

Fall 2008

VOR
836 S. Arlington Heights #351
Elk Grove Village, IL 60007
847-253-0675

President's Message

This Fall offers more than pretty leaves: "Tis the season for speaking out" – VOTE!!



By Robin Sims
President

Happy Fall to all of you!

With elections just around the corner it is important to be a part of the process on a state and national level.

The people running for your state and local offices have great influence on the way services are delivered to individuals with developmental disabilities in your state. Look into their positions on choice and their philosophy on services for the developmentally disabled, work for a candidate that meets your needs, and VOTE!

GET INFORMED!!
The following websites provide information on the candidates' positions on disability issues (Source: AAPD):

OBAMA
<http://www.aapd-dc.org/News/election/08bobama.htm>

McCAIN
<http://www.aapd-dc.org/News/election/08jmccain.htm>

On the federal level these issues are also important. Not only will this election usher in a new president, but there will also be many new and returning members of Congress to educate. VOR will continue to seek support for H.R. 3995. (Note: It is not too late to ask your U.S. Representative to cosponsor H.R. 3995; cosponsors will pave the way for the next session.)

The new Congress will also consider the reauthorization of the Developmental Disabilities Assistance and Bill of Right Act (DD Act), adequate funding for the Medicaid programs so critical to our loved ones' health, safety and well being, and other important issues.

Your VOTE does make a difference!

VOR Update: The 2008-2009 Committees have been named and are hard at work.

Since our last newsletter, members of all VOR Standing Committees have been assigned and all committees have met at least once.

We are so fortunate to have such a wonderful group of volunteers who work so hard on all our behalf. VOR staff members, Tamie and Julie, provide support to these committees, as well as many other things, to help keep VOR's leaders and members informed.

Homework!

I need your help! First, I would like to hear your story. We are going to work on our website and would love pictures of your loved ones and their homes to post there. Second, does a facility near you offer respite services? If so, what type (planned, emergency, etc.?) If you can help with either of these requests, please e-mail me at rsims23@aol.com.

VOR Standing Committees
Executive Nominating Legislative Membership Government Affairs Finance Legal Affairs

Also serving in 2008-2009:
DD Act Task Force
VOR Advisory Board

Committee Rosters
<http://vor.net/committees.htm>

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Photos from VOR's 25th Annual Meeting appear throughout these pages. Thank you Advocacy Network and others for your contributions.

President:
Robin Sims
Editor:
Rochelle Hagel

SPECIAL EDUCATION:

Abuse allegations in public school on the rise

In dozens of interviews, parents, special education experts and lawyers who work to protect disabled people said they now regularly hear of cases of abuse in public schools, much more often than a decade ago.

The issue is politically sensitive at a time when schools have done a lot to accommodate students with special needs, and some have questioned whether mainstreaming has gone too far. For teachers, who have many other responsibilities – not the least, to teach – managing even one child with a disability can add a wild card to the day. The line between skillful conflict resolution and abuse is slipperier than many assume.

Federal law requires that schools develop a behavioral plan for every student with a disability, which may include techniques to defuse the child's frustration. But in a hectic classroom, children with diagnosis that can lead to defiant, edgy or aggressive behaviors, and the plan, if one exists, can go straight out the window, investigators have found. Federal law leaves it to states and school districts to decide when physical restraints and seclusion are appropriate, and standards vary widely.

Oversight is virtually nonexistent in most states, despite the potential for harm. In one case, the parents of a boy with Asperger's syndrome are suing the school district, in part for costs of therapy for their son as a result of restraints used to "calm him down." (*New York Times*, July 15, 2008).

Legal NEWS Legal NEWS Legal NEWS

GEORGIA: Families seek place as stakeholders on Olmstead Planning Committee

A Voluntary Compliance *Olmstead* Settlement Agreement between the State of Georgia and U.S. Department of Health and Human Services' Office of Civil Rights (OCR) calls for the transition of all MR/DD and most mentally ill residents of the state's ICFs/MR and hospitals within five years.

The agreement demands that community programs be developed before individuals are moved; there will be no "dumping" of people in unprepared community settings, an OCR official stated in a recent presentation.

The agreement also calls for the development of an Olmstead Planning Committee. With VOR's support, several families of ICFs/MR residents applied to serve on the Planning Committee, which will submit a blueprint in seven months.

"Families and the legal guardians of the residents of Georgia's public facility residents must be prominently represented on Georgia's Olmstead Planning Committee. It is our loved ones', after all, who are directly impacted by this Agreement," one applicant wrote.

KENTUCKY: Surprise federal visit to Oakwood ICF/MR goes well

State officials believe they will get most federal Medicaid funds restored at Kentucky's largest residential center for

adults with mental and physical disabilities, based on results of a surprise inspection last week by federal authorities. Officials gave preliminary approval to conditions at three of four units at Bluegrass Communities at Oakwood.

