

Summer 2008

President's Message

VOR
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605-399-1631 fax

Filling big shoes:
Thank you
for the honor
of serving you



By Robin Sims
President

It is a great honor to be the president of VOR. For the past 25 years there have been great leaders of VOR and I am humbled to be among them. My immediate predecessor Mary McTernan worked diligently for our organization well before her term as president, then as the president and now as immediate past president and a returning board member. This is a great comfort to me.

I started my tenure on July 1, 2008 and began by looking through the responses from our members and our current board regarding their willingness to serve on our various committees and the board. It was wonderful to see so many people willing to do this important work.

Federal ⇔ ⇔ ⇔ State:
Connecting the dots

I know that many of our members are busy within their own states and with their own children. The reports from the states on Friday during our Washington Initiative (see pages 8 -9) show us that we must work on the state and the federal level and connect the dots where we can.

It is part of my plan to help each VOR member understand how the federal laws affect your states and even the daily services and activities of your loved ones.

President:
Robin Sims
Editor:
Rochelle Hagel

Incredible opportunity: H.R. 3995

It is important to understand that the passage of H.R. 3995 and the creation of a companion bill on the Senate side will help us directly within our states and move us ahead in our battle to keep control of our loved ones' futures in our hands where it belongs.

A list of cosponsors (as of July 28, 2008) is on page 4 of this newsletter. If your representative is not on the list, call him/her, ask that he/she cosponsor H.R. 3995, and make an appointment to visit when your representative is in the district. It is up to you to tell your U.S. Representative how important H.R. 3995 is to you and your family. If we are silent then they will only hear from those who want to keep this bill from seeing the light of day (see p. 6 for details on what opposition is misrepresenting about H.R. 3995).

VOR is YOUR resource:
We are here to help

Along with Tamie Hopp who is the backbone of many of our efforts, you will also be hearing from our new Director of Resource Development, Julie Huso. Those of you who were in Washington, DC this year met Julie. For those of you who have not, I encourage you to welcome Julie and help her find opportunities within your state to grow our VOR membership and resources (see page 10 to "meet" Julie).

Please feel free to contact me with any suggestions, comments or information that you would like to share.

Thank you for putting your faith
in me to lead VOR this year.
I will not let you down.



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THANK YOU SPONSORS!!

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25th Anniversary Celebration

Sponsor: \$5,500

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Mary Beth Engberg

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Welcome new and returning VOR officers and board members New officers introduced VOR 2008 Annual Conference

Mary McTernan kicked off VOR's 2008 Annual Conference with a President's Address to the membership that highlighted VOR's accomplishments in the past year and provided updates on what's to come. This was Mary's last address as president. She passed the baton on July 1, 2008 to **Robin Sims**, VOR's new president. In addition to Robin, Mary introduced the 2008-2009 VOR Officers.

Mary also introduced two new board members, **Maxine Richey** (CA) and **Barbara Cukierski** (IL), and returning board members, **Marty Dwyer** and herself, both elected by the membership, with their three year terms beginning June 1, 2008.

The VOR board bids goodbye to two retiring board members, **Bert Springstead**, who served six years on VOR's board, and **Sam Golden**, who served an amazing 24 years on the VOR board of directors.

Happy 25th Anniversary VOR! A night for celebrating!

On the evening of June 14, VOR members enjoyed a 25th Anniversary Celebration at the historic Monocle restaurant in Washington, D.C. Attendees were treated to a lovely program that kicked off with a blessing by Ann Knighton and a song by Robin Sims.

During the program members shared their VOR memories and reflections. All past VOR presidents - Marty Pratt, Polly Spare, Marilyn Straw, Nancy Ward and Mary McTernan - were presented with a President's Award in gratitude for their many years of service to VOR.

Irene Welch, Ann Knighton, and Martha Dwyer served as the event's planning committee.

Happy 25th Anniversary VOR!

On June 14, 2008, nearly 100 VOR members from across the country came together to "Network, Learn, Grow and Advocate," the theme of this year's VOR's Annual Conference in Washington, D.C.

Attendees enjoyed programs relating to the Individual Planning Process (IPP), insight on federal law and policymaking,

2008-2009 VOR Officers

Robin Sims (NJ)

President

Sybil Finken (IA)

First Vice President

Carole Sherman (AR)

Second Vice President

David Swain (NV)

Treasurer

Elbirda Haley (KY)

Secretary

and tips on successful advocacy, including reaching the media and coalition building.

