

Spring 2007

President's Message

**New Faces,
New Beginnings**
by Mary McTernan,
President



I am writing this message after spending a week in VOR's Chicago office orienting our new Executive Director/Director of Resource Development, while we endure record setting, bone-chilling cold here in New England. Tony Padgett, whom some of you had the pleasure of speaking with over the past year, gave his notice of resignation in mid-December after receiving an offer from a university in Illinois that includes tuition for his son – clearly an offer not to be refused and one VOR could not match! We regret Tony's departure, but do wish him all the best as he pursues his new endeavor.

As we pondered the process for seeking a new Director, a board member referred us to Geoff Dubrowsky. Geoff has considerable experience raising funds for organizations dedicated to autism research and awareness.



Geoff is also the parent of a young son with autism. Given his professional and personal dedication to disability advocacy, and his good track record of success, we decided to interview Geoff before embarking upon a costly advertising and interviewing process.

With all information in hand, the Board voted on February 19 to offer Geoff the Executive Director/Director of Resource Development position and he accepted.

Geoff "hit the ground running;" he was visiting VOR Board Member/Secretary Elbirda Haley and long-time Board Member, Louise Underwood, in Kentucky on February 23, and was in the VOR Chicago office on February 26 – all before March 1, his official first day! Geoff will be doing additional traveling, including to the

Washington Initiative in June. If you would like to meet Geoff, contact the VOR office – who knows – he may soon be in your area!

VOR's 2007 Annual Meeting and Washington Initiative

The second important issue this quarter is the VOR Annual Meeting and Washington Initiative in June. **Please plan to attend.** If you are not able to attend, please help another person from your state attend. Please see pages 10-11 of this newsletter for details about VOR's Annual Meeting, and a registration form to attend the Annual Meeting and Initiative.

There are a plethora of "new ideas" being transformed into federal bills this year; they all attempt to expand federal spending for people with disabilities – from long term care insurance funded through payroll deductions to federal wage-enhancement grants to address the unconscionably low wage scales endured by direct care workers in community settings. The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (the DD Act) is also on this year's Congressional agenda and MiCASSA, which proposes a new mandatory personal attendant care Medicaid entitlement, was recently introduced. Summaries of these bills and proposals are shared on pages 3 – 5 of this newsletter.

The VOR Board, Government Affairs Committee, and Legislative Committee, with the expert guidance of our Washington Representative, Larry Innis, are in the process of reviewing all the new proposals to determine which ones we can support and which ones require our opposition.

Regardless of what we face in the 110th Congress, VOR's Mission is to protect Medicaid and Social Security/SSDI funding, and to preserve individual and family/guardian choice.

Thank you for your support. We hope to see you in June! **V**

Coming Up

June 8, 2007:
VOR Annual Board Meeting
June 9, 2007:
VOR Annual Meeting.
June 10-15, 2007:
VOR Washington Initiative
See pages 10-11 for details.

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President:
Mary McTernan
Editor: Tamie Hopp

More Staff Changes: Tony Padgett and Tamie Hopp

Some of you might be wondering about Tamie Hopp and Tony Padgett.

As reported by Mary McTernan in her President's Message (page 1), **Tony Padgett**, VOR's Director of Resource Development during calendar year 2006, resigned to pursue a position with an Illinois University.

VOR's long-time Executive Director, **Tamie Hopp**, is still working hard for VOR. In light of her travel limitations – she has 2 small children – she graciously opted to step aside and let Geoff carry forward with the “Executive Director” title, a position that has been restructured to include the fundraising responsibilities previously held by Tony. Tamie will continue doing what she does best – government and member advocacy, with a new title: Director of Government Relations and Advocacy. As part of her role, Tamie remains primarily responsible for organizing the Annual Meeting and Washington Initiative.

If you have any questions for Tamie, please feel free to contact her directly at 605-399-1624, or Tamie327@hotmail.com.

Long-time VOR employee, **Joanne Kluck**, continues in her role as Administrative Association, working in the VOR Rolling Meadows office.

VOR's Board of Directors is optimistic that this staff restructuring will further enhance VOR's overall member relations and advocacy effectiveness. **V**

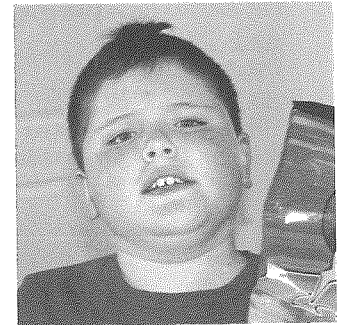
Donor's Forum

Out of the Box

By Geoffrey Dubrowsky, Executive Director

I would like to take this time to thank the members and supporters of VOR for the opportunity to serve as your new Executive Director. The fact that I have the opportunity to serve is a direct result of the efforts that so many of you have made for these past 24 years to advocate for our children. Without your voices and your vision, I am sure that the residential options that we have today would be gone. I also believe that the only way we can keep what options we have left is to push even harder and never stop providing a voice for our loved ones. I am proud that the VOR Board of Directors has asked me to help guide this initiative both as a professional and as a parent.

