the voice VOR

news and views by VOR supporters

Summer 2006

Contents

President:
Mary McTernan
Editor: Tamie Hopp

President's Message

Going the extra mile for people with mental retardation

by Mary McTernan, President

Reports in this newsletter chronicle the success of the Annual Meeting and Washington Initiative. The Initiative is the most important, the most visible, and the most successful of all VOR activities. It is the time when each member who participates speaks directly to people on Capitol Hill who influence our nation's policy. Because of the annual Initiative, VOR is recognized in most Congressional offices. Thus, our work throughout the year is easier and more successful. Plan now to come to Washington, D.C. and participate next June 9 -12 (see box page 4). If you are unable to come in person, consider sponsoring in whole or in part the expenses of someone from your state. We need all the advocates we can muster!

The remainder of this message briefly highlights some my report to the Membership at the June Annual Meeting. Read on and enjoy what's left of summer!

Government Affairs and Advocacy

July 2005: VOR sent written comments to every Medicaid Commission member.

August 2005: VOR sent out an Action Alert calling for letters to the National Conference on State Legislators Health Committee, successfully defeating a negative long term care proposal.

August 2005: VOR met by teleconference with CMS officials to discuss Medicare reform and the Money Follows the Person proposal.

August 2005: VOR met by teleconference with Senator Bunning's office to discuss the Money Follows the Person proposal. An Action Alert to leaders and key members followed.

October 2005: I hosted a one-day grassroots organization and advocacy training workshop for DSI Supporters, Inc., a statewide advocacy organization in Florida. For this program, VOR developed a toolkit that has since been updated and distributed more widely.

October 2005 – February 2006: VOR sent out several Action Alerts relating to the federal budget and Medicaid.

January 2006: VOR met by teleconference with the Virginia Office of Protection and Advocacy, presenting VOR's arguments as to why "Deinstitutionalization is Not Mandated by the Developmental Disabilities Assistance and Bill of Rights Act."

February 2006: Our new Director of Resource Development, Tony Padgett, arrived in the Rolling Meadows VOR Office (see p. 10 for his report).

March 2006: VOR hired its first Washington Representative – Larry Innis!

March 2006, May 2006 and July 2006: VOR representatives delivered public comment at the Medicaid Commission meetings in Atlanta, GA (Irene Welch); Irving, TX (Past Pres. Nancy Ward); and Arlington, VA (Patricia Bennett).

May 2006: Larry Innis, presented at the Interagency Committee on Disability Research, calling for further research regarding quality of care in community settings.

May 2006: VOR sent every Member of Congress a position paper supporting technical changes to the Deficit Reduction Act.

Legal Advocacy

VOR's "Choices for a Lifetime, Options for All" legal advocacy project has resulted in support for legal efforts in Florida, Illinois, Maryland, Ohio, Massachusetts, and Pennsylvania.

VOR History Project

Author Deb Gilbert will be writing VOR's history. For more details about this exciting project – and how you can help– see page 9 for details. **Thank you for your support!**

An association for Individuals and Parent Groups working for Persons with Mental Retardation

Voice Of the Retarded

VOR 2006 Annual Meeting

Members enjoy a day of presentations focused on maximizing grassroots advocacy in their states.

The VOR Annual Meeting, held every June in Washington, D.C., gives members a chance to meet other advocates from across the country and exchange information and network. The 2007 meeting was attended by more than 100 people from 25 states. This year's Annual Meeting focused on "The Power of Grassroots Advocacy in the Legislature, Courts, and Media: How to develop, nurture, and harness our strengths." Following Mary McTernan's President's Message (see page 1), attendees heard from speakers who provided helpful grassroots advocacy tips.

Tom Frain
Immediate Past President, Massachusetts Coalition of Families and Advocates for the Retarded (COFAR)

Tom Frain, gave an energizing presentation that spoke of how to encourage others, including siblings, to be proactive advocates on behalf of people with mental retardation. He noted that organizations can attract active advocates by providing information and advocacy support. Individual families face fairly similar challenges regarding access to services and protection choice of services. Ultimately, working as a unified voice only strengthens the overall cause, plus provides families access to valuable information.