VOR is grateful to the presenters that donated their time and

expertise to inform and empower Annual Meeting participants. See <http://vor.net/2008AnnualMeetingandInitiative.htm> for a complete agenda. Pictures of VOR's annual event will be included in the Fall edition of *The Voice*.

The Voice Award 2008

In consideration and in gratitude of his decades long service to VOR, **Sam Golden** was presented with The Voice Award at VOR's Annual Conference. Sam Golden began volunteering his talents just one year after VOR was founded. In addition to his board service, Sam has served on VOR's Government Affairs Committee, including as chair. Mary McTernan noted that, "Sam's humble and charitable nature means he will continue to help VOR as he is able, even after 'retiring' from the board."

Thank you, Sam!

Remembering Louise Underwood



It is with great sadness that VOR reports the passing of our dear friend and long-time VOR leader, Louise Underwood. On June 23, Louise passed away unexpectedly in her Louisville, KY home. Louise helped co-found VOR with Marty Pratt and others 25 years ago. Until 2007, she served on VOR's Board of Directors and for nearly a decade served on VOR's Legislative Committee, many years as chairperson.

Sam Golden remarked, "Marty Pratt held her in high regard. Her work in the legislative field in the state and national government was legendary. I remember one briefing session for the Washington Initiative where she practically swept us off our feet with her cogent arguments on behalf of VOR's platform. If all of us could do what Louise did, we would not need to fear our enemies."

VOR is in the process of putting together a tribute to Louise for our website (<http://www.vor.net>). If you would like to share your memories, please email Tamie327@hotmail.com.

Champion of the Disabled

By Bob Heleringer

Special to *The Courier-Journal*

Friday, June 27, 2008

In February 1977, I had been a lawyer less than six months when an urgent telephone call came into my office. "Bobby, this is Louise. The state is closing Hazelwood," she said, "and moving our children out to nursing homes. And they're doing it right now."

"Louise," I replied, "What and where is Hazelwood?" I soon learned that Hazelwood was the old South Louisville Catarium the state had converted in the early 1970s to an ICF/MR for nearly 250 severe/profoundly retarded adults. Louise had a brother-in-law, Ronnie Underwood, who lived there.

Unthinkable but true, state officials had given no advance notice to the parents/families about Hazelwood's closing or the ultimate destinations of their loved ones' transfer. Galvanized into action by Louise, I soon found myself standing before U.S. District Judge Thomas Ballantine, who, after a hearing, granted our motion for a temporary restraining order, stopping Hazelwood's closure, and then ordered the immediate return of those residents who had already been sent to nursing homes. For the first time, and certainly not the last, Louise had saved the day by packing a federal courtroom, at a pivotal hearing, with anxious family members of Hazelwood's residents.

With Hazelwood saved, at least temporarily, Louise endeavored to prevent a similar crisis in the future by getting a bill through the 1978 session of the General Assembly. The passage of Senate Bill 285 represents some of the most progressive legislation ever adopted by Kentucky's legislature. It provided due process rights to parents/guardians of ICF/MR residents, including a right to prior notice of any intended transfer, a right to attend interdisciplinary team meetings

(often the prelude to a transfer), a right to legal counsel and a right to appeal adverse decisions to court.

Thus began a 30-year odyssey which ended sadly with her sudden passing -- a virtual one-woman tsunami who took up the cudgels, not just for Hazelwood's residents, but for every disabled citizen of our commonwealth. Not blessed with children of her own, Louise adopted every retarded adult citizen in Kentucky and became their champion, their voice.

And what a voice! When governors, U.S. senators, cabinet secretaries and committee chairmen were told "Louise" was on the phone, they never had to ask "Louise who?" If we legislators were the quarterbacks "executing the game plan," Louise was the resourceful offensive coordinator up in the press box. She, and her allies, the families, ensured that every rally in Frankfort, and every good piece of legislation or budget allocation, had literally a cast of thousands on hand for the stretch drive. Louise's boundless determination was often reflected in more than one harried legislator who would plead with me: "Heleringer, just tell me how to vote -- and would you please ask Mrs. Underwood to stop calling?"

Louise was never shy or apologetic about her passion or her, at times, bellicose demeanor when confronted with bureaucratic intransigence. In the Capitol, she had all the subtlety of Gen. George Patton sweeping through Germany's Ruhr valley. And she achieved similar results.