Federal officials will return for another unannounced visit before giving final approval that would lead to reinstatement of

Medicaid money. Officials declined to approve a fourth unit and cited it for a safety violation. About 210 residents live at Oakwood, which the state has divided into four clusters of cottages. (Source: *Courier-Journal*, Sept. 2008).



L-R: Kathleen Miller (CA), Robin Sims (NJ), Dianne Smith (CMS) during IPP Panel Discussion at VOR Annual Meeting.

Photo courtesy Advocacy Network, Inc.

CALIFORNIA: Settlement calls for expanded community services

On Sept. 18, federal district court Judge William H. Alsup granted final approval of the settlement agreement in a civil rights class action involving Laguna Honda Hospital, a nursing facility in San Francisco. Among its many provisions, the agreement creates an innovative program to coordinate services across city departments, enabling San Franciscans with disabilities who live at, or are referred to, Laguna Honda, to instead receive community-based housing and services.

Eligible individuals will be assessed for, referred to, and provided with subsidized housing, attendant and nursing care, case management, substance abuse treatment, mental health services, and assistance with meals. In addition, several hundred

Medi-Cal Home and Community-Based waiver slots will be made available to those who qualify.

The agreement also calls for the development of a rental subsidy program, through which San Francisco will, over the next five years, secure and subsidize scattered-site, accessible, independent housing for approximately 500 people with disabilities and seniors who are eligible for community-based services. (Source: *PAI Press Release*, Sept. 18, 2008).

UTAH: Mentally retarded do not belong in jail

At the request of Sheriff Jim Tracy, county commissioners will likely declare that mentally retarded adults and those diagnosed with long-term mental illness will no longer be accepted at the jail when they commit acts of violence. No one seems to know where they should go instead. Sheriff Tracy says he can't justify, on moral or manpower grounds, taking in mentally retarded or ill suspects.

While population growth has contributed to the shortage of available space in programs for the mentally ill or retarded, the state has removed or stopped funding for

thousands of beds for long-term care over the decades at places like the Developmental Center in American Fork and the State Hospital in Provo. Some professionals and advocates blame, in part, mental health advocate groups that would rather see such people try to be integrated into society. (Source: *Daily Herald*, Sept. 17, 2008).

NEW MEXICO: Suit now 21; Taxpayers' bill \$4M a year

Filed in 1987, the P&A Jackson v. Fort Stanton class action lawsuit led to the closure of two state ICFs/MR. The case is costing the state more than \$4 million a year in legal fees, compliance monitoring and administrative expenses.

Current figures are not known, but in 2000 the State said the suit had cost about \$19 million. These costs do not include expenses related to direct care of the 3,700 developmentally disabled people in New Mexico's system whose services cost the state more than \$70,000 each per year. The total, much of it federal money, exceeds \$250 million a year.

Another 3,700 people with developmental disabilities on a waiting list for services from the department — a practice advocates are challenging in court. Dr. Alfredo



Tamie Hopp, Govt. Relations/Advocacy speaks at VOR Annual Meeting.

Photo Courtesy of Advocacy Network

...the state has faced a challenge in complying because the standard of care for the developmentally disabled has changed over the years, with care standards "evolving very rapidly."

**Dr. Alfredo Vigil,
Secretary of the (NM)Department of Health**

Vigil, secretary of the Department of Health, said the state has faced a challenge in complying because the standard of care for the developmentally disabled has changed over the years, with care standards "evolving very rapidly."

Attorneys representing developmentally disabled clients says the state's argument about moving targets would have more credence if it had met even the original goals. But the state is running into some concrete problems beyond its control, including a shortage of primary care physicians and dentists in the state. (Source: 2008 Source: *Albuquerque Journal*, July 20, 2008).

NEBRASKA: Committee hears testimony about Beatrice center

About a dozen parents and siblings of people living at Beatrice State Developmental Center (BSDC) got their chance to defend the place their loved ones call home during a daylong legislative public hearing. State senators on the committee also heard from some who want the center closed.

In support of BSDC, Sandra Ham told the Committee about her teenage son, Ian, who ran away from group homes, only to be picked up by police and returned to a sleeping group home staff. Another time, he wandered off in the dead of winter, located miles from home after an intensive, public search. Still another time he was in the car

when his group home staff was stopped for drunk driving. Chairman Lathrop commented on the obvious philosophical split between Beatrice center supporters — who want to make certain an institutional choice exists — and groups like ARC of Nebraska — that would like to see the Beatrice campus eventually closed and its \$52 million in state and federal funding used for community programs.

Sen. Steve Lathrop is chairman of the special committee, which is looking at issues involving BSDC. "It seems to me this is not a black and white issue. There is room for both (community programs and institutional programs)," Lathrop said. (*Lincoln Journal Star*, August 21, 2008).