Michael Rato, Attorney, Sidley Austin LLP (picture, right)
Michael Bibo, Illinois Health Care Association (picture, center)
Tamie Hopp, VOR Exec. Dir. and Dir. of Govt Affairs and Advocacy (left)

Michael Rato, provided an overview of the Ligas v. Maram lawsuit and the efforts by his clients, residents of private ICFs/MR in Illinois, to gain intervention. Intervenors hope to prevent certain future outcomes, including the elimination of the ICFs/MR option. Already, their participation has helped educate the lower court as to their concerns, with a similar effort now ongoing at the appellate level. **Mike Bibo** stressed the importance of grassroots advocacy to compliment related legal efforts. During the Ligas lawsuit there were a number of threats that choice advocates successfully rallied against. The key to this success was collaboration between private and public facility supporters and a joint effort to keep individual advocates informed. Tamie Hopp stressed "take away" points from the panel's presentation, including the need for representation on state planning committees, the critical importance of private/public alliances, and the opportunity to submit "dissenting reports," which give the minority perspective visibility.

Peter Kinzler, VOR Legislative Committee, Past Second VP (center)
Larry Innis, VOR Washington Representative (right)
Tamie Hopp (left)

Larry Innis provided an overview of what we can expect in Congress this session, with so few working days leading up to the November elections. In a nutshell, "not much," says Mr. Innis. "2006 has become a year of political protection and a time of political rhetoric on issues designed to clog the Congressional agenda." That said, VOR members must watch closely budget reform efforts, including proposals which change the budget process (see pages 2 and 3). **Peter Kinzler** provided further insight into effective legislative advocacy, citing VOR's decade long effort to gain important improvements in the Developmental Disabilities Assistance and Bill of Rights Act. VOR's Government Affairs Committee is already preparing VOR's 2007 reauthorization strategy. **Tamie Hopp** spoke on VOR's organizational structure, including its committee structure (a model for state organizations), and the role of staff.

Welcome New VOR Board Members

The following individuals have been elected to serve a three year term on VOR's Board of Directors:

Alfred Bennett (NM)
Carolyn Cowans (TN)
Sybil Finken (IA)
Elbirda Haley (KY)
Catherine Gover (MA)
Anne Knighton (GA)
Mary O'Riordan (CA)
Carole Sherman (AR)
Kathryn Spare (PA)

Sybil Finken, Barry McCahill, and Lex Wells were re-elected to the Board.

Mary McTernan (President), Nancy Ward (Past President), Robin Sims (First VP), Carole Sherman (Second VP), David Swain (Treasurer) and Elbirda Haley (Secretary) were elected to serve a 1 year term as VOR officers.

VOR 2006 Washington Initiative

VOR's complete Congressional presentation can be found at: http://vor.net/LeaveBehindPositions2006.html

Nearly 75 people from 25 states attended the 2006 Washington Initiative, which focused on the following critical issues impacting people with mental retardation:

1. Opposition to several Sunset Commission proposals;
2. Support for a technical correction to the Deficit Reduction Act of 2005;
3. Support for adequate federal funding for programs serving people with mental retardation, including Medicaid; and
4. Support for the introduction of federal legislation to address the need to enhance access to health care by people with mental retardation in community settings.

The VOR presentation folder, delivered to every Member of Congress, included position papers related to the above issues, as well as background papers on the critical needs of people with severe and profound mental retardation, medical needs, and/or behavioral challenges, and the importance of the "optional" Medicaid benefit, including ICFs/MR, and other basic life-sustaining services that Medicaid supports.