My son Danny is 11 years old and has autism. My wife Rosemarie and I have always searched out what would serve him best and we have always believed that one size does not fit all. We first dealt with the narrow mindedness of doctors when we started searching for a diagnosis. This led me to first serve as President of New Jersey Cure Autism Now, in an effort to try to make the autism community see past the diagnosis. Then, as Danny grew, we turned our focus to education and recreation, serving in various capacities always knowing that what works well with one kid, may not work with another.



My son, Danny, age 11.

As we move through our journey we see what lies ahead. People are out there with no stake in the game making decisions that take away our future options. As a father, I will not allow that to happen. As the Director of VOR, I will help VOR continue to successfully make sure that choice of residential placements and the funding to support choices will be there for all of our loved ones now and in the future.

Much work lies ahead. All of us in the advocacy community at war. Daily we fight public perceptions regarding the abilities of our loved ones and the elimination of services that best accommodate their needs. Luckily, however, we have an exit strategy. By empowering more and more people with the facts and the ability to advocate, we will be heard. By placing our loved ones faces at the front of the debate we will allow people to see how happy and safe they can be in every setting based on need. By taking a little more time out of each day to tell someone how special your loved one is, and how important VOR is to them, together we can all help win the war.

Now, since this is my first newsletter, the hard sell for donations will be replaced by a softer one with no specific request. However, you should begin to think about how you can help raise the VOR war chest and begin to think beyond your own checkbooks: Who do you know out there that can make a difference?

Begin to think *out of the box* and when a development idea to support VOR comes to mind, however weird it may seem, give me a call at 201-264-8654 and we'll talk it through. You never know – sometimes the best ideas start out that way.

I look forward to working with all of you. Thank you!

ACTION ALERT:
**Members of Congress need
to hear from you!**

With your help, in 1993 and 2000, VOR secured important federal statutory language that confirms that individuals and their families are the primary decisionmakers regarding residential services, supports and policy.

With your help once again, VOR will seize the opportunity in 2007 and call for dramatic DD Act reforms so that lawsuits against ICFs/MR can't be filed until you – as the family and guardian of your loved one – say it is OK. VOR's vision for tomorrow is one that puts you in the driver's seat BEFORE a lawsuit is filed.

If you feel strongly that **choice and family/guardian decisionmaking** must take precedence over the ideology of taxpayer funded organizations – state P&A's – then now is the time to act. This may be our only chance for another 7 years to secure critical choice first/family first reforms.

What you can do

Contact your U.S. Senators and Representative and ask them to support VOR's DD Act reform proposals. **Share with them this page from your newsletter**, which outlines the reforms you feel are critical to ensuring individual and family choice.

Spread the word! Share this call for action with others who will write in support of VOR's call for reforms.

Congressional Contact Information

To find out who represents you in Congress, visit <http://www.congress.org> and enter your zip code; or contact Tamie at 605-399-1624.

Please Act Now!
Thank You!

Choice First – Family First: VOR seeks critically necessary reforms to the Developmental Disabilities Assistance and Bill of Rights Act

Background

In 2007, for the first time in seven years, Congress is required to consider the reauthorization of programs receiving federal funding under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), especially Protection and Advocacy (P&A).

While the DD Act's policy endorses residential choice, some P&A agencies, through class action litigation, act to eliminate one of those choices – Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). These practices force the transfer of thousands of individuals from specialized ICFs/MR that are uniquely suited to meet their extreme needs. P&A lawsuits, for example, have been filed without regard to the choices of the people affected and their families/guardians. The resulting closures of some ICFs/MR have led to higher incidences of abuse, neglect and death of people with severe and profound mental retardation, who also have other debilitating physical, medical and/or behavioral disabilities. What's more, when P&A (funded by the U.S. Department of Health and Human Services (HHS)) sues to close an ICF/MR (funded and certified by HHS), the lawsuit could be titled HHS v. HHS – an absurd use of federal dollars.

VOR urges Congress to adopt the critical reforms

- A. Freeze P&A funding to give Congress time to review the programs and consider reforms.
- B. Freeze the use of funds for class action lawsuits involving the residents of ICFs/MR or, in the alternative, include language in the DD Act to further Congressional intent by:
 - i. Requiring that no P&A lawsuit may be filed against a Centers for Medicare and Medicaid Services (CMS)-certified facility that is in compliance with CMS regulations. If a facility is out of compliance, all CMS remedies must be exhausted before a P&A lawsuit can be filed; and
 - ii. Requiring that P&A's consult with, and obtain agreement from all the residents of an ICF/MR it seeks to represent, or, where appropriate, their families or guardians, before filing any type of lawsuit on behalf of those residents.
- C. A three year reauthorization so that the Congress can more closely monitor the effectiveness of DD Act policy and activity and how HHS is overseeing it.

