poe (R-TX)*
Rep. Ron Paul (R-TX)*
Rep. Bob Goodlatte (R-VA)*
Rep. David Dreier (R-CA)*
Rep. Daniel Lungren (R-CA)*
Rep. Frank Wolf (R-VA)
Rep. John Culberson (R-TX)
Rep. Charles Boustany (R-LA)
Rep. Peter Roskam (R-IL)
Rep. John Boozman (R-AR)
Rep. Anh "Joseph" Cao (R-LA)
Rep. Chris Smith (R-NJ)
Rep. Pete Olson (R-TX)
Rep. Judy Biggert (R-IL)
Rep. Gary Miller (R-CA)
Rep. Brett Guthrie (R-KY)
Rep. Bill Cassidy (R-LA)
Rep. Michael Burgess (R-TX)
Rep. Phil Gingrey (R-GA)
Rep. Devin Nunes (R-CA)
Rep. Sam Johnson (R-TX)
Rep. Steve King (R-IA)
Rep. Pete Sessions (R-TX)
Rep. John Fleming (R-LA)
Rep. Erik Paulsen (R-MN)
Rep. Steve Scalise (R-LA)
Rep. Kenny Marchant (R-TX)
Rep. Rodney Alexander (R-LA)
Rep. Randy Neugebauer (R-TX)
Rep. Michael McCaul (R-TX)

*=Original cosponsors

Legislative UPDATE

VOR's Washington Initiative: Strength in Numbers

MEMBERS GROW H.R. 1255 SUPPORT

During the week of June 15, nearly 80 Initiative participants hand-carried VOR's legislative positions to EVERY Congressional office. Together, volunteer advocates covered 535 offices in about three days.

VOR priority legislative issue was H.R. 1255. Securing H.R. 1255 cosponsors was our main goal. We succeeded! The numbers tell the story:

- **Before VOR's Washington Initiative, H.R. 1255 had 28 cosponsors.**
- **During the week of VOR's Initiative, we gained 10 more.**
- **The week after VOR's Initiative, we gained seven more.**

There are now 58 COSPONSORS – a remarkable jump of 30 new cosponsors in the short time since VOR's Initiative!

This success is due entirely to dedicated follow-up by the VOR volunteers who traveled to Washington, D.C., and also great efforts by many, many other VOR members.

THANK YOU FOR YOUR HELP!

About H.R. 1255, a disability and family rights bill

If passed, H.R. 1255 would require that residents of facilities and their legal guardians be notified before a federally-funded class action lawsuit is filed, and be given an opportunity to opt out.

Since 1996, the lawsuits addressed by H.R. 1255 have sought to force community integration, despite the fact that most residents or their guardians oppose the move. Such displacement violates the civil and human rights of the affected residents to maximize their development potential in safe and specialized

residential homes where they are very much integrated in the surrounding community.

H.R. 1255 respects the role of court-appointed legal guardians, often close relatives of the affected residents. Many of

H.R. 1255 would require that residents of facilities and their legal guardians be notified before a federally-funded class action lawsuit is filed, and be given an opportunity to opt out.

these residents have the cognitive ability of infants or young toddlers. No one would question the right of parents to make fundamental care decisions on behalf of a one year old.

**Call or visit
your US Representative today!**

HOW YOU CAN HELP!!

ASK YOUR CONGRESSMAN TO COSPONSOR H.R. 1255

Contact your U.S. Representative and ask him/her to COSPONSOR H.R. 1255. If you have already made contact via letter, email or phone call, please try again. It often takes several tries before an issue makes it to the top of an aide's "to do" pile. Be respectful, but persistent.

To find contact information for your representative, visit <http://www.congress.org>. For background information about H.R. 1255, visit <http://vor.net/HR1255positions.htm>.

AUGUST DISTRICT VISITS!! Your best opportunity for success

Face-to-face meetings are by far the most effective. Members of Congress will be working from their district offices, near your home, through most of August. Today, please request a meeting with your representative in his/her DISTRICT office to discuss the importance of H.R. 1255.

The Need for Immediate Reforms: Reauthorization of the DDA and Bill of Rights Act

The CLASS Act

It has been nearly a decade since Congress reviewed the federally funded Developmental Disabilities Assistance and Bill of Rights Act (DD Act) programs.

