

**2011 Annual  
Conference &  
Washington  
Initiative**

**pgs 6-7**

***Empowering  
Choice Advocates :  
The Voice Of Reason***

**featuring:  
Stephanie Vance  
Clare Ansberry  
Samuel Bagenstos**

**Also Inside**

**Check out our Facebook page**

**page 2**

**Ligas class action blueprint to win**

**page 9**

**Conference sponsorship opportunities pages 6-7**



## VOR-moving forward in volunteerism through online organizing (or "hey, check out our Facebook page!")

By Robin Sims, President

As I watched the historical events in Cairo recently, I was struck by one particular part of the story: how it all started. A young man who worked for Google set up a Facebook page and from that outreach, thousands of people joined the ranks of protestors. People of all ages and all levels of education and employment came out and with one voice and very little else changed the history of that country forever.

For those of you now asking what is "Facebook?," know that you are not alone. The age of technology is moving so fast that those who only use e-mail may not know about Facebook, but it is shaping our future. Facebook is a social networking site that provides people with common interests the opportunity to post messages, pictures, communicate with each other in "real time" and more. **To be a more effective advocacy voice, VOR has just set up a Facebook page.** Facebook users can find VOR's page by searching for "VOR" from your Facebook page. Invite your children and grandchildren too!

Facebook is an important step toward engaging those who use technology to build our base, organize within states, and help us to raise money for our very worthy organization. If we can use this new media to help us with those goals we will stay on track.

### Increased Advocacy and Financial Needs

Our work is necessary and expanded support is critical. VOR is up against the "non-for-profit" adversaries with millions of dollars to spend to keep up the fight in Washington,

*Never doubt that a small group of thoughtful, committed citizens can change the world.*

*Indeed, it is the only thing that ever has."*

**Margaret Meade**

D.C. and locally. With federally-funded support from the Department of Justice and P&A, our adversaries have

limitless power to take us on in the courts. While some state governments have shown a willingness to defend their continuum of care, including ICFs/MR, in other cases, it is the family members that are fighting alone and VOR has been receiving an increasing number of requests to help. VOR's role is continuing to empower members through information, education and training about the ways to be good advocates, but often it is legal help that is desperately needed.

By continuing and increasing your gifts to VOR, you make sure we will have the resources necessary to assist in nationally significant cases so that each victory is a victory for all of us.

### Like no other – the 2011 Annual Conference & Initiative

Several VOR members have said, "This could very well be the best VOR conference ever." I agree! It is one you don't want to miss.

The schedule and plans for this year's initiative are wonderful and the advocacy-training workshop that VOR has secured is being tailored for our



**Robin Sims**

group and our advocacy needs. To find that kind of workshop in your home state would be very difficult; the Washington trip this year will be well worth your time and effort to attend.

**Annual Conference continued on page 11**

## In this issue

<b>ADD supports closing ICF/MRs</b>	<b>4</b>
<b>A Sibling's Perspective</b>	<b>5</b>
<b>Annual Conference &amp; Washington Initiative</b>	<b>6-7</b>
<b>Legal News</b>	<b>8</b>
<b>Every Member Campaign</b>	<b>10</b>
<b>Contribution Form</b>	<b>11</b>
<b>Annual Conference Registration Form</b>	<b>12</b>

### 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.

*On The Cover:*  
**Stephanie Vance**



# Welcome 2011!

## Executive Director's Message March 2011



**Julie M. Huso**

This year, VOR will be addressing amazing challenges and opportunities.

All of us at VOR recognize the increasing need for VOR to continue to provide you with up-to-date information about what is happening throughout the United States. We also recognize the need to provide more educational opportunities to each of you so you can better respond to your state's initiatives that will affect your loved one.

The 2011 VOR Annual Conference and Initiative provide an excel-

lent opportunity for information and training. At the Annual Conference, we will host a half-day advocacy-training workshop led by Stephanie Vance. Ms. Vance, known as the "Advocacy Guru," knows the challenges that grassroots advocates have getting access and being heard by elected officials. Sam Bagenstos with the Department of Justice, and Clare Ansberry, a reporter for the Wall Street Journal will also speak.

### By Julie Huso Executive Director

You can read more about our Annual Conference

agenda on pages 6-7, and look for the registration form on page 12. We promise an event that will train, empower and inform! This is truly a wonderful opportunity for all attendees to listen, learn and take back some wonderful information to your state and to share with your parent/family groups. Please plan to attend and registering early!