“With your help, VOR will seize the opportunity in 2007 and call for dramatic DD Act reforms so that lawsuits against ICFs/MR can't be filed until you – as the family and guardian of your loved one – say it is OK. VOR's vision for tomorrow is one that puts you in the driver's seat BEFORE a lawsuit is filed.”

About VOR: Voice of the Retarded is a national organization advocating for the right of individuals with MR/DD and their families to choose from among a full array of high quality residential and other support options. For more information, please contact Tamie Hopp, Director of Government Relations and Advocacy at 605-399-1624 (direct); 410-757-1VOR(1867) (VOR Washington, D.C. office); or Tamie327@hotmail.com.

**Thank you for your compassionate consideration of
VOR's DD Act reform proposals.**

VOR Action Alert!

As the article on this page will detail, 17 states have been awarded Money Follows the Person (MFP) grants. Before these states can receive their grant funds, they must develop for Centers for Medicare & Medicaid Services review and approval, a "Demonstration Operation Protocol" (DOP). This DOP must "... formally engage all needed stakeholders ..." This is your opportunity to proactively demand a seat at the table. Contact your state's Medicaid office to determine what process will be used to develop the DOP and get involved.

This is another real opportunity for choice advocates - get informed and involved! **V**

2007 Money Follows the Person Awards for FY 2007

WI -- \$8,020,388
NY -- \$192,981
WA -- \$108,500
CT -- \$1,313,823
MI -- \$2,034,732
OK -- \$3,526,428
AR -- \$139,519
MD -- \$1,000,000
NE -- \$202,500
NH -- \$297,671
CA -- \$90,000
IN -- \$860,514
TX -- \$143,401
SC -- \$34,789
MO -- \$3,398,225
IA -- \$307,933
OH -- \$2,079,488
Total : \$23,750,892

Legislative Update

CMS Awards Demonstration Grants to 17 states for alternatives to institutional care

Seventeen states will receive more than \$23 million in grants for FY 07 and up to \$900 million over 5 years for demonstration programs that will help build Medicaid long-term care programs to keep people in the community and out of institutions. This Money Follows the Person (MFP) "rebalancing" initiative was included in the Deficit Reduction Act of 2005 (DRA) currently being implemented by CMS. States receiving grants under the MFP initiative (see list, sidebar) will design programs with four major objectives:

1. Eliminate barriers or mechanisms that prevent Medicaid-eligible individuals from receiving support for appropriate and necessary long-term services in the settings of their choice;
2. Increase the ability of the state Medicaid program to assure continued provision of home and community based long-term care services to eligible individuals who choose to move from an institutional to a community setting; and
3. Ensure that procedures are in place to provide quality assurance for individuals receiving Medicaid home and community-based long-term care services and to provide for continuous quality improvement in such services.

All states were eligible to apply for participation in the five-year demonstration that requires a commitment to participate in the demonstration services for at least two consecutive years. In addition to the 17 states awarded MFP grants during the first round, 22 other states received a letter from CMS telling them that they have to revise their proposal and resubmit it to CMS. A second round of state grants may be announced in March 2007.

For the first year of the demonstration, States receiving grant funds are eligible to receive a higher percentage of federal matching dollars to help cover the costs for people moving out of institutions and into community settings. The higher matching rate will be applied to certain services provided to an individual for a one-year period after the individual moves out of an institution and into the community. The state must continue to provide community services after that period as long as the person needs community services and is Medicaid eligible (Source: CMS, January 12, 2007). **V**

MiCASSA reintroduced

The legislation formerly known as MiCASSA, has been reintroduced in the 110th Congress under a new name. S. 799, the Community Choice Act of 2007 was introduced on March 7, 2007 by Senator Tom Harkin (D-IA), and co-sponsored by Senator Arlen Specter (R-PA). S. 799 aims to "increase access to community-based services and other supports for Americans with disabilities and older Americans," by giving individuals who are eligible for nursing home services or other institutional care "equal access to community-based services and supports." (Harkin Press Release, March 7).