VOR

Gets It Done!

Legislative & Government Affairs Program

Leveraging the power of its grassroots membership, VOR coordinates regular communication with federal officials on issues of critical importance, including an annual Washington Initiative, where volunteer participants hand-deliver VOR's positions to Congressional offices and federal officials.

Legislative Milestones

1993: VOR secures individual and family "primary decision-maker" language in the federal DD Act.

1997: VOR forms its first Legislative Committee.

1998: VOR secures the introduction of federal legislation seeking protections for people with mental retardation in Medicaid managed care. VOR receives commendation by the bill's sponsor in the Congressional Record.

2000: VOR secures stronger "primary decision-making" language in the DD Act.

2006: VOR hires its first Washington Representative, Larry Innis.

2006: VOR presents oral and written testimony in support of the facility option at U.S. Medicaid Commission hearings.

2007- 2008: VOR secures the introduction of H.R. 3995, a bill aimed at requiring federally funded lawyers to notify individuals and their guardians prior to filing class action lawsuits, and offer an opportunity to opt out of the lawsuit.

Donor's Forum

By Julie M. Huso
Director of
Resource
Development



Milestones...One step at a time!

Each new day brings new opportunities and new challenges. These opportunities and challenges allow us to grow and mature as individuals. As we mature, we become more patient. We become willing and able to pass up immediate pleasure in favor of the long term gain.

As we gain patience, we also gain perseverance - the ability to sweat out a project or a situation in spite of heavy opposition and discouraging setbacks. We become dependable; we keep our word and come through in crises.

Patience. Perseverance. Dependability.

All signs of maturity. All describe VOR and its 25 years of finding opportunities and facing

challenges. 25 years of legislative milestones, VOR awareness and outreach, and an ever-growing legal advocacy program. 25 years of assisting individuals and organizations, standing beside them as they advocated for their loved ones with mental retardation and developmental disabilities. 25 years of advancing VOR's mission 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 residences, congregate and intermediate facilities."

***Will you also step up your commitment to VOR?
It takes continued and growing advocacy
and financial commitments
by individuals like you and me
to get this important job done.***

As I wrote in the last newsletter, I'm new to VOR. As the new kid on the block, I marvel each and every day at all that VOR has accomplished. Since last writing, I have also had the opportunity to meet some people and tour some residential programs that really represent, to me, the real importance of VOR's Mission.

In Illinois, I had the pleasure of touring Misericordia, where I met an energetic young man who proudly showed me how to fold a fitted sheet that would fit in my linen closet. He was folding a sheet that he or his "Misericordia family", and friends may sleep on in their home! He took pride in his accomplishment, his contribution to his home.

In Minnesota, I met a bright young lady who gave me a tour of her room at the Lake Owasso Residence. I was honored to be invited into her home where she told me all about her neighbors and roommates - her community.

I have always thought of myself as mature - patient, persistent, dependable. Although I certainly remain proud of my lifetime accomplishments so far, the folks I met in Illinois and Minnesota left me feeling humbled and reminded me about the importance of VOR and my place in VOR's advocacy success. I am eager to do more to ensure that all individuals are able to stay in the home that

they have lived in for years and that their family

member or guardian be notified, if the state in which they live has different plans.

Will you also step up your commitment to VOR? It takes continued and growing advocacy and financial commitments by individuals like you and me to get this important job done.

Thank you for standing strong and helping VOR advocate for the right of everyone to live in the home of their choice, with the supports they need to ensure a dignified life. Your advocacy and financial support is appreciated!

Giving Opportunities Abound IN-KIND CONTRIBUTIONS TO VOR: Why VOR?

BACKGROUND & POLICY

During the June Annual Board Meeting there was a discussion about in-kind gifts to VOR.

An in-kind contribution is a voluntary contribution of an asset. In addition to being a gift, an in-kind donation must also be a contribution that is non-cash or not readily converted to cash. As bonds, and certain securities are readily converted to cash, they are not considered in-kind contributions.

In-kind donations generally fall into the following categories: donated goods; donated services; sales discounts and cancellations; or reductions of liabilities.

Throughout VOR's history there have been many in-kind gifts – such as accounting services, marketing design, and legal services – that represent hundreds of thousands of dollars benefit to VOR. In-kind donations are greatly appreciated and meaningful!

The VOR Board in June made a commitment to better account for these invaluable gifts. We have developed an In-Kind Donation Agreement form that will help VOR track these generous gifts, as well as assist you in determining if your gift is tax deductible.

If you would like additional information on how you can benefit VOR with an in-kind contribution, or to receive a In-Kind Donation Agreement form, please contact Julie M. Huso, Director of Resource Development, email husoj@sio.midco.net or call 605-370-4652.

**For more information
or
to join VOR
(\$25/year/individual)
877.399.4VOR • www.vor.net**

The Mission

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 residences, congregate and institutional settings.