VOR's annual event in Washington, D.C. will also include, once again, a roundtable discussion session for VOR State Coordinators and a Member Forum, to allow participants to visit directly with the VOR Board of Directors, and I know they look forward to hearing from you.

This edition of *The Voice* also includes information regarding individual or organization sponsorship opportunities. VOR is again 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/](http://www.vor.net/events/). Or call Julie Huso at 605-370-4652.

### Thank you in advance for your financial support!

VOR is the only national organization that advocates for you and your loved one's ability to choose where they live and what is best for each person. We have assisted in at least 26 states by providing testimony support, legal support, advocacy support plus much more.

Please remember that VOR relies solely on donations and receives *no government funding*. We will continue to be there for you and your state when you need us; however, we must also increase our funding and donations.

In this newsletter, you will find several ways to give: The VOR Every Member Campaign, (details on page 10), general donations, gifts in honor or in memory of a loved one or a special person, and there are also opportunities for you or your family group to become a sponsor at the 2011 Annual Meeting and Initiative (details on pages 6-7).

The desperation and misery experienced by millions of individuals with ID/DD compel us to continue the work at VOR. Thank you for your past and future support.

### VOR Board of Directors

#### Officers

Robin Sims (NJ), *President*  
Mary McTernan (MA), *Past President*  
Sybil Finken (IA), *First VP*  
Ann Knighton (GA), *Second VP*  
Barbara Cukierski (IL), *Treasurer*  
Elbirda Haley (KY), *Secretary*

#### Board Members

Jill Barker (MI)  
Brian Boxall (CA)  
Mary Kay Cowen (LA)  
Martha Dwyer (NY)  
Catherine Gover (MA)  
Mary O'Riordan (CA)  
Sandra Reeves (TX)  
Bill Ryerson (NC)  
David Swain (NV)

VOR



## Proposal to eliminate "provider tax" cause for concern

Thirty-seven states and the District of Columbia have a federally-approved provider tax program to generate additional funds to more adequately fund long term care services for seniors and people with disabilities. The tax is imposed on health care providers, including ICFs/MR, based on a percentage of the providers' gross revenue. The percentage taxed, up to 5.5% (6% after Oct.), differs by state. The tax collected by the state is matched by federal funds. States use this additional revenue in varying ways, including support for community-based programs, skilled nursing services, or higher Medicaid rates to nursing homes.

The President's Fiscal Year 2012 budget proposal includes a provision to reduce the provider tax threshold in phases over a 3-year period beginning in 2015. From 6% in 2015, the percentage would be phased down to 4.5% with reductions to 3.5% by 2017. VOR is concerned that such reductions will leave a gaping hole in Medicaid funding that participating states now rely on for quality long term care, including additional funding for community-based programs.

The President's budget only serves as a recommendation to Congress. While the House and Senate Budget Committees will take the document under advisement, they are not required to incorporate any of the President's recommendations into their own budget bills, and often do not. (Source: [www.ahcancal.org](http://www.ahcancal.org)).

## ADD recommends closure of ICF/MRs

In late 2010, VOR participants in Orlando, Dallas and Detroit testified at "listening sessions" hosted by the Administration on Developmental Disabilities (ADD). ADD is the federal agency that oversees the state DD Act programs, including P&A and DD Councils. VOR participants objected to activities by some DD Act programs to eliminate the ICF/MR option, placing fragile constituents at risk and contrary to the DD Act requirement that individuals and their families be primary decisionmakers.

In spite of VOR's comments, ADD recommendations include: "Develop and implement plans to

close public and private institutions and segregated workshops."

(Prioritization Session Summary, [www.envision2010.net](http://www.envision2010.net), p. 12).

In response, VOR issued an Action Alert and hundreds of people in support of residential choice responded. ADD's support of ICF/MR closure is contrary to law and Congressional intent. DD Act programs receive federal funding to represent ALL individuals with developmental disabilities, no matter where they choose to reside.

***ADD, in supporting ICF/MR closure, is acting contrary to law and Congressional intent.***

***DD Act programs receive federal funding to represent ALL individuals with developmental disabilities, no matter where they choose to reside.***

## VOR seeks reintroduction of class action reform bill

Due to outstanding advocacy by VOR members, at the conclusion of the 111<sup>th</sup> Congress H.R. 1255 had support of 91 U.S. Representatives from both sides of the aisle. H.R. 1255 proposed giving individual and guardian decisionmaking rights in class action lawsuits filed by federally-funded lawyer organizations (such as P&A) against ICFs/MR by requiring advance notice and opt out rights.