Louise Underwood's immense legacy will endure. She made a seismic difference in thousands of lives across the commonwealth, in the buildings and programs she shepherded so inspiringly from dream to reality -- all on behalf of her special people, who had no power, no influence, no respect, no consideration, indeed, no chance, until her full-throated, firebell-in-the-night voice demanded that public officials be accountable for all of our citizens, including our disabled.

Well done, Louise.

Well done, Thy good and faithful servant.

ADA Amendments 08

Originally titled the "ADA Restoration Act," the bill was filed in response to a series of Supreme Court decisions that advocates and many lawmakers felt chipped away at the protections of the ADA, "leaving millions of citizens vulnerable to a narrow interpretation of the law."

According to the bill's sponsor, Rep. James Sensenbrenner (R-WI), the Supreme Court has "created a broad range of people who benefit from 'mitigating measures' such as improvements in medicine, who still experience discrimination from employers, yet have been labeled 'not disabled enough' to gain the protections of the ADA."

Successful negotiations between disability advocates and the business community led to amendments that rely on the original ADA's phrasing - "substantially limited in a major life activity" - while defining it differently and adding explicit direction that courts are to interpret the legislation broadly for robust protections."

The revised bill easily passed the House 402 - 17, and is now being considered by the Senate.

Alaska

An Alaska Superior Court ruled last fall that the state's Division of Senior and Disabilities Services cannot deny respite services to family members who provide caregiving for an individual with a developmental disability. Alaska had claimed that its "respite limitation" policy was appropriate to "minimize fraud and abuse of the Medicaid system by families and the risk that Medicaid would become over-utilized by families who should be performing these services through informal supports." The court didn't find the Division's respite policies "to be a reasonable or rational fit regarding prevention of fraud," noting that a family member was no more likely to permit fraud than any other provider. Case: Gary McGrew v. Alaska (*NASDDDS, May 2008*).

Kentucky

A federal judge told Kentucky that it had to comply with a settlement agreement in a waiting list lawsuit by March 7. The settlement agreement in Michelle P. had been approved March 29, 2006 and included a stipulation that the state would increase funding for home and community-based waiver services. Kentucky eventually received federal approval for a community waiver to be available January 1, 2008, but due to a "mistake in calculating the costs of the Waiver," could not start the program. After a challenge by the plaintiffs, the Court concluded that the state "cannot be excused from performance of an obligation based on financial reasons, where they knowingly entered into the obligation after lengthy negotiation in which they were represented by counsel." (*NASDDDS, April 2008*).

Connecticut

A class action lawsuit filed eight years ago that accused the state of violating the rights of 300,000 low-income residents who have effectively been shut out of dentists' offices due to stingy state Medicaid rates has been settled. The terms of the settlement promise drastically increased state payments to dentists and the removal of some red tape that dentists say have made them reluctant to treat Medicaid patients. Case: Carr v. Wilson-Coker (*Hartford Courant, May 16, 2008*).

Georgia

Georgia and the Health and Human Services' Office for Civil Rights signed a voluntary compliance settlement agreement July 1 that formalizes efforts to transition Georgians with developmental disabilities or mental health issues out of state hospitals. Georgia's implementation of the settlement agreement will rely, in part, on a \$44 million Money Follows the Person Rebalancing Demonstration Grant, which was awarded to the state by the HHS Centers for Medicare & Medicaid Services June 30, 2008. The state will involve individuals receiving services and other advocates in planning how best to provide adequate community services to meet the needs of all Georgians with disabilities who are either living in institutions or at risk of institutionalization without community supports. (*NASDDDS, July 2008*).

Indiana

Getting substantial compliance - improved quality of care in community settings and the closure of 2 state centers - a 2000 Consent Decree between Indiana and the Department of Justice has been dismissed. (*NASDDDS, May 2008*)

Illinois

A case involving a young man with multiple disabilities who was living at home and receiving services under the State's medically fragile waiver (Katie Beckett waiver) was settled March 26. At trial, the state had argued that to provide the plaintiff services at home would amount to a fundamental alternation. The court disagreed finding the state's position was contrary to *Olmstead*. Case: *Radaszewski v. Maram (NASDDDS, May 2008)*.