Awareness and Outreach

Family-to-family advocacy, publications, media outreach, disability policy forums, and conferences help promote VOR's experienced perspective to affected families, policymakers and the general public.

Membership Benefits

Members also receive The Voice, a quarterly newsletter, the VOR Weekly E-Mail Update, Action Alerts with legislative updates and calls to action, and individual advocacy. Thousands of individuals, families, professionals and organizations support VOR through annual membership dues and additional contributions.



Brian Boxall, Enid Emde of California visit the nation's capital during VOR's Annual Meeting.

Information Is Power!

VOR Publications:
Future Life and Estate
Planning for Persons
with Mental Retardation
and Developmental
Disabilities, rev. 2008:

Life and estate planning supported by sound financial and legal planning is one of the most important steps parents and family members can take to help ensure the future welfare of their family members with mental retardation and developmental disabilities (MR/DD).

This publication, first published by VOR a few years ago, was recently updated. To view and print the publication, visit <http://vor.net/guardianship.htm>.

**VOR handouts
available
for your next
meeting!**

VOR has a number of handouts available for your next association's meeting, including information about VOR, cost comparisons, Olmstead, the "Myth of an Institutional Bias," and a new "VOR Programs and Milestones" card. These can be mailed to your association's membership, or placed as handouts at your next meeting. Contact Tamie at Tamie327@hotmail.com, or 605-399-1624, for more information.

In the last issue of The Voice, VOR featured summaries of reports received by members at VOR's 2008 State Report Forum in Washington, D.C. We offer the following corrections and updates.

Arkansas

The report incorrectly stated that the "statewide family association actively challenged the DD Council's harmful activities. . ." As reported, the statewide family association has worked to inform the Arkansas Council of its current objections to the National Association of DD Councils (NACDD) activities.

Pennsylvania

The report incorrectly stated that the "PA budget includes funds for eliminating all waiting lists." Rather, the budget at the time of the report was only proposed by the governor, and only for the emergency waiting list. Ultimately, the legislature approved funding for less than 1/3 of those on the emergency waiting list – a list with nearly 4,500 people and growing daily.

Texas

The report refers to "state centers." In Texas, state operated facilities are called "state schools."

Rhode Island: Medicaid proposal, closed-door talks draw concerns

Rhode Island's unprecedented attempt to transform its health-care system for its Medicaid population has drawn criticism from key congressional leaders, who fear that closed-door negotiations between the Bush administration and Governor Carcieri may put "beneficiaries, providers, and the entire state at risk...."

In recent weeks, at least eight members of the U.S. Congress — including the entire Rhode Island delegation — have submitted letters urging caution and transparency as the federal Department of Health and Human Services begins to review Carcieri's "global Medicaid waiver" application.

The plan has far-reaching implications for the 180,000 disabled, elderly and low-income residents touched by Medicaid programs last year. But, if approved, it would also pave a new road for other states eager to limit the cost of expensive and sometimes controversial "entitlement" programs.

"Medicaid provides a federal guarantee of health benefits for those in need," Sen. Jay Rockefeller (D-WV) said in a statement. "And that guarantee cannot be negotiated away through secret pacts between the Bush administration and governors seeking to cut Medicaid." Rockefeller chairs the Senate Health Subcommittee.

Rhode Island is trying to do what no state has done before. Therefore, it's unclear exactly how the federal review process will play out.

A Centers for Medicare & Medicaid Services spokesman yesterday refused to answer questions, only saying "We're looking very closely at the Rhode Island proposal."

In theory, the waiver concept is relatively simple. The governor will agree to limit all spending on Medicaid programs for the next five years. In exchange, the Bush administration will grant Carcieri broad authority to change health-care programs that consume roughly \$1.8 billion in state and federal spending this year, or 25 percent of the total state budget.

The governor has outlined dramatic changes to the state's long-term care system for the elderly and disabled, but changes may

VOR participates in the NC

For the second year, VOR exhibited at the National Summit in New Orleans. The 2008 Summit was attended by 1,000 attendees and 797 legislative staff. VOR member Paula Miller volunteered her time at VOR's exhibit, and Mary Kay supported by coordinating a very dedicated and effective team. VOR's exhibit was manned at all times.

The annual NCSL conference is a unique opportunity for VOR staff. Our exhibit materials strongly urge support for ICFs/MR and provide state lawmakers with information and more.

States face budget deficits: N

In looking at their FY 2009 budgets, states are facing a 10 percent shortfall, according to a report for June said.

Several states are proposing to balance their budgets by shrinking eligibility, or reducing benefits, according to a report for June said. The reason: falling revenues, Medicaid, and the need to balance state budgets. California is the state often acts as a "bellweather state" for health care cuts.