DD Act programs – DD Councils, Protection & Advocacy, and University Centers for Excellence on Developmental Disabilities – operate in every state.

The reauthorization of these programs, the process whereby Congress reviews and can make changes to the DD Act, was due in 2007, but other Congressional priorities have delayed this action. Reauthorization is anticipated this fall, or in early 2010.

In 1993, VOR's advocacy led to the important inclusion of the "primary decision-making" section in the DD Act which expressly states individuals and their families are the primary decision-makers regarding services, supports and policies.

The 1993 Congressional Committee Report language which explains the "primary decisionmaking" addition to the Act states, in part, that "The Committee recognizes and supports the belief that each individual and each respective family have different goals and needs . . . the Committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy in support of the closure of residential institutions."

Some DD Act programs, however, still act to eliminate one of those choices – ICFs/MR – which sometimes leads to the abuse, neglect and death. A volunteer VOR task force has identified over 70 examples in 20 states of the DD Act programs' disregard for Congressional intent. These results have been shared with Congress, the administration and researchers.

VOR urges Congress to adopt the following reform proposals:

A. Level fund DD Act programs (no increases!) to give Congress time to review the programs and consider reforms.

B. Pass H.R. 1255 (see p. 8 for details about this bill).

C. Secure an HHS audit of how all DD Act programs are working and if they are respecting family choice and the Olmstead Supreme Court decision, to be submitted to Congress within one year.

D. Limit the reauthorization to three years so that the Congress can more closely monitor the effectiveness of DD Act policy and DD Act program activity and how HHS is overseeing it.

VOR also calls on Congress to require that CMS conduct a study of whether states are offering people the choice between an ICF/MR and Home and Community Based Services (HCBS) waiver settings, a required by law.

How you can help

† Send VOR examples of DD Act abuses in your state.

Tamie327@hotmail.com; or call 877-399-4VOR.

† Contact your elected officials in Congress. Share examples of DD Act abuses in your state. Ask your elected officials to support meaningful DD Act reform, consistent with VOR's call for reform (see above).

The Community Living Assistance Services and Supports Act (CLASS) Act was introduced by Senator Ted Kennedy, as part of his larger health care reform package. The CLASS Act would allow working Americans to set aside money from their paychecks, and after five years, could draw upon these savings if needed for long-term services and supports as they age, or acquire a disability.

HHS rescinds harmful regs

The Department of Health and Human Services (HHS) announced that the administration will rescind all or part of three Medicaid regulations that were previously issued. This action restores reimbursement for school-based administrative and transportation costs; removes limits to outpatient hospital and clinic services for Medicaid beneficiaries; and restores beneficiary access to care management services. Each of these rules had been subject to Congressional moratoria set to expire on July 1, 2009.

Administration announces "Year of Community Living"

On June 22, President Obama launched a new initiative to improve opportunities for community living, including collaboration between key agencies such as HUD and HHS; grants for HHS Aging and Disability Resource Centers; and proposed changes to Home-and-Community-Based Waiver regulations. White House press release stated, "The Administration acknowledges that strides have been made, and knows and accepts that there is much work to do in order to maximize the choices and opportunities for individuals to receive long-term services and supports in institutional and community settings."

Donor's Forum

By Julie M. Huso
Executive Director

Uniting People in Advocacy and Assisting in the Quality of Live and Choice for Person's with Mental Retardation

This summarizes the VOR mission and we are working directly to benefit our loved ones with mental retardation and developmental disabilities.

That reality was clearly apparent at VOR's Annual Conference in Washington, D.C.

During the Friday Night State Report Forum, everyone in the room was reminded why we are members and committed to VOR. Closure proposals and budget cuts underscored many of the participants' presentations. Yet, even amidst these challenges, VOR has realized some tangible successes:

- H.R. 1255, a federal bill to restore family/guardian decision making authority when Protection and Advocacy (P&A) plans to file a class action lawsuit. In the short time since VOR's Initiative, nearly 30 new cosponsors have been secured!
- With VOR's help, a coalition of families, representing residents of private and public ICFs/MR in Illinois, successfully objected to a proposed settlement. The court received 2,500 written objections and 250 people showed up in court. The court not only rejected the settlement proposal, it also decertified the class.
- In addition to visiting EVERY Congressional office, VOR secured audiences with the White House, the U.S. Department of Health and Human Services, the U.S. Department of Justice, and the Centers for Medicare and Medicaid Services. In every instance, we advanced our mission in support of residential choice and family empowerment!