In addition to creating a mandatory Medicaid entitlement for community-based personal attendant care services, the legislation provides enhanced federal matching funds to help states develop their long-term care infrastructure and grant funds to help states increase their ability to provide home and community-based services. The Congressional Budget Office, in its review of this legislation in a prior Congress, estimated the new benefit to cost \$10-20 billion in new federal revenues annually. **V**

Direct Support Professionals Fairness and Security Act of 2007

H.R. 1279, if passed, will provide Medicaid funds to states to enable states to increase the wages paid to targeted direct support professionals serving people with disabilities. The bill also calls for the Secretary of Health and Human Services to audit a sample from among participating states to assess the effectiveness of progress made in reducing or eliminating the wage gap between public and private service settings. **V**

DOL Announces \$2.5 Million in Grants Available for Healthcare Worker Programs

As part of President Bush's high-growth job training initiative, the Labor Department is making \$2.5 million in grants available to organizations seeking to develop and implement regional strategies for increasing the number of qualified workers for jobs in the long-term health care industry (Source: BNA, Vol. 12, No. 32, February 16, 2007). **V**

The CLASS Act

To be introduced soon, the Community Living Assistance Services and Supports (CLASS) Act proposes to create a new national insurance program that will be financed through voluntary payroll deductions of \$30/month. Anyone who is at least 18 years old and actively working will automatically be enrolled, unless they opt out. After 5 years benefits are available if the participating worker is unable to perform 2 activities of daily living (ADLs), or have an equivalent cognitive disability. **V**

Lifespan Respite Care Act signed into law

On December 31, 2006, the Lifespan Respite Care Act was signed into law. The new law authorize \$289 million over five years for state grants to develop Lifespan Respite Programs to help families access quality, affordable respite care. Advocates are calling on Congress to fund \$30 million in FY 2008 for Lifespan Respite Care benefits. **V**

Federal Budget News

The President's Budget Proposal

“[T]he Presidents budget includes legislative proposals that would cut key entitlement programs by \$101.5 billion over the next five years \$75.8 billion in Medicare and \$25.7 billion in Medicaid. Some of these cuts, \$10.2 billion in Medicare and \$12.7 billion in Medicaid, would be achieved through administrative actions by the Centers for Medicare and Medicaid Services (CMS) while the remaining cuts would need to be enacted by Congress” (Source: Consortium for Citizens with Disabilities, February 6, 2007).

The President's budget also recommends the elimination of the Supported Employment State Grant program, a 46% reduction to the Section 811 HUD Supportive Housing Program, a 32% reduction in the Dept. of Labor's Office of Disability Employment, and no new funding for IDEA, the Lifespan Respite Act, and the Combating Autism Act (Source: Disability Policy Collaboration, FY 2008 Budget and Appropriations Fact Sheet).

Next Steps – The Budget and Congress

Throughout February and March, both the House and Senate Budget Committees will prepare their responses to the President's budget, with the goal of completing the Joint Budget Resolution by April 15. The Joint Budget Resolution sets a blueprint for revenue and spending policy, including any potential changes to taxes or entitlements. Relevant committees must then craft legislation to accomplish the reconciliation instructions. The Budget Resolution will also establish spending limits for all discretionary programs (Source: Disability Policy Collaboration, FY 2008 Budget and Appropriations Fact Sheet).

Budget Research News: Two recent studies offer conflicting views of future Medicaid spending

In February 2007, the **Kaiser Family Foundation** released a study that concludes that expected growth in government revenues is likely to be large enough to sustain Medicaid spending increases over the next 40 years, while also allowing substantial real growth in spending for other public services. (Source: Kaiser Family Foundation, February 23, 2007).

In March 2007, the **Congressional Budget Office (CBO)** released its findings, which are dramatically different from the conclusions of the Kaiser Family Foundation research. Instead, CBO says that due to the rising costs of health care, spending on Medicare and Medicaid will continue to grow faster than the economy and faster than other government programs, even if the rate of growth in health care falls well below historic levels. (Source: CBO, March 8, 2007).

SCHIP Funding

The State Children's Health Insurance Program (SCHIP), provides Medicaid funding for states to cover 4 million eligible children. Advocates are calling on Congress to Reauthorize SCHIP and expand its funding by \$60 billion over the next five years – money needed to ensure that the children who are already eligible for Medicaid or SCHIP stay enrolled.

State admonished in Ricci for intimidation tactics

In the recent court proceedings (*see, "Ricci v. Okin – Fernald should stay open"*), Judge Joseph Tauro reviewed a letter from the state to families, which he characterized as an "attempt at intimidation."

The letter stated, in part, "As you know, the Fernald Developmental Center is closing, and remaining at the facility will no longer be an option." Tauro responded, "You may be wrong on that. I'd be very unhappy if another letter like that went out." V

Supreme Court to Decide Mental Illness Severity Threshold for Death Penalty

On April 18, 2007, the U.S. Supreme Court will hear arguments in the case of Panetti v. Quarterman, involving a Texas death row inmate with schizophrenia, to determine when a mental illness is severe enough to make execution impermissible under the Constitution. Although the Supreme Court ruled in 1986 that the Eighth Amendment's ban on cruel and unusual punishment would prohibit executions of those with mental illness, the decision (Ford v. Wainwright) stopped short of providing a definition of mental illness which could be used when determining competency for execution (Source: *AAPD*, January 2007). V

Litigation Concerning Home and Community Services for People with Disabilities

This report provides information about lawsuits concerning Medicaid community services for people with developmental and other disabilities. Published by the Human Services Resources Institution, a revised report is issued every 4-6 weeks. See, www.hsri.org/docs/litigation010907.PDF.