Congress is debating whether to temporarily increase federal support enhanced federal support at this time, which would impact Medicaid beneficiaries with disabilities.

also affect subsidized transportation programs for the disabled and elderly, health insurance for low-income children and their parents, and prescription drug coverage for seniors. General language in the 91-page waiver application outlines possible waiting lists for services, in addition to new co-pays for low-income residents.

Medicaid provides a health benefits for that guarantee cannot be negotiated away through secret pacts between the Bush administration and governors seeking to cut Medicaid.

Sen. Jay Rockefeller

But most details — including the size of the five-year spending cap and "escape clauses" that would allow Rhode Island to back out of the deal — will be decided in private negotiations.

Rhode Island's General Assembly would have 30 days to veto any tentative agreement that is reached.

But as the national debate plays out, state legislators are growing more anxious that the delay will jeopardize \$67 million in promised budget savings this year. Any substantial delay

NCSL 2008 Legislative Summit

Annual Conference of State Legislatures. Legislative attendees by 6,500 people, including 968 legislators. Hollon (Louisiana) enlisted other VOR members to pay Cowan, VOR member/volunteer provided onsite coordinative team of VOR volunteers who, with Cowan, as an opportunity for VOR to reach state legislators and their families for a full continuum of residential options, including information about cost comparisons, model state legisla-

Medicaid beneficiaries at risk

Facing collective deficits of over \$40 billion, three Annual Conference of State Legislatures (NCSL) recommendations budgets by cutting Medicaid – raising cost-sharing, according to Families USA, which cites a “perfect storm” of spikes in unemployment, increased demand for health care. California’s budget woes are of particular concern. Recent actions in California have spared some

increase federal Medicaid payments to the states, as part of the financial crisis. Advocates, including VOR, strongly oppose budget cuts in several states that are directly im-

could knock the budget out of whack, forcing “significant supplemental appropriations, significant service reductions to human service programs,” or other changes, House Finance Committee Chairman Steven M. Costantino recently wrote in a letter to the Carcieri administration.

“It has come to my attention that the global waiver application is encountering significant congressional concern, and possible opposition,” Costantino wrote, asking the administration to provide a detailed “Plan B” for reaching budget targets.

Carcieri has yet to provide such details, although Alexander said yesterday that a Plan B is nearly complete. Any alternative plan “will be onerous and will take a long time,” he said. “That’s what we’re trying to avoid.” (Source: *Providence Journal*, Sept. 16, 2008).

Florida

A deficit of \$153 million in the Medicaid waiver program and other budget woes led to a provider rate cut of \$43.5 million and a restructured Medicaid plan that, according to *The Times-Union*, includes four tiers for benefits with a cap on the amount that can be spent on services. The result is service cuts for about 7,500 people. Advocates for the disabled say the tier system was rushed and poorly executed.

Illinois

The state plans about \$600 million in health-care cuts, including making hospitals and nursing homes wait longer for Medicaid reimbursements. More than \$210 will be cut from social services – including services for people with developmental disabilities and “eliminates a rate increase for nursing services for people with disabilities” living in Medicaid community homes. Rates to private ICFs/MR will also be reduced by 2.5%, and funding to enroll persons in the community Medicaid Waiver will be reduced by \$3 million.

State News continued on page 8



L-R: David Hart (MA) and Don Putnam (KY) at Annual Meeting. Both are members of VOR's Legislative Committee.

Photo Courtesy of Advocacy Network, Inc.

Louisiana

The state’s budget reflects a 13% cut, which could mean cuts to Medicaid.

Maine

The state’s budget affects a number of health and human services, including cutting \$4 million in state funds, plus the additional federal match, to the Office of Adults with Cognitive and Physical Disabilities.

Massachusetts

The State House News Service says the state is offering financial incentives to state facility employees if they agree to be laid off or retire. The “voluntary” layoff plan is in response to budget shortfalls rather than declining residential populations.

New Jersey

The state’s “new \$32.9 billion budget reflects the largest absolute spending reduction in state history . . . and is only the sixth time in nearly 60 years that a governor will sign a budget that is less than the budget enacted in the previous year,” according to the Division of Developmental Disabilities.

New York

“Economic weakness has had a significant impact on state revenues and created a potential \$630 million imbalance in the 2008-09 fiscal year,” Gov. David Paterson said.

Washington

Hiring freezes and other cuts address a \$60 million gap in lost revenue due to the housing market slowdown and lower business taxes. Some are estimating the budget gap to reach \$2.7 billion.

**Maryland:
Relatives say
closing facility
would harm
disabled residents**

Relatives of Rosewood Center residents remain concerned about what will happen to their disabled family members when the state shuts down the long-troubled facility next year. They consider many of the group homes where officials want to move residents to be unacceptable.

Since January, when Gov. Martin O'Malley announced he would close the facility by executive order, about 40 of the 166 residents who were housed there have left. Rosewood officials have found homes for another 30 residents and have completed personal plans for 82 others.