January marked the beginning of the 112<sup>th</sup> Congress and with a new Congress, all legislation must be introduced and assigned new bill numbers. Due to the leadership change in the House from Democrat to Republican, VOR is seeking a Republican sponsor to join Rep. Barney Frank (D-MA), who remains very supportive.

VOR's class action reform objectives are a key part of the organization's overall DD Act reform proposal. In January, VOR legislative leaders met with key Congressional staff to urge DD Act reauthorization with meaningful reform aimed at ensuring that DD Act program recipients carry out the Act's requirement to respect family decisionmaking regarding residential choice.

### Congress at Home

Throughout the year there are "Constituent Work Weeks" when your Senators and U.S. Representative work in state offices, in or near your city.

Spring dates include:

March 21-25, an Easter break, May 16-20, & June 6-10.

To request a meeting, call as soon as possible - schedules fill quickly.

For contact information, check your phone book, visit [congress.org](http://congress.org), or contact Tamie at 877-399-4867 or [thopp@vor.net](mailto:thopp@vor.net).

### National Council on Disability (NCD) releases DD Act report

In Feb., NCD released "Rising Expectations: The DD Act Revisited," based on a year-long study of how well these programs are meeting the needs of people with developmental disabilities and their families.

VOR's Government Affairs Committee is reviewing the study. See, [www.ncd.gov](http://www.ncd.gov).



# A Sibling's Perspective

***Sisters with a 20-year age gap are normally very different; and in my case, I was the younger sibling and my 20-year older sister was severely mentally retarded. This is my story.***

As a young child, I remember playing with my sister Darlene, but I didn't really understand that she was different from anyone else. To me, she was an adult-sized playmate who liked Mickey Mouse, dolls, coloring books and purses--just like me! I have so many fond memories of us spending play-time together when I was young.

By the age of ten, I had become interested in sports and softball was my summer game. The community softball fields in Jonesboro were located next to the Human Development Center campus, the place where Darlene lived. On special occasions my dad would walk her across campus and let her watch me and my team play. But not real often. I think he sensed that, at age 10, it made me a bit uncomfortable having her present for my games. I knew my teammates didn't understand my big sister's condition, and sometimes I even felt embarrassed by her presence there. She was different. She was loud and she cursed! I didn't know how to explain her being different to the girls on my team.

During my teenage years, spending time with Darlene was not a priority to me at all. I had better things to do, I thought. But she still adored me. I was always her "Baby Heather." She still liked Mickey Mouse, dolls, coloring books and purses--but I had outgrown her simple life. She was my sister and I loved her, but I was too busy with school, friends, part time job, and other extracurricular activities to show her the love and attention she so rightfully deserved.

During my formative years I would ask questions about Darlene. Why was she different? Why did she live at "the center?" Why did she do "this" and why did she do "that?" Dad and Mom would always respond with age appropriate answers and as I grew older I began to develop a new and different love and admiration for my big sister.

As a young adult, I became committed to doing for Darlene those things she couldn't do for herself. I was a fresh-

man in college when I first learned there are people in this world who either don't understand the needs of my sister or don't care about her best interest. I learned about "Jane Doe" lawsuits being filed against the center where she lived and my sister being drawn into such lawsuits as a class action participant. The involvement of my sister and other residents of the center were against the wishes of their families and guardians. Our family vigorously opposed such tactics and I became exposed to what has become an ongoing challenge for residents of ICF/MR's--- the fight to keep them open and available so special people like my sister can have a choice in where they choose to live. The center where my sister resides is a beautiful facility and provides

*At age 10...*

*I didn't know how to explain her being different to the girls on my team.*



Heather Pickney-Bradway (left) and her sister, Darlene

*Today, at 25 years of age,  
I am what my mom and dad affectionately  
refer to as their AIT--- their "advocate in training".*

wonderfully for her needs. I remember taking the lawsuit situation and converting it into a persuasion speech for my freshmen oral communication class. I was successful in persuading the class to think twice before believing everything they hear on the news regarding the HDC's.