Massachusetts

VOR and COFAR, VOR's state affiliate, filed a joint brief in the U.S. Court of Appeals supporting a federal judge's decision to keep Fernald Developmental Center open for its residents, arguing the decision is consistent with *Olmstead*. In August 2007, U.S. District Judge Joseph Tauro ruled Fernald must remain an option for its current residents. The state, which has long planned to close Fernald, appealed. The appellate court will hear the case on Sept. 3. Case: *Ricci v. Patrick (Daily News Tribune, May 5, 2008)*.

Massachusetts

Families have filed a motion to certify the class in *Rolland v. Patrick*. Class members, including

plaintiffs' loved ones, are MR/DD residents of nursing facilities. The parents object to a settlement agreement between the state and P&A, which calls for the transfer of their family members from specialized skilled nursing facilities. The parents say the lack of round-the-clock care at the group homes would not meet the needs of their children, who suffer from serious medical conditions, cannot talk or walk, and have a mental age of less than one year. (*Boston Globe, July 17, 2008*).

National

The Americans with Disabilities Act (ADA) protects against discrimination against caregivers of disabled people. In two cases, plaintiffs allege that PacifiCorp fired them after needing to take time off of work to care for disabled family members. Called "association-discrimination," experts expect more such lawsuits due to the slowing economy, rising health-care costs, more women and other caregivers in the workforce, and a growing ADA awareness.

New Jersey

The New Jersey Protection and Advocacy (P&A) filed a lawsuit in April against the State for not providing home and community-based services for individuals with developmental disabilities. The complaint specifically describes six individuals with developmental disabilities who have been placed on a waiting list for home and community-based waiver services, along with some 8,000 other individuals, for a number of years. Case: *New Jersey P&A v. Velez (NASDDDS, May 2008)*.

Washington, DC

A federal judge rejected a proposed agreement between the District and U.S. Department of Justice that proposed to establish programs and deadlines intended to improve health care for the District's developmental disabled group home residents. Not convinced the proposal would change anything, Judge Ellen Huvelle noted, "I've heard similar things over and over again." Trial is set for December. Attorneys for the residents hope the judge will order a takeover of the DC agency in charge of these residents and their care. A special monitor appointed by Huvelle found continued poor care, with some residents dying. Case: *Evans v. Fenty (Washington Post, May 16, 2008)*

H.R. 3995

Advocacy S Grassroots efforts gain

**42 H.R. 3995
cosponsors to-date:**
25 Democrats / 17 Republicans

Rep. John Barrow (D-GA)
Rep. Judy Biggert (R-IL)
Rep. John Boozman (R-AR)
Rep. Charles Boustany, Jr. (R-LA)
Rep. Steve Cohen (D-TN)
Rep. Michael Capuano (D-MA)
Rep. Elijah Cummings (D-MD)
Rep. Danny Davis (D-IL)
Rep. Tom Davis (R-VA)
Rep. David Dreier (R-CA)
Rep. Bob Etheridge (D-NC)
Rep. Bob Filner (D-CA)
Rep. Charles Gonzales (D-TX)
Rep. Bob Goodlatte (R-VA)
Rep. Al Green (D-TX)
Rep. Raul Grijalva (D-AZ)
Rep. Luis Guterres (D-IL)
Rep. Sheila Jackson Lee (D-TX)
Rep. Timothy Johnson (R-IL)
Rep. Paul E. Kanjorski (D-PA)
Rep. John Lewis (D-GA)
Rep. Dan Lungren (R-CA)
Rep. Stephen Lynch (D-MA)
Rep. John Larson (D-CT)
Rep. Doris Matsui (D-CA)
Rep. James McGovern (D-MA)
Rep. Brad Miller (D-NC)
Rep. Gary Miller (R-CA)
Rep. James Moran (D-VA)
Rep. Ron Paul (R-TX)
Rep. Jon Porter (R-NV)
Rep. Todd Platts (R-PA)
Rep. Ted Poe (R-TX)
Rep. Peter Roskam (R-IL)
Rep. Christopher Shays (R-CT)
Rep. Carol Shea-Porter (D-NH)
Rep. Pete Stark (D-CA)
Rep. Niki Tsongas (D-MA)
Rep. Tim Walberg (R-MI)
Rep. Frank Wolf (R-VA)
Rep. Debbie Wasserman
Schultz (D-FL)
Rep. Lynn Woolsey (D-CA)

You can help!