Harry Yost, who heads a group of Rosewood families opposed to the closing, estimated that about 70 relatives want to keep their loved ones at the facility. He said he is refusing to participate in the discharge process and is hoping the federal government will intervene to keep the center open. Last month, the U.S. Department of Justice launched an investigation into Rosewood to determine whether conditions at the facility violated residents' civil rights, including plans for their placement in the community. (Source: *Baltimore Sun*, Sept. 15, 2008).

Illinois: State calls for closure of Howe

Illinois officials announced in early September that they will begin downsizing Howe Developmental Center, now home to 300 people, by winter, calling for its closure no later than July 1.

Residents of Howe and their families will have the final say on whether they move into community-based settings or other state-run institutions. The state has promised to place many of the 755 staff members at Howe in other state facilities.

Families are challenging the state's decision.

Texas: State not reviewing 'natural' deaths in waiver program for disabled

This summer, a 14-state report released by the U.S. Government Accountability Office found Texas was the only state that didn't review the deaths of people who succumb to "natural causes" in home or community-based care.

"There have been cases around the country of people in this population dying prematurely because of abuse and neglect," said Walter Ochinko, assistant director of health care for the GAO, which is the investigative arm for Congress. "There need to be systems in place to ensure that when a person dies, it really is of natural causes. Of all the states we looked at, it's clear Texas was the outlier."

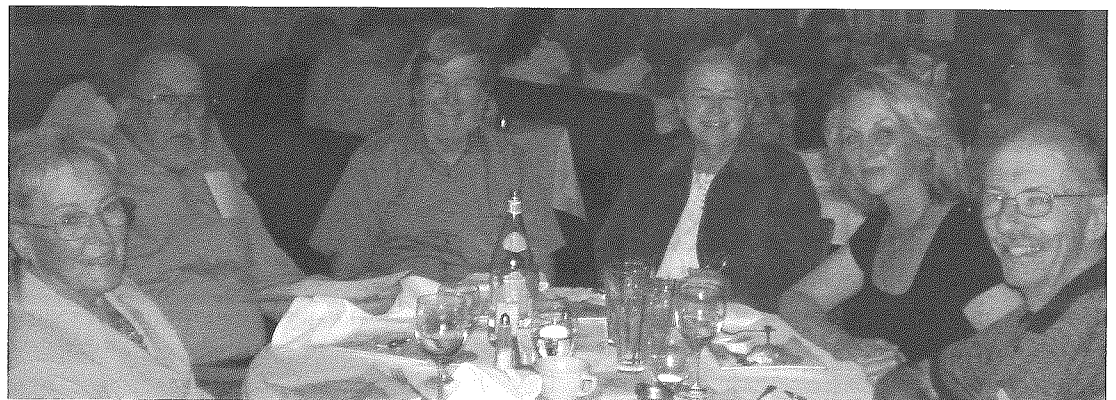
Texas officials say that at the time the report was issued, they were already exploring ways to improve their death data in home and community-based care settings.

Texas' Medicaid waiver programs give people with disabilities the option to receive care in group homes, with parents or in foster care – all alternatives to living in one of Texas' 13 state schools (large ICFs/MR). But the waiver slots are in high demand; tens of thousands of people are on state waiting lists for them. While opponents of institutionalized care champion these home-living scenarios as the best and safest solution for people with disabilities, state school supporters say community-based living isn't for everyone – and they point to shortfalls such as the absence of death investigations.

Since 2002, 447 people have died in Texas' Home and Community-based Services program, one of several state waiver programs. There's no way to know whether they died of natural causes, abuse or neglect; the state doesn't separate those numbers.

While all deaths in waiver programs must be reported to the state, this summer's federal report found that Texas did the bare minimum. At the time, the state didn't review "unexpected deaths" – only deaths where there was obvious abuse and neglect. It didn't use medical professionals to conduct death reviews, the report found. It didn't use death statistics to address quality-of-care issues, or to identify dangerous trends.

Of the 14 states that make up two-thirds of all Medicaid waiver patients, Texas is the only one that simply reported deaths and did nothing more. (Source: *Dallas Morning News*, Sept. 18, 2008).



Left to Right: Enid Emde, Dale Emde, Jim Grivich, Ann Grivich, Terry DeBell and Bob Hazard, all of California, enjoy dinner at Monocle, during VOR's 25th Anniversary Celebration.

Legislative Briefs

H.R. 3995 efforts continue

VOR members continue to advocate in support of H.R. 3995, a federal bill which would help put individuals with mental retardation and their families in the driver's seat regarding the decision whether or not to participate in a class action lawsuit against an ICF/MR. Forty-one members of the House of Representatives currently are cosponsoring H.R. 3995, and several Senators have indicated their support when the issue makes its way to the Senate.