Today, at 25 years of age, I am what my mom and dad affectionately refer to as their AIT--- their "advocate in training". Dad says when he and Mom are gone someone will have to be there to speak up for my sister. Someone will have to protect her and fight for her right to choose. Someone will have to make sure the needs of her and her friends are met. I plan to be that someone. I hope there are other siblings out there who plan to be the next generation of advocates on behalf of their brothers and

sisters residing in the ICF/MR's of America.

VOR

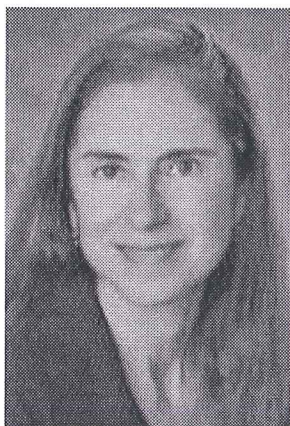


# VOR 2011 Annual Conference and Washington Initiative: Empowering Choice Advocates – The Voice Of Reason

**This is one conference you don't want to miss!**

With great speakers and an unprecedented grassroots training opportunity, the 2011 VOR Annual Conference is shaping up to be among the best that VOR has ever offered.

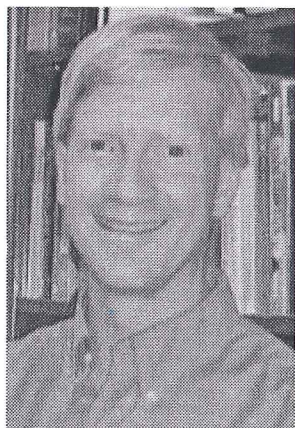
In addition to an inspiring President's Message by Robin Sims, speakers this year include



**Clare Ansberry**

Clare Ansberry is a seasoned writer who has focused on long term care issues, often featuring the plight of aging parents caring for their adult children with disabilities. In 2006, Ms. Ansberry received the "Darrell Sifford Memorial Prize in Journalism" for

Clare Ansberry, author and Pittsburgh Bureau Chief for the *Wall Street Journal*; and Samuel Bagenstos, principal deputy assistant attorney general for civil rights at DOJ.



**Samuel Bagenstos**

noted that, "In spite of considerable media coverage about the aging, the plight of [a generation of parents who have been consumed with caring for their disabled children] has been largely overlooked." Ms.

three such articles.

The Sifford Award recognizes reporters who "depict the personal struggles and triumphs that together make up the fabric of everyday lives." *Wall Street Journal* Managing Editor Paul Steiger

**Please Join VOR  
In Washington, D.C.  
June 10 – 14, 2011**

Ansberry's series of stories portrays the "heroic efforts of two of the nation's most vulnerable populations – the aging and the disabled – struggling in concert."

Sam Bagenstos, principal deputy assistant attorney general for DOJ's Civil Rights Division, will present to VOR's membership at a time when DOJ is active in several states, aggressively pursuing "Olmstead enforcement" actions (see Legal Briefs, p. 8). Mr. Bagenstos' presentation provides Conference participants with a unique opportunity to hear directly from a top official at DOJ.

Both presentations will include time for questions and answers.

**Why Advocacy Matters:  
Grassroots Advocacy Workshop  
Featuring Stephanie Vance,  
the "Advocacy Guru"**

This year's conference will for the first time feature a professionally-moderated grassroots advocacy training experience. Led by Stephanie Vance of Advocacy Associates, the workshop will provide training on effectively impacting laws and policies in support of people with intellectual disabilities and their families.

Ms. Vance has over 20 years experience in Congressional affairs. Her work on congressional communications stems from a deep and abiding belief that government is effective only when citizens are active participants. Ms. Vance will also host a related webinar separate from our conference (contact Tamie at [thopp@vor.net](mailto:thopp@vor.net) for webinar details).



**Stephanie Vance**

**VOR's WAS**  
**Taking our mes**

For more than 15 years, VOR members have carried our CHOICE message to Congress. VOR members will walk the halls of Congress the week of June 13.

This year we will seek Congressional support to vindicate our right "primary decision-makers" for our family members with profound intellectual disabilities (as established under the Developmental Disabilities Assistance and Bill of Rights Act, Medicaid law and the Supreme Court in the Olmstead decision). We are working now on securing the reintroduction of a bill that would require that individuals and their legal guardians receive advance notice and opt rights in certain federally-financed class action lawsuits. The bill enjoyed broad bipartisan support last Congressional session and we will work hard to secure significant support this Congressional session.