Legal Briefs

Massachusetts: Ricci v. Okin - Fernald should stay open

U.S. District Court Judge Joseph L. Tauro relied on Olmstead and agreed with court monitor Michael Sullivan's recommendation that the mostly elderly and profoundly retarded residents of the Walter E. Fernald Development Center should be allowed to stay there and that moving some of the 189 residents could put their physical and mental health in "unwarranted jeopardy."

However, Tauro gave the Department of Mental Retardation (DMR), the defendants in the case, until May 31 to respond and appeal the court monitor's report before he makes his final ruling.

Tauro's words came following a year-long investigation into the quality of care provided for 49 residents transferred out of Fernald since then-Gov. Mitt Romney announced his intentions to close the facility in 2003. In February 2006, Tauro halted further transfers from Fernald pending an investigation based on Attorney Beryl Cohen's claim, on behalf of the residents he represents, that DMR had not provided transfers with equal or better care as required by law.

After visiting all six state facilities and over 30 community homes, Sullivan's report found that the state's six institutions for the mentally retarded were well-maintained, clean, and well-staffed and that the state Department of Mental Retardation properly handled the most recent transfers of 49 residents out of Fernald. Sullivan's office determined that residents who had been relocated were receiving equal or better care.

The report also says, however, that "our office did note some very concerning neglect and abuse trends in contract vendor-operated community residences, as compared to the [state institutions] and state-operated community residences. These neglect and abuse trends, particularly sexual abuse, were of great concern to our office and shows that residents in our community homes are at a greater risk of being abused and/or neglected."

Sullivan also expressed concern about staff turnover in community residences, noting that, in some instances, staff turnover was 100% every 18 months. In contrast, Sullivan noted, a "strong sense of [staff] pride within the facility and it is evident in the longevity of the workforce as the average years of employment at the facility is 20 years, and the average age of the employee is 45 years."

Sullivan recommended that guardians who wish to voluntarily transfer their loved ones from Fernald to another state facility or a community home should be permitted to do so as long as the proper procedures are followed and safeguards are in place. But he strongly recommended that those who want to stay in Fernald should not have to leave.

The bar on transfers remains in place, but Tauro said he would look at making exceptions on an individual basis for a couple residents who want to move into the community and have been waiting for a year. Tauro said whatever is best for the individual should be respected in all cases, including the option to stay where they are. (Sources: *Daily News Tribune*, March 7, 2007; *Boston Globe*, March 8, 2007; Michael Sullivan, U.S. Attorney, Ricci Recommendations letter, March 6, 2007). V

Illinois: Ligas v. Maram – Intervention denied

In 2005, Equip for Equality (Illinois' Protection and Advocacy) filed a class action lawsuit on behalf of nine plaintiffs against the State of Illinois. Plaintiffs allege that state policy prevents them from accessing community services. The plaintiffs seek an order that would require the state to provide services within a smaller community setting instead of "segregating" them in large private institutions.

A group of private facility residents (Golden Intervenors) filed a Motion to

Ligas, continued

Intervene, fearing a systems-change remedy that would force upon them community-based care. The District Court denied the Golden group's request for intervention, finding that their interests "could not be impaired" by the remedy sought by plaintiffs, given the plaintiffs' assurances that choice would be protected.

Hearing an appeal brought by the Golden Intervenors, the 7th Circuit Court of Appeals agreed. "[T]he relief [Plaintiffs] seek would only require that Illinois provide that which (they allege) it does not currently provide: the existence of appropriate services tailored to the needs of the individual." Furthermore, since the Golden did not allege "gross negligence or bad faith on the part of the state defendants," it could be presumed that the state will protect the interests of the proposed intervenors.

Although disagreeing with the Golden Intervenors that a legitimate threat to residential choice exists, the appellate Court agreed with the intervenors' assertion that a range of services was necessary to meet individualized needs. Citing Olmstead, the court stated, "For some, institutionalized care is the best plan, while others are best served by integration into the community." (Source: Ligas v. Maram, No. 06-1327, 7th Circuit Court of Appeals, February 15, 2007). **V**

Florida: Brown v. Bush – Intervention denied

The 11th Circuit Court of Appeals upheld the lower court's denial of intervention, ending once and for all the families' attempts to intervene in Brown v. Bush. Despite overwhelming and prompt written opposition to the state and P&As settlement to close two state centers, a deal families first read about in the newspaper, the 11th Circuit Court of Appeals agreed with the lower court's determination that the families request to intervene was not timely. Both courts found significance in the fact that the Motion to Intervene was filed at the Fairness Hearing to consider the settlement, rather than in the months preceding that date when families were expressing their opposition in letters to the judge. (Source: Brown v. Bush, No. 05-15167, 11th Circuit Court of Appeals, September 11, 2006).