Peter Kinzler, chairman of the VOR Legislative Committee, which is spearheading VOR's H.R. 3995 advocacy efforts, is pleased with the attention and support the bill has gained since first introduced a year ago.

"The diversity in party and philosophy among the cosponsors is remarkable," he noted. "It isn't often that Rep. Ron Paul, a very conservative Texas Republican, and Rep. Barney Frank, one of the most liberal members of the House, find themselves supporting the same bill," he added.

Kinzler cites the common sense underpinnings of the bill as one reason for such bipartisan support. "Why shouldn't families of

facility residents with profound mental retardation be notified and have the right to opt out of a class action lawsuit?" Kinzler asked. "I for one don't want P&A lawyers telling me what's right for my son, Jason. That's my job, not theirs."

With the session winding down, it is unlikely that the bill will be considered by Congress this year. VOR's Legislative Committee is not discouraged.

"We've done a lot of critical groundwork in the year since H.R. 3995 has been introduced," said Kinzler. "Rep. Frank has pledged to reintroduce the bill again early next session. We also anticipate that the issue could well be considered during the DD Act Reauthorization, another issue that VOR's Legislative Committee and a VOR ad hoc task force have been working hard to prepare for," added Kinzler. "The work we have done this year on H.R. 3995 is absolutely not in vain," he said. "We are well positioned to pick up this debate in the next Congress. We are determined to secure critically necessary reforms for our loved ones with developmental disabilities."

VOR submits additional federal comments in response to the proposed DD Act regs

In the last issue of *The Voice*, we reported that VOR submitted comments in response to proposed Developmental Disabilities Assistance and Bill of Rights Act (DD Act) regulations. The initial comment period closed in early June, but due to widespread difficulties in submitting comments electronically, the comment period was reopened and extended until September 29. VOR took advantage of this renewed opportunity to comment to resubmit our original comments and attach additional comments which reinforce critical themes, including support for informed consent in P&A class action lawsuits and strong opposition to "unfettered, unjustified and dangerous discretion" which the proposed regulations would, if finalized, place in the hands of state P&As.

VOR's new comments also recommend
Legislative News continued on page 10



Pilar Faló, Legislative Counsel to Rep. Barney Frank (D-MA), speaks at VOR's 2008 Annual Conference

Photo Courtesy of Advocacy Network, Inc.

VOR fights

for family rights!

VOR's Legal Advocacy

Program: Choices for a

Lifetime, Options For All

1993: VOR is Amicus Curiae in *Heller v. Doe* (U.S. Supreme Court), successfully arguing in support of family participation in placement decisions.

1999: VOR, with 141 organizations, is Amicus Curiae in the landmark U.S. Supreme Court case *Olmstead v. L.C.* The Supreme Court cites VOR's brief.

2000: VOR, with 93 organizations, is Amicus Curiae in *Garrett v. University of Alabama*, defending the constitutionality of the Americans with Disabilities Act.

2005: VOR establishes the Burke Legal Support Fund and recruits Martha Dwyer to serve as VOR's volunteer Pro Bono Coordinating Counsel.

2006- 2008: VOR secures representation for families in nationally significant cases in Florida, Illinois, Maryland, and New Jersey; and participated as Amicus Curiae in cases in Washington State, California and Massachusetts.

Education Milestones

1983: Editorials, interviews and quotes in major newspapers across the country.

2003: VOR's peer-reviewed cost comparison study is published in a respected professional journal.

2004: VOR's articles regarding measuring quality care are published.

2005: VOR publishes the Grassroots Organization and Advocacy Toolkit and hosts its first member training.

Bill would amend HCBS option

S. 3327 proposes to amend the Medicaid Home and Community Based State Plan option by giving states greater flexibility in determining eligibility and increasing the services states can offer. In exchange, states could no longer cap enrollment (no waiting lists) and services would have to be available statewide. The bill seeks to improve overall quality of Medicaid community services by providing grants for states to invest in organizations and initiatives relating, in part, to staffing issues. VOR is currently studying this bill.

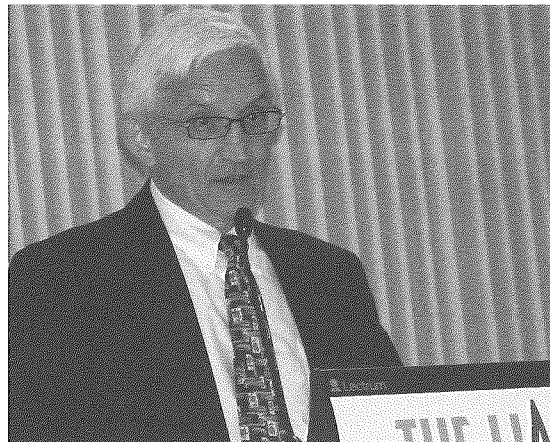
Congress extends SSI benefits to certain noncitizens

H.R. 2608 cleared Congress on September 17, 2008 and is now awaiting the President's signature. If approved by the President, the new law will temporarily extend the seven-year SSI eligibility period for refugees, asylees, and certain other humanitarian immigrants to nine years, from 2008 through 2011.