Julie M. Huso

- VOR regularly fields calls and emails from individuals needing advocacy assistance, helping individuals secure services or remedy abusive situations.

VOR would not realize these successes without your membership and philanthropic support!

We need to maintain VOR's strength, growth and presence in the years to come!! **We cannot do this without sufficient charitable donations and memberships.** Visit our website at www.vor.net or call Julie Huso 605-370-4652 to learn more. Quoting our president, Robin Sims "If not us, who?"

YOUR MEMBERSHIP AND GIFTS MAKE A DIFFERENCE

VOR is the only national advocacy organization that expressly opposes efforts to eliminate the facility option while also supporting expansion of quality community programs. VOR advocates that final determination of what is appropriate depends on the unique abilities, needs and desires of each individual, with the input of family guardians where necessary and appropriate.

Why we give

About this column:

VOR is as strong as its members, people like you. Periodically, we will be introducing you to individuals who will share why they donate to VOR. In this issue, we would like to introduce you to Sam Golden, Paula and family.



The Golden's

My wife, Paula, and I have been members of VOR since 1984. I credit Marty Pratt, VOR's founder, for getting me involved. I've been active ever since serving on the board and on committees.

Paula and I have four children, Daniel, Jonathon, Anne Ruth and Miriam. Anne was born in 1956 with problems from the start. She was very small and developed severe seizures early on. When Anne was four years she attended a regular nursery school run by dedicated and understanding people. She stayed there for six years, during which time she lived at home. We had a wonderful woman who cared for her who Anne still remembers.

At age 10, Anne moved to a residential home that was a good place for her from age 10-24. She then moved to Mt. St. Joseph which is run by the Daughters of St. Mary of Providence. It is a beautiful facility on a 160 acre tract of land. The nuns who run it are inspired, dedicated and truly do a wonderful job.

Anne, a very small person, is said to have an IQ of 20 and to function on the level of a 2 year old child. She is friendly to everyone, greets everyone who passes by and knows no guile. She is very good natured and laughs a lot, often at her own jokes. She loves music and sings along, in tune and rhythm. Music is a big part of our life. Paula and I play the cello, Daniel is a professional vio-

Continued on page 11

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Goldens --continued from page 10
list, and Miriam and Jonathan are musical too.

We credit Anne's good nature, happiness, and development to the many people who have touched her life in such a positive way, especially the good Sisters at Mt. St. Joseph. A small home or apartment would confine and isolate her.

We also credit VOR for how Anne is doing today. While other groups worked very hard to take away Anne's choices throughout her life, VOR has been right there by her side and our's. In 1984, Marty and I with other advocates defeated the Chafee legislation.

Recently, VOR helped protect Anne and her peers from a federal lawsuit in Illinois. VOR has been a tremendous resource. I don't know where we would be in Illinois if not for VOR.

The money we have contributed to VOR over the years has reaped big dividends for us. VOR has enabled Anne to stay in a marvelous home, ideally suited to her needs.

Huso new VOR Executive Director

At the June 2009 Annual Board of Directors meeting, Julie Huso, our director of development, was named VOR's new executive director.

"Julie's primary role for VOR will continue to be increasing VOR's resource base, as well as working with the Board and volunteers. This will involve meeting with many new organizations and individuals," explained Robin Sims, VOR president. "In the past year, Julie has made presentations to groups and individuals in over 10 states and we feel very comfortable that she will handle the job of executive director effectively."

President:
Robin Sims
Editor:
Rochelle Hagel

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		
Address			An additional gift/pledge is enclosed for: ___ \$1,000 ___ \$500 ___ \$250 ___ \$100 ___ Other		
City	State	Zip	<input type="checkbox"/> A check made payable to VOR is enclosed. Or please charge to my <input type="checkbox"/> VISA <input type="checkbox"/> Mastercard		
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Fax	Email	Expires: _____			
Please check as appropriate: _____ I am a new member _____ 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. _____ 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. Jul.09NL					

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