VOR and its members have worked hard in support of H.R. 3995. VOR grassroots advocacy before the VOR June 2008 Washington Initiative, including visits in the Members' district offices, resulted in 28 cosponsors. VOR Initiative participants leveraged this momentum and, following personal visits in Washington, D.C., the number of cosponsors is now 42 - and counting!

If you do nothing, your U.S. Representative will h

As recently as July 1, the National Association of Councils on DD (NACDD) issued an action alert calling on DD Councils across the country to write Congress opposing H.R. 3995. The NACDD alert and related correspondence contain a number of serious inaccuracies:

DD Council MYTH: H.R. 3995 would "severely inhibit the ability of P&As to take action to protect individuals with developmental disabilities [and] would place significant burdens on P&As' ability to pursue legal remedies against institutions that are neglecting or abusing their residents."

TRUTH: H.R. 3995 will not affect any advocacy activities of P&A on behalf of people with MR/DD, other than class action lawsuits against ICFs/MR. The requirements relating to notice and the opportunity for individuals and their legal guardians to opt out are limited to a 90 day period. After that,

Many more cosponsors are needed.

Please review the list of cosponsors on this page. If your U.S. Representative IS listed - write and say "Thanks!" If your U.S. Representative is NOT listed, call the office today and ask him/her to cosponsor H.R. 3995 and ask for a meeting in his/her District office near your home. Reference the long, bipartisan list of cosponsors, from the very far right to the very far left, and everyone in between.

P&A may still file the class action lawsuit on behalf of individuals who have not opted out.

DD Council MYTH: "Downsizing and closure are very good things."

TRUTH: Not always. In 30 states, reports of systemic abuse, neglect and death have appeared in newspapers, state audits, and scholarly journal articles. Congress, the U.S. Surgeon General, the General Accountability Office (GAO) and CMS have also cited serious concerns regarding compromised quality in community settings. As recently as May 2008, GAO raised concerns about tracking mortality in community programs.

DD Council MYTH: Because the DD Act promotes "self-direction, inclusion, productivity and integration within the community for people with developmental disabilities," NACDD must oppose H.R. 3995.

ccess! ng momentum

About H.R. 3995

passed, H.R. 3995, introduced by Rep. Barney Frank (D-MA), will help assure individual and family decision-making in federally-financed class action lawsuits against Medicaid-certified and funded

Intermediate Care Facilities

for Persons with Mental Retardation (ICFs/MR).

H.R. 3995 requires that before lawsuits against ICFs/MR can be filed, residents and their legal guardians must receive notice of the proposed lawsuit and be given an opportunity to opt out before the lawsuit is filed.

ar from the opposition

TRUTH: Nothing in the DD Act mandates the downsizing and closure of ICFs/MR. Nothing requires DD Act programs to only advocate for people with MR/DD who live in community settings. The DD Act expressly states that individuals and their families are the “primary decisionmakers” (not the DD Act

CALL YOUR

U.S. REPRESENTATIVE TODAY.

SCHEDULE A VISIT.

ASK YOUR U.S. REP

TO COSPONSOR H.R. 3995!!

programs). Congress has also stated very clearly that the Act’s support for community integration must “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.” (Emphasis added.)

Legislative Briefs

VOR comments on proposed federal regulations

In early June, VOR submitted two sets of written comments in response to ADD administration on DD and HHS proposed regulations. The ADD proposed regulation related to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

VOR’s comments supported proposals calling for enhanced oversight of DD Act programs, including P&A, and supported a process to ensure informed consent in class action lawsuits, citing H.R. 3995 as a model to follow.

VOR’s comments also strongly objected to the proposal’s apparent “significant expansion of unfettered, unjustified and dangerous discretion which this proposed rule leaves in the hands of state Protection and Advocacy agencies.” VOR’s comments noted that, “the combination of definitions and provisions of authority will allow P&A to access family homes to investigate the care provided by family caregivers, thus giving to the P&As authority not enjoyed by local police departments in ‘communities.’”

The HHS proposed regulation related to a new Medicaid Home and Community Based Services (HCBS) program. VOR expressed concern about the potential of some Medicaid beneficiaries being too disabled for the new benefit, but not disabled enough for other HCBS or ICFs/MR services.

House Introduces autism support bill

The Helping HANDS for Autism Act (HR 6282), introduced in June, is a three-part legislative package designed to support families dealing with autism spectrum disorders, increase awareness among first responders and public safety officials and provide housing options and services for adults with autism.