**2011 Con  
Prog**

Register online or use the form. All VOR members at the Liaison

**Friday, June 10**  
VOR Board of Directors State Report

**Saturday, June 11**  
VOR Annual Meeting Evening Net

**Sunday, June 12**  
State of the Union VOR Membership Legislative Briefing

**Week of Monday, June 13**  
Congressional Session

**Monday & Tuesday, June 13-14**  
Evening Debates

Each year, individuals, organizations associated with VOR's Annual Conference will be invited to participate at the conference, in VOR's public policy forum, and in VOR's Sponsoring levels and also "Representative" business, organization or individual.

[www.vor.net](http://www.vor.net)



## WASHINGTON INITIATIVE: Message straight to Congress

The VOR Washington Initiative provides VOR members with the opportunity to inform Congress (again) that VOR is the only national advocacy organization that supports a full range of residential options, from own home, to small residential settings to federally-licensed facility-based care (ICFs). We

### Conference and Initiative Program at a Glance

Website at: [www.vor.net/events/](http://www.vor.net/events/)  
Program on page 12

Meetings take place  
on Capitol Hill.

June 10  
Meeting  
Forum

June 11  
Conference  
Working Dinner

June 12  
Plenary Forum  
Forum w/ Board  
Briefing

Monday June 13  
Visits

Tuesday, June 13-14  
Briefings

Share their love of a family member who  
needs them to be their voice.

### Be a Sponsor

Businesses and businesses help cover the expenses associated with the Washington Initiative. All sponsors are recognized in the program, and on VOR's website. There are many "recognition" opportunities – a chance to honor a family member in VOR's conference program. Visit [www.vor.net/events/](http://www.vor.net/events/) for details.

## The fierce urgency of NOW: If not us, who?

By **Tamie Hopp**  
Director of Government Relations  
& Advocacy

Please join VOR  
in Washington, D.C. this June 2011!

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

VOR has used this first part of this quote often. President Barak Obama used the complete quote in February when giving U.S. Rep. John Lewis (D-GA) the Medal of Freedom Award. According to President Obama, "If not us, then who? If not now, then when?" is inscribed over a doorway in Nashville, where black students first refused to leave lunch counters 51 years ago this February.

**There is a powerful message  
in these few words.**

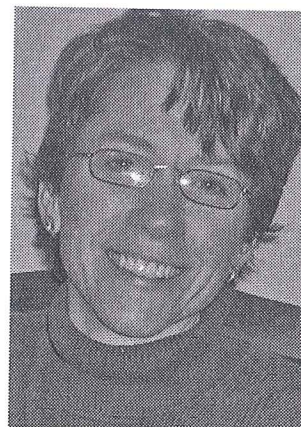
About 49.7 million Americans have a disability. Of these Americans, fewer than nine million are diagnosed with mental retardation, and less than 3% of these individuals have severe or profound mental retardation. When we consider these numbers, one can see how easily

our voices can get lost if we don't speak up loud and often. So, I say again: "If not us, who? If not now, when?"

**Don't take my word for it**

A recent survey of congressional staff members confirmed that in-person constituent contact is the top method for influencing legislators ("Communicating with Congress," Partnership for a More Perfect Union, Jan. 26, 2011). Another recent study looked at how U.S. Representatives,

each of whom represents about 700,000 constituents, determine who they meet with and what issues they support. The study found that some constituents have "mental access" to legislators and staff, namely "people who contact the legislative office often." (Source: *Unconscious Shortcuts*, U of Illinois, Feb. 2011).



**Tamie Hopp**

**The fierce urgency of now**

President Obama honored Rep. Lewis as an "American who knew that change could not wait for some other person or some other time; whose life is a lesson in the fierce urgency of now."

**Numbers count  
and we're counting on you**

VOR's advocacy is also a lesson in the "fierce urgency of now." Our fragile constituency is counting on

VOR's voice to ensure they continue to receive high quality services in the residential settings of their choice. We are motivated by a moral imperative, and though compelling to us, without regular contact – preferably in person in Washington, D.C. or in district offices – our issue may not rise to the top. Numbers count and we are counting on you. **Please join us in Washington, D.C. and do all you can from home. Thank you!**

**VOR**