Here is an update on VOR's legislative priorities:

1. Opposition to several Sunset Commission proposals

Two Sunset Commission Proposals are currently being considered by the U.S. House of Representatives. VOR strongly opposes both bills, as do a broad based coalition of advocates. A scheduled House vote on July 27 was postponed until September due to the opposition of a small group of Republican moderates who are refusing to support H.R. 5766 (see below) unless it is modified. Most advocates feel that the requested changes do not go far enough.

H.R. 5766, the Government Efficiency Act of 2006, and H.R. 3282, the Abolishment of Obsolete Agencies and Federal Sunset Act of 2005, both propose the creation of "Sunset Commissions" with unelected members to review federal agencies and programs. Unelected members, with no requirement for public input, will have the authority to recommend whether federal programs live, die or get "realigned." H.R. 3282 goes further to include an irresponsible proposal that calls for the elimination of any agency that Congress does not reauthorize within one year of the sunset commission report. VOR will remain watchful for any further attempts to pass a Sunset Commission bill. We remain strongly opposed.

2. Support for a technical correction to the Deficit Reduction Act (DRA) of 2005

During the Initiative, and in subsequent communications with the Centers for Medicare and Medicaid Services (CMS), VOR has called for a legislative or regulatory "fix" to a provision in the DRA which potentially imposes unlimited cost sharing obligations on low income Medicaid beneficiaries, including people with mental retardation in community settings.

To date, it appears that DRA technical correction bill is unlikely. Members of Congress, reportedly, worry about the prospect of further debate on the DRA, which was the subject of a series of votes and lengthy debate in late 2005 and early 2006.

There is support for a correction through regulation. On May 25, 2006, 19 House Republicans sent a letter to CMS asking that the regulatory process be used to ensure careful implementation of key provisions of the DRA, noting that the intent of Congress is that these "new policies should not harm innocent people who rely on Medicaid for essential health and long term care needs." The letter, coordinated by Rep. Peter King (R-NY), covers cost sharing, urging CMS to "make clear in your regulations that the previous cost sharing rules remain in effect for beneficiaries below the poverty level."

By way of precedent, on July 6, HHS published final regulations relating to the new documentation of citizenship requirement passed as part of the Deficit Reduction Act of 2005.

2006 Voice Award Recipients

Elbirda Haley, VOR Secretary (July 1) and Legislative Committee Member was honored with the 2006 Voice Award for her longtime contributions to VOR's legislative efforts. Ms. Haley is credited for securing thousands of dollars and countless hours of volunteer time preparing the Congressional leave-behind folders. These folders allow VOR participants to provide a unified presentation of critical issues – a priceless gift to VOR.

The **Sidley Austin LLP** law firm (New York, Chicago and Maryland office) was also honored for their pro bono representation of disabled individuals in Illnois, Maryland and Florida. In each case, choice of residential care is being tested. Mike Rato, who is active in the Illinois lawsuit (Ligas), accepted on behalf of the Sidley Austin New York office.

Each year, individuals and organizations whose dedication of leadership, skill and time has had an enduring impact on VOR's Mission, are honored with The Voice Award.

VOR extends sincere gratitude to the 2006 recipients – Elbirda Haley and Sidley Austin LLP – for their contributions. **V**

(Section 6036). The regulations exempt seniors and people with disabilities who receive Medicare or Supplemental Security Income (SSI), reasoning that these beneficiaries have already met certain documentation requirements. This exemption reflects the special treatment of these groups in statute, implying that they should be exempt from additional documentation requirements.

3. Support for adequate federal funding for programs serving people with mental retardation, including Medicaid

The budget process remains in flux. Both the Senate and the House continue to debate the budget, working at this time on individual spending bills. Advocates remain on guard.

There is support in Congress for adequate Medicaid funding. On May 8, 88 Congressional Republicans asked Michael Leavitt, Secretary of HHS, not to implement the Medicaid cuts proposed in President Bush's fiscal year 2007 budget proposal through the regulatory process, asking instead that the Administration work with Members of Congress to "protect and improve the Medicaid program for our constituents."