Appropriations will not be done before Sept. 26 adjournment

Congress is not expected to complete appropriations, including the Labor, Health and Human Services, and Education bill, before it adjourns September 26. Instead, a Continuing Resolution (“CR”) will fund the government until appropriations for the coming fiscal year are finalized.

Medicaid regulations’ implementation postponed

The implementation of six Medicaid regulations has been postponed until April 1, 2009. The measure passed as an amendment to the supplemental war appropriations bill, which was signed by the President in June. Disability advocates and states had complained that the Medicaid regulations in question, which related to case management, reimbursement for school-based administrative and transportation services, and rehabilitation services, would result in such steep cuts to federal reimbursement that vital services for Medicaid beneficiaries were at risk.

Legislative Briefs continued on page 4

Florida

Elysia Watkins: FL's budget crisis is resulting in cuts to nursing homes and DD programs, hurting FL's most vulnerable citizens. Over the past 4 years, \$180 million has been cut from the DD budget resulting in 8,000 people losing services. FL is considering a tiered approach, like triage, where needs are prioritized. Already 16,000 are waiting for services. Gulf Coast is still slated to close by 2010 due to a settlement agreement between P&A and the state.

Georgia

Ann Knighton: The East Central Georgia Family Council adopted a resolution endorsing H.R. 3995, which has been presented to the Georgia Congressional Delegation. In February 2008, VOR GA representatives attended legislative rally in Atlanta regarding the long waiting list. In October, families will host Federal Legislators, and their staff, for a picnic and facility tour.

Pennsylvania

Bert Springstead: Movement to the community in PA continues but has slowed. There are 5 PA developmental centers with 1,150 residents. Admissions by court order only. PA will receive Money Follows the Person (MFP) funding. The PA budget includes funds for eliminating all waiting lists.

State NEWS State NEWS State NEWS

On June 13, 2008, VOR hosted its 3rd annual State Report Forum in Washington, D.C. On these pages is a summary of those reports.

Arkansas

Carole Sherman: AR has six state operated centers. Six years ago these centers faced a budget cut which mobilized the families and resulted in budget language that has continued to protect the centers from budget cuts. Finding and keeping qualified staff remains a challenge. Families were successful in getting a bill introduced that would provide a higher pay for the second shift. It passed but was not funded. AR will receive Money Follows the Person (MFP) federal funds to transition facility residents to community settings. Due to strong stakeholder input, the impact of MFP in AR will not be as bad as it could have been. The statewide family association actively challenged the DD Council's harmful activities, and asked for the elimination of the DD Council "non-interference clause" in proposed regulations.

California

Mary O'Riordian, Terry DeBell, Brian Boxall, and Brad Whitehead: State bill 1183 was introduced to allow nonresidents to access needed medical and dental care at Sonoma Developmental Center. The bill is supported by a broad cross section of advocates, from families, unions, UCP, and even the CA P&A. Downsizing at Sonoma has slowed, thanks to a lawsuit that brought public attention to the tactics used to move some residents. CASHPCR, an organization representing three of CA's Developmental Centers (DCs), has been working on a project with P&A to annually assess the quality of life of people transferred from state DCs. CASHPCR has also responded to "interpretive conference guidelines" proposals that point to meaningless gestures as an indication someone wants leave a DC. CASHPCR also challenged "community readiness" presumptions by the interdisciplinary care teams, and is considering end of life issues. State bill 112 will establish a Blue Ribbon Commission to review and recommend changes to the Lanterman Act, the state's landmark disability law. Another bill will require that workers charged with abuse be in-

cluded on a registry so they can't be hired again. Agnews DC, originally slated to close in 2004, still has 140 residents due to very effective, coordinated advocacy by families that focused on holding the state to its promises; alternate homes are simply not ready. Some state-owned community homes are specially designed for medically fragile residents; finding good staff is a challenge. At state operated settings, direct care staff are represented by the CA Association of Psychiatric Technicians and participate in a 12-18 month training and licensing course before they are hired.

Illinois

Caroline Walsworth: There are nine state operated facilities in IL, but they face many challenges. Ligas is a P&A lawsuit that threatens private ICFs/MR. IL will receive MFP funds. MFP planning has included talk of "dignified risk." This year, a Community Resource Center bill, which would apply to all state operated centers, was introduced. Families supported the bill but the State DD Council opposed it because community residents would have to visit a center to receive services. The council proposed "mobile centers" instead. The state also opposed the bill, citing cost concerns.