The two-year extension will also apply retroactively to those noncitizens whose SSI had previously ceased solely due to the expiration of the seven-year period. For these individuals, SSI benefits would be paid prospectively, monthly over the duration of the noncitizen's renewed eligibility.

Legislative News continued from page 9 that "the regulations must make clear that DD Act funding shall not be used to advocate against the purposes of the Act, including advocacy to downsize or close a Medicaid certified and licensed ICF/MR." Although the DD Act does allow for "educating policymakers" as one role of DD Act programs, VOR's comments argued that "lobbying motivated by an ideological objection to ICFs/MR goes beyond what the Act allows and is counter to Congressional intent."

In both statute and report language, Congress made it clear that individuals and their families, not the DD Act programs, were the "primary decision-makers" regarding needed and desired services, "including regarding choosing where the individuals live." Congress expressly cautioned, in the House Energy and Commerce Committee report accompanying this language, "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 supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system."



Andy Schneider, Chief Health Counsel for the House Oversight and Government Reform Committee [Henry Waxman (D-CA), chair], addresses the crowd at VOR's 25th Annual Meeting.

Photo Courtesy of Advocacy Network, Inc.

Congress passes Continuing Resolution; Stimulus package fails

Days before the end of the budget year ... Sept. 30, Congress passed a continuing resolution (CR) to fund the federal government through March 2009. Efforts to clear a stimulus package through the Senate failed, following the House's approval of a package that contained a significant increase in the federal Medicaid funds (FMAP) to states. The failure of a Medicaid increase disappointed disability advocates who had worked to secure a Medicaid increase for states.

Congress amends the Americans with Disabilities Act

Congress gave final approval on September 17 to a major civil rights bill which amends the Americans with Disabilities Act (ADA) by expanding protections for people with disabilities and overturning several recent Supreme Court decisions. The voice vote in the House, following Senate passage by unanimous consent last week, clears the bill for President Bush.

The bill expands the definition of disability and explicitly rejects the strict standards used by the Supreme Court to determine who is disabled. Initial disagreements over the bill were worked out in two years of intense behind-the-scenes negotiations that included members of both parties, people with disabilities, and employers. In deciding whether a person is disabled, the bill says, courts should not consider the effects of "mitigating measures" like prescription drugs, hearing aids and artificial limbs. Moreover, it says, "an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active."

Senator Tom Harkin, Democrat of Iowa, the chief sponsor of the bill, said the new law corrects the "Catch-22" situation created by the Supreme Court when the "more successful a person is at coping with a disability, the more likely it is the court will find that they are no longer disabled and therefore no longer covered under the ADA." (Source: *New York Times*, Sept. 18).

VOR

Contact Information

Membership Dues/Contributions

836 S. Arlington Heights Rd., #351
Grove Village, IL 60007
847-253-0675 fax

Development

Julie Huso
3605 W. Ralph Rogers Rd.
Sioux Falls, SD 57108
605-370-4652 direct / 605-271-0445 fax
husoj@sio.midco.net

Washington, DC

Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1VOR phone/fax
LarryInnis@aol.com

Govt. Relations/Advocacy

Tamie Hopp
P.O. Box 1208
Rapid City, SD 57709
605-399-1624 voice / 605-399-1631 fax
Tamie327@hotmail.com

Toll Free
877-399-4VOR

Website
<http://www.vor.net>

VOR
Weekly
E-Mail Update

<http://www.vor.net/current.htm>

To receive
the update directly,
contact
Tamie327@hotmail.com

About VOR

VOR is a national non-profit, 501(c)(3), volunteer-based advocacy organization. VOR is dedicated to ensuring that individuals with mental retardation and DD receive the care and support they require in quality settings appropriate to their needs.

Send articles to be considered for use in *The Voice*, or other VOR publications, to:
VOR, attn: Tamie Hopp
P.O. Box 1208
Rapid City, SD 57709
Tamie327@hotmail.com

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Or please charge to my VISA Mastercard

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- No changes are needed.

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence. It is in our best interest that you receive VOR's information, so please call if \$25 per year poses a financial hardship. Oct 08NL

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Louise Gayheart Underwood

A Champion of the Disabled

1936 – 2008

<http://www.vor.net/LouiseTribute.htm>

A Tribute to Louise Gayheart Underwood is now on VOR's website. The site features tributes received from Louise's friends and fellow advocates from around the country.

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836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
877-399-4VOR toll free
605-399-1631 fax
<http://www.vor.net>

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