The settlement language requires the closure of two state centers, Landmark and Gulf Coast. Landmark closed in 2005, and the State has submitted its plan to close Gulf Coast by 2010. The closure of Gulf Coast and downsizing of the remaining Florida state facilities is subject to the legislature adequately funding the "census reduction."

Families have secured the introduction of state legislation that, if passed, will provide for greater controls and oversight before the Florida Cabinet can agree to future center closures. **V**

Supreme Court to Decide Case Involving Nonlawyer Parents Right to Sue Under the IDEA

On Feb. 27, the U.S. Supreme Court heard oral arguments in the case which will address whether or not parents who are not lawyers (*pro se*) have the right to represent their children with disabilities in federal court in Individuals with Disabilities Education Act (IDEA) cases. The case of Winkelman v. Parma City School District (No. 05-983) addresses a split among circuit courts, one circuit deciding that there are no limitations on the parents' ability to prosecute *pro se* an IDEA case in federal court, several circuits ruling that under IDEA parents can only represent *pro se* their own interests and not those of their child.

The National Council on Disability (NCD), states, "... it is clearly established that parents are a main enforcement vehicle for ensuring compliance with IDEA. The statutory scheme of IDEA makes parental involvement and access to legal services integral to the protection of a child's rights under IDEA." **V**

7th Circuit Court of Appeals: Olmstead stands for Choice

The 7th Circuit Court of Appeals found in favor of Omega Health Care Investors in its contract dispute with Res-Care over the operation of ICF/MR in Lexington, Kentucky. As part of its defense, Res-Care, citing Olmstead v. L.C., argued that enforcing the terms of the contract "would effectively prevent people with disabilities from leaving large institutional facilities like Exceptionicon [the ICF/MR in question], contrary to clearly stated federal and state public policies."

Dismissing this defense, the Court stated that "Res-Care's reliance on the integration mandate, as expressed by Olmstead, is misplaced. Res-Care overlooks the fact that Olmstead requires only that particular individuals be given the choice of community placement or institutional care. Olmstead specifically does not stand for the proposition that ICF/MRs must be closed. The Supreme Court explicitly rejected the argument that Res-Care is now making, that the ADA somehow requires that institutional care be discontinued. 'We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.' [citing Olmstead] . . . To the extent that there is a public policy on community-based care, it is a mandate that individuals be given choices, not a mandate to force the lessees of institutional facilities to shut the doors of their facilities in violation of lease terms."

The United State Court of Appeals for the Seventh Circuit is a federal court with appellate jurisdiction in Illinois, Wisconsin and Indiana (Source: Omega v. Res-Care, No. 06-1157, 7th Circuit Court of Appeals, January 22, 2007). **V**

News from Washington State

Bill encourages MR/DD med training

Washington State House Bill 1394, if passed, directs the Washington School of Medicine to develop a plan to train students to work with patients with developmental disabilities. As part of the plan, the medical school must include incentives to encourage students to participate in the training.

Families of persons with MR/DD have worked cooperatively with representatives of the Washington School of Medicine in support of H.B. 1394. The bill is expected to pass the House. **V**

Bills seek "institution review"

House Bill 1584 and Senate Bill 6013 calls for the creation of a 9-member "Institution Review Commission" to review the effectiveness of, and the need for, state institutions. H.B. 1584 proposes that the Commission have the authority to make determinations, including consolidation, expansion, or closure. S.B. 6013 proposes an advisory commission, with final determination left with the legislature (constitutional majority).

The House is not expected to act on H.B. 1584. SB 6013 has been reported out of Committee. **V**

State News

Missouri Center for developmentally disabled to remain open

Gov. Matt Blunt reversed a decision he made two years ago Tuesday, saying that a once-troubled center for the developmentally disabled will remain open, to the surprise of residents' families and advocates. Blunt unveiled a new plan involving both private and public care at a news conference at the Bellefontaine Habilitation Center in north St. Louis County.

Under the new plan, the center would help 156 people at a time, the governor's office said. A private-care provider would oversee 120 beds at the center, while a state-operated program would serve 24 residents with the most severe developmental, medical and behavioral conditions. The state also wants to create a new 12-bed crisis stabilization unit onsite to provide temporary care to developmentally disabled people from throughout the region. Also, an outside provider working with the state would provide programming for residents during the day.

In 2004, about 350 people lived at the center, state officials said. There are 172 residents today. Plans to place 28 Bellefontaine residents in programs elsewhere will move forward.

When Blunt said Bellefontaine should close in 2005, residents' families were surprised. Some again expressed shock Tuesday about the reversal and, as an aside, questioned why they weren't given advance notice about their relatives' future.

"It's good, whatever it is, it's good," said Mickey Slawson, 74, of the plan to keep the center open. Her daughter Carol has lived at Bellefontaine for about four decades. "This is the safety net for the severely and profoundly retarded," she said.