Despite this support, Medicaid cuts remain a real threat. Efforts to reform the budget process also threaten future Medicaid funding. For example, **S. 3521**, the Stop Over Spending Act of 2005 (SOS) introduced by Sen. Judd Gregg (R-NH), Chairman of the Senate Budget Committee, proposes to new federal budget process to "regain control of the Federal budget process." The bill includes provisions for the establishment of a Sunset Commission, a Presidential line item veto authority, and Medicaid and Medicare solvency commission. S. 3521 has passed Senator Gregg's Budget Committee, although passage by the full Senate is not expected. In response, VOR is watching piece meal efforts, including Sunset Commission proposals and S. 4890, the Legislative Line Item Veto Act, which recently passed the House.

H.R. 4890, Legislative Line Item Veto Act, if passed, will give the President the authority to cancel certain discretionary, mandatory and tax expenditures subject to congressional approval within 45 days of passage.

4. Support for the introduction of federal legislation to address the need to enhance access to health care by people with mental retardation in community settings

While in Washington, D.C., VOR called for a "legislative solution to address the widespread lack of access to quality health care for people with mental retardation" noting that "people with mental retardation often have extensive health challenges, but lack access to health care professionals" due to financial, accessibility, and consistency of care concerns.

On July 24, Senator Tom Harkin (D-IA), introduced the Promoting Wellness for Individuals with Disabilities Act of 2006 to establish accessibility standards for medical diagnostic equipment and create wellness grants to fund health programs that focus on the unique challenges faced by individuals with disabilities. The bill also proposes the creation of a National Advisory Committee on Wellness for Individuals with Disabilities."

"We must recognize the unique situation of individuals with disabilities and work to make certain they are not limited in their access to quality medical care, or in their opportunities for health and wellness," Harkin said. "We want to set standards, ensure proper funding, and make certain that medical professionals receive the appropriate training so that they can provide the best quality care for all." **V**

Thank You 2006 Sponsors!

Each year generous Annual Meeting and Washington Initiative Sponsors make VOR's most important annual event possible. Thank you 2006 Sponsors:

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Mark Your Calendars – Join VOR in Washington, D.C.

June 8, 2007: VOR Annual Board of Directors Meeting
June 8, 2007: Friday Night Forum – State of the State Reports
June 9, 2007: Annual Meeting
June 10, 2007: Washington Initiative Legislative Briefing and Kick-Off
June 11, 2007: Visits to Congress

Legal Briefs

Appeals court: Missouri Medicaid Policy Appears Unreasonable

In 2005, Republican Gov. Matt Blunt and the GOP-led Legislature enacted numerous cost-cutting changes to the Medicaid health care program for the poor. One of those eliminated coverage of such things as wheelchair batteries, catheters, bed rails and communication devices to most adults while continuing the coverage for the blind, pregnant, homebound and children. The Legislature this year voted to restore coverage of wheelchair accessories but none of the other items. That change was to take effect with the next state budget July 1.

A panel of the 8th U.S. Circuit Court of Appeals said Missouri's policy of covering some durable medical equipment but not others appears unreasonable under federal Medicaid rules and court precedent. The court also said the plaintiffs, several disabled Missourians, had shown a likelihood of legal success, and therefore overturned the denial of a preliminary injunction last September by a trial judge and instead directed him to reconsider the case.

The appeals court ruling said states have discretion to determine the optional services in their Medicaid plans, however, "failure to provide Medicaid coverage for non-experimental, medically necessary services" within a Medicaid category is both "unreasonable and inconsistent with the stated goals of Medicaid," the court said. The appellate panel said the lower court had not addressed claims that Missouri's list of covered medical equipment was so limited that it failed to meet Medicaid's objectives of providing medically necessary services and enabling people to care for themselves.

State attorneys claimed Missouri met those federal mandates, because Medicaid recipients still could seek an exception to the cuts or continue to receive coverage of the medical equipment if they qualified for home health care services.