Washington

Jim Hardiman and Rick Jensen: In one court case (Parsons), former Fircrest center residents received \$325,000 for harm suffered following their forced transfer from Fircrest. The lawsuit claimed that the state violated the Abuse of Vulnerable Persons Act (AVPA). The state opted to settle with the Fircrest plaintiffs after losing their attempt to claim immunity from violations of AVPA. VOR submitted an amicus brief arguing against immunity. WA officials, including the governor and key legislators, realize there is a need for specialized services for people with extreme needs. Both Fircrest and Frances Haddon Morgan received more funding, and \$4.5 million was appropriated for educating children at the state's ICFs/MR. Another bill was passed providing incentive grants to state medical schools for MR/DD coursework and inter-

Kentucky

Don Putnam: Despite budget cuts of \$130 million, the Kentucky legislature approved the development of three 8-bed ICFs/MR on the Hazelwood ICF/MR campus. Hazelwood's Lee and Underwood Clinic also continues to serve 600 people from the surrounding community (dental and medical). Kentucky will receive MFP funding, but families have been very involved in the planning, minimizing (but not eliminating) many concerns. Money will be used to transition people from nursing facilities and ICFs/MR to community settings. A 2006 P&A lawsuit led to a settlement which calls for public ICF/MR "beds" to be closed when a resident is transferred. Oakwood, a public ICF/MR, lost its Medicaid funding on May 17, 2008, following a federal survey. The state has appealed the decertification decision. Oakwood is also under scrutiny by DOJ. It was also reported that community based service providers can be appointed as legal guardians to their clients.

Louisiana

Mary Kay Cowan: Families are busy educating a whole new legislature, due to term limits, and a new governor. LA has also faced a budget crisis which led to cuts to disability services. Centers did receive a small increase in pay but a hiring freeze meant many workers were working double shifts. LA has six state ICFs/MR now called Supports and Service Centers. Centers are also running some of the newer group homes.

Massachusetts

David Hart: P&A and MA settled a lawsuit regarding the transition of MR/DD nursing facility residents to the community. The families of some residents, who receive care in specialized MR/DD nursing facilities, were not notified or included in the settlement and are objecting. In another lawsuit (Ricci) involving the state's plan to close Fernald developmental center, VOR and COFAR, a statewide family organization, filed a joint amicus brief, supporting the right of residents and their families to leave Fernald. In related case, the transfer

of a 91 year old Fernald resident from Fernald at the behest of her corporate guardian, the Greater Boston Arc, but clearly against her wishes, was challenged. A decision is pending. COFAR and VOR also advocated for speedy justice in a situation where a young man with DD has been the victim of a stalker and his gang.

Michigan

Jill Barker: Due to a poor economy, services for people with disabilities are at risk. The MI governor pledged to protect Medicaid services, but cuts are having an impact on Medicaid beneficiaries for example increased case loads and families assuming more care responsibilities and costs. Mount Pleasant Center is the only publicly run ICF/MR in MI. After a long campaign by the state Arc, P&A and other advocacy organizations, the MI Department of Community Health announced last Nov. that nearly all of the residents should move to community placements. Families only found out after information appeared on the Arc's website. Even now, the state denies that MPC is about to close, but has instructed local community health agencies to develop community placement plans. Families of MPC residents have organized and are challenging the state's actions with regard to MPC.

Iowa

Sybil Finken: Glenwood Resource Center (GRC) has 327 residents and 920 employees. GRC also operates nine community homes for 34 people. DOJ is still involved in regular monitoring of Glenwood and Woodward, the state's other ICF/MR. DOJ reviews have gone well. GRC admissions continue, including "Time Limited Assessment" admissions, where someone is admitted for only 30 days to assess program and medical assessments. IA will receive MFP funds. The state has stressed that participation is strictly voluntary and many parents are wary because they recognize that once their loved one transfers from the ICF/MR, there will be no way to return if community placement doesn't work out.

Missouri

Mary Vitale: Families have worked very hard since 2005, when the state said it would close Bellefontaine center, and have seen some success. The legislature approved the construction of a crisis center to be built on the Bellefontaine campus and efforts to privatize Bellefontaine have been defeated largely due to the lack of interest by community providers. MO VOR efforts also led to \$2.6 million for sheltered workshops, the defeat of a proposal to drop "mental retardation" from the agency's title, and passage of a bill that will require additional oversight of community providers (S. 1081). MO will receive two MFP grants; families are monitoring.