However, another mother, Betty Coll, was worried about involving private providers. "They're out to make a profit, no matter what they say."

State Rep. Regina Walsh, D-Bellefontaine Neighbors, said of the plan, "I really don't think privatization is the answer." The answer, she said "is prosecuting the people perpetuating the abuse."

Walsh said she has filed a bill that would require private mental-health facilities to be held to the same safety, staffing and training standards as state facilities (Source: *Associated Press*, March 13, 2007). **V**

New Jersey Supreme Court rejects Division of DD eligibility limits

In a unanimous opinion March 1, the New Jersey Supreme Court said that the state's Division of Developmental Disabilities (DDD) "exceeded its power" in creating regulations that denied state aid for people with developmental disabilities who could not prove they had the disabilities before age 22. The Court said the limitation DDD created "adds an eligibility requirement not contemplated by the Legislature" and ordered DDD to rewrite its rules to conform to state law. The Court also pointed out that "there is nothing in the federal act or regulations on which our [state] statute is modeled to support DDD's view." The ruling reversed an Appellate Division judgment (Source: NASDDDS, March 7, 2007). **V**

Agency name changes proposed in three states

Massachusetts, Ohio, and Connecticut all have bills pending that propose changing the names of their "Departments of Mental Retardation," to reflect a trend away from the use of "mental retardation." In related news, the American Association on Mental Retardation is now the American Association on Intellectual and Developmental Disabilities (AAMR), and its premier research journal, *Mental Retardation*, is now *Intellectual & Developmental Disabilities*. **V**

Still Failing the Vulnerable

The neglected lives of the mentally retarded men and women entrusted to the District's care were sketched in dreadful detail on the front pages of this newspaper eight years ago. City officials voiced outrage and vowed to make things better. That promise has not been kept. The city's treatment of the developmentally disabled is as troubled as ever.

A recent report by a federal court monitor documented poor health care, lack of critical services, and allegations of abuse and indifference involving the city's most vulnerable residents. Most alarming was the finding that 13 of some 650 people whose cases are being monitored had died in just four months. The number is high, but the population in question is aging and medically fragile. What's worrisome is the absence of any vigorous, independent investigation into their deaths.

Thankfully, the city has acknowledged the shortcomings of its current system, agreeing to hire an outside investigator and also to reinvestigate any case seen as tainted. It's a sad commentary on how far the city must go in meeting the needs of helpless people that it had to have the court monitor define what she meant by "clean," "pleasant" and "safe." Or that, in advertising for a new director, the city warned any successful applicant to be prepared to cope with "many under-qualified and/or unmotivated staff."

So far, Mayor Adrian M. Fenty has anointed his general counsel to ride herd on the department and cut through red tape. All are promising moves. But we've heard promises before (Source: *Washington Post*, Feb. 26, 2007). **V**

State Medicaid Fact Sheets Available

State Medicaid Fact Sheets are available for each of the 50 states and the District of Columbia. See, <http://www.childrenshospitals.net/state/medicaidfacts>.

What Will Become Of The Mary Woods?

Editor's Note: Bob Wood is VOR's Connecticut State Coordinator.

Mary Wood wasn't going to live to her teens. When Mary was born 47 years ago, doctors told her parents that because she had Down syndrome, she was only expected to live till she was 9. So, she wasn't supposed to outlive her mother, who died from colon cancer nearly three decades ago. Bob Wood never planned for his daughter's life to go on without him. Looking into her almond-shaped, hazel eyes, just a shade darker than his, he wondered, what will become of her?

"That's what really scares me. There's no set plan," said Wood, a meat cutter turned activist for the mentally retarded. "There will come a point where she can't stay at her group home. ... She will need more care, and a nursing home is not the place for my child."

This helplessness, some say, is what prompted 81-year-old Richard C. Brown to shoot his wife, his two adult, mentally retarded children and then himself a week ago in Enfield. He left a note explaining that he didn't want his family "to be a burden to anyone." Brown, a longtime activist for the mentally retarded, knew his options - and they were scarce, his friends and colleagues say.

Parents of mentally retarded adults say they're in desperate need of a retirement home for their aging children, a place where trained nurses can sense their patients' needs from body language and facial expressions. But they are fighting against advocates who believe people with mental retardation should be treated like other aging members of society. "We believe in people getting out of institutions. We don't believe it's where people are most productive and most healthy," said Lynn Warner, head of The Arc of Connecticut. Warner said a family that can't provide medical attention for an aging, mentally retarded relative should consider a nursing home, like everyone else's families. Says Sue Swenson, executive director of The Arc - US, "My son is living with me because the waiting list for a group home is full of these crisis cases of elderly people." She expects that her son will live with family or in a group home for seniors when he gets older.