Texas

Sandra Reeves: There are 13 state centers ("schools") with about 500 residents in each. The Lt. Gov. formed a task force to listen to families about the need for state schools. Over the years the number of residents has not changed much, but there has been a shift away from the traditional resident, with more behaviorally complex residents (often children) being served. DOJ investigated Lubbock State School, which led to new management and other changes. DOJ is now looking at Denton State School. Lack of qualified staff is part of the problem. Additional funding was used for nurses.

Utah

Carola Zitzmann (a member of VOR's DD Act Task Force) sent the Utah congressional delegation proposed amendments to the DD Act.

1,000 TEDDY BEAR HUGS!

During the 2008 Washington Initiative, Jane Anthony had a wonderful idea that was inspired by a donated Teddy Bear for the VOR raffle. The Teddy Bear maker is VOR's own Mary Reese and she has agreed to make and donate as many Teddy Bears as we can raise money for.



For a \$1000 donation you will not only contribute to the great efforts of VOR, but receive a very special handmade Teddy Bear. For further information, please contact Julie Huso, Director of Resource Development, 605-370-4652 or husoj@sio.midco.net

Donor's Forum

By Julie M. Huso
Director of
Resource
Development



Just eight days after becoming VOR's new director of resource development, I found myself arriving in Washington, D.C. for VOR's 2008 Annual Meeting and Washington Initiative and 25th Anniversary. Although I was a bit nervous, I was also

excited to meet VOR's board members and some of its most active members.

I realize I have a lot to learn and who better to learn from than those who are so involved in VOR's advocacy?

What a blessing it is to be a part of VOR. The people I met in Washington, D.C., who I have no doubt are representative of every VOR member, are caring, committed, each with an internal fight that could not be measured. It became very clear why I was so fortunate to be part of VOR.

I would like to take this opportunity to share with you a little bit about me. I reside in Sioux Falls, SD and have three beautiful children and a wonderful daughter-in-law, who each day remind me how blessed I am and each in their own way teach me something new. I have been in the development field for over 20 years. My experience has included working with primarily healthcare organizations and a residential center that serves mentally and physically challenged children from birth to age 21. The mission of this organization and the work they continue to do have changed my life. That change led me to VOR.

It is with great pleasure that I am serv-

ing VOR as the resource development director. I was humbled by everyone I met and the stories each shared.

The mission that VOR stands for makes good common sense. But as we all know sometimes common sense to one person is viewed differently by another. The experience of being on Capitol Hill and sharing the importance of HR 3995 – and meeting other VOR members with our bright neon VOR bags in the halls of the Senate and House buildings – really emphasized to me (and I believe also Members of Congress) that VOR is an organization that works as a TEAM.

When geese fly in formation, they travel about 70% faster than when they fly alone. That's because geese share leadership. When the lead goose tires, it rotates back into the "V" and another flies forward to become the leader. Geese also help their fallen.

When a sick or weak goose drops out of the flight formation, at least one other goose joins in to help and protect. You

may have heard this before, but when I read it last week it reminded me of the people I met in Washington and the loved ones each of you are advocating for and protecting.

By being part of a team, we too can accomplish much more, much faster. Words of encouragement and support (honking from behind) help inspire and energize those on the front lines, helping them to keep pace in the face of pressures and fatigue. And finally, showing compassion and active caring for our fellow man.

Thank you for having me as part of the team. Without each and every one of you I cannot fly in formation to reach the goals of VOR. The immediate goals are to increase awareness of VOR and enhance the financial stability so VOR is in a position to continue to speak out for people with mental retardation and developmental disabilities. Please contact me with any questions or suggestions: 605-370-4652; husoj@sio.midco.net.

*By being part of a team,
we too can accomplish
much more, much faster.*

VOR

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

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the update directly,
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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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Membership/Contribution Form: Please send dues to—
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Membership Categories:

- Individual --- \$25
- Parents' Association --- \$150
- Professional Assoc./Corp. --- \$200

An additional gift/pledge is enclosed for:

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A check made payable to VOR is enclosed.
Or please charge to my VISA Mastercard

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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.

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. Aug 08NL

VOR Welcomes Tribute Donations

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