Brown belonged to, and was once president of, the Friends of Retarded Citizens of Connecticut (FORConn), a group that lobbies state officials to turn Southbury Training School into a senior home for mentally retarded people, where the average age of residents is now 59. "The real asset the state has [in Southbury Training School] isn't the land or the buildings. It is the personnel, who learned the hard way over time how to take care of elderly mentally disabled people," said state Rep. Arthur O'Neill, R-Southbury, who headed a 1994 task force investigating the future of the institution.

Few group homes have the staffing to handle residents once more medical problems complicate their health. Because many parents are too frail to care for them or the parents have already died, the group home residents are often sent to nursing homes or to live with relatives. Like Wood, some parents aren't comfortable placing their children in nursing homes and would prefer not to burden relatives.

Going against then-Gov. Lowell P. Weicker Jr.'s plan to close Southbury Training School, the task force recommended that it be turned into a "life care community" for the state's aging mentally retarded population. Criteria for admission to the home would be based on age, disabilities and "length of residence." (Source: *Hartford Courant*, March 4, 2007). **V**

**VOR 2007 Annual Meeting and Washington Initiative
June 8 -12, 2007
JOIN VOICES AND MAKE A DIFFERENCE! PLEASE JOIN US!**

NEW!

As in 2006, all participants of VOR's 2007 Annual Meeting and Washington Initiative staying at the Holiday Inn on the Hill (registration information below) will receive a **free buffet breakfast every day** of their stay.

We are indebted to the hotel's management for agreeing to bring some financial relief to our members. Please thank them when you see them!

Program Agenda

Friday, June 8, 2007 1 – 3 pm
VOR Annual Board Meeting – Open to Members

Friday June 8, 2007 6 – 8 pm
Reports from the States
Participate in reports on news from your state. This more casual session, moderated by VOR Board Members, will be a time for sharing and participating. Appetizers and beverages will be provided.

Saturday June 9, 2007 9 am – 4 pm
Annual Meeting

**“Policymaking from Governors to Congress:
A focus on the issues and the role of advocates”**

Speakers: **Matt Salo**, Director, Health and Human Services Committee, National Governors Association; **Ron Pollack**, Executive Director, Families USA (invited); and a panel of **Congressional Committee Staff** who deal with health care policy (from both sides of the aisle).

Saturday June 9, 2007 6:30 pm
Networking Dinner
Optional. Located at the Hyatt Regency (across the street from the Holiday Inn). Additional cost about \$25. Details will provided to all attendees.

Sunday, June 10, 2007 3 – 7 pm
Initiative Briefing
Learn what to do, what to say, and receive folders for distribution to Congress. Complete instructions will be provided and you will learn from experienced attendees. Keynote Speaker: Kenni Gill, Senior Legislative Counsel, Senate Rules Committee (invited).

Begins Monday, June 11, 2007

The Washington Initiative

If possible, please plan to spend at least Monday and Tuesday visiting as many Senators and Representatives as possible. The more workers, the lighter the burden.

Monday, June 11 and Tuesday, June 12, 2007

Informal De-briefings, networking, reporting

Appetizers and beverages will be provided on Monday evening prior to de-briefing reports by state spokespersons (identified in advance of the meeting).

Social: 6 – 6:30 pm

Reports: 6:30 – 8 pm

Hotel Information

Holiday Inn on the Hill

415 New Jersey Ave., N.W. Washington, D.C. 20001
Reservations due by May 13, 2007

202-434-0125 Marcea Hopkins (preferred)
800-638-1116 (call center)

Group rate: \$159 for single or double, plus tax, per night. Mention VOR for group rate. **All meetings will be held at the Holiday Inn on the Hill.** Take advantage of networking with other VOR members by staying here. Please let us know if you would like to be paired with a roommate if possible.

Transportation Information

Ground Transportation

Taxi cabs and "Super Shuttle" are available at Reagan International Airport. "Super Shuttle" is \$13 per person from Reagan. At the airport follow signs to "Ground Transportation." Super Shuttle reservations are required only from the hotel to the airport (800-258-3826). Union Train Station is just 3 blocks from the hotel.

For more information please contact Tamie Hopp at 605-399-1624 or tamie327@hotmail.com

Registration Form

I want to personally tell Congress how important residential choice is for people with mental retardation. I'll be there!

Send form to Voice of the Retarded 5005 Newport Dr. #108, Rolling Meadows, IL 60008

Fax: 847-253-6054 * Tamie327@hotmail.com * Phone: 847-253-6020 * A 501(c)(3) organization

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___ \$50 per person for **member** registration at the Annual Meeting on Saturday, June 9 if paid by 5/31.

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___ \$60 per person for member registration **after 5/31**.

<2007 WASH-REG>

___ \$75 per person for **non-member** registration at the Annual Meeting on Saturday, June 9 includes one-year membership if paid by 5/31.

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___ \$85 per person for non-member registration **after 5/31**. Membership included.

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