But the appeals panel said those options were empty. None of the seven plaintiffs appear to qualify for home health care, and Missouri was told in April that its homebound guidelines did not comply with federal policy anyway. Additionally, the state's exception process does not appear to provide a reasonable way to gain coverage, the ruling said. (Source: *Associated Press*, June 22, 2006). **V**

Constitutionality of the Deficit Reduction Act Challenged

Public Citizen and the federal government squared off in U.S. District Court on a case challenging the Deficit Reduction Act of 2005 (DRA). Public Citizen claimed that the DRA violated a provision of the Constitutional requiring Congress to approve identical legislation before it can become law. The discrepancy is over a correction in a provision governing Medicare payments inserted by the Senate clerk, passed by the Senate, but not included in the House bill. Public Citizen also challenged the certification statements by Congressional leaders claiming the bills were identical. The federal government asserted that an 1892 Supreme Court ruling required courts to uphold a law's validity based on that statement. The case is pending. (Source: *Capitol Insider*, Disability Policy Collaboration, Vol. 11, Issue 28, July 17, 2006). **V**

Supreme Court won't block Part D program

The Supreme Court refused last week to block part of the six-month-old Medicare Part D prescription drug program, a defeat for states that claim they may get stuck with the bill, according to an *Associated Press* report. Justices declined without comment to temporarily stop part of the law that added a prescription drug benefit to Medicare. States were contesting a requirement that they pay the federal government part of the money they are expected to save because they no longer must pay for drugs for people enrolled in both Medicare and Medicaid. Kentucky, Texas, Maine, Missouri, and New Jersey argued that the "clawback requirement" is an unconstitutional tax on the states. The Justices said that the states' class-action lawsuit belonged in a lower court. (Source: *HCpro.com*, June 2006). **V**

Active Case File Update:

Illinois: The Golden Intervenors in Ligas v. Maram appealed the District Court's denial of intervention. The Golden Intervenors seek to ensure the right of choice in residential options. Oral argument is Sept. 26.

Florida: In mid-June, attorneys for the "Stover Objectors" presented oral argument in support of intervention before a federal appellate court panel. A decision is pending.

Pennsylvania: The State has appealed a District Court ruling which, per state promise, allowed transfers from Altoona Center only with written consent of residents' legal guardians. Several pending motions have delayed an appellate decision. Settlement negotiations are also ongoing.

Pennsylvania: The Third Circuit Court of Appeals in Torisky v. Schweicker has ruled that the state has no duty of reasonable care and safety, per Youngberg standards, to individuals who are *voluntarily* committed. The court left open the question of how "voluntary" is defined.

Georgia Settles Civil Rights Lawsuit Regarding Access to Community Care

The state has settled a civil rights lawsuit from seven Georgians with physical disabilities. The lawsuit, filed in 2003, alleged that forcing the physically disabled to live in nursing homes violated the Americans with Disabilities Act and other laws. The suit demanded the state provide services so they could move into a community setting if they chose that alternative. The agreement cites a state program that will spend $4.3 million during the fiscal year beginning July 1 to offer community services to 1,000 more people, ranging from home-delivered meals and home health aides to physical, speech and occupational therapy. (Source: *Atlanta Journal-Constitution*, June 29, 2006). **V**

Supreme Court says expert fees not recoverable in IDEA cases

On June 26, the U.S. Supreme Court in Arlington Central School District Board of Education v. Murphy ruled that parents may not recover expert fees under the Individuals with Disabilities Education Act (IDEA).

The Court overruled the 2nd Circuit Court of Appeal's decision, noting that since IDEA's text "makes no mention of expert fees," such expenses are not recoverable by prevailing parents. In reaching this conclusion, the majority determined that the term "costs" mentioned in the statute is a "term of art" that did not include expert expenses. While the majority recognized the various reports supporting a finding that expert costs were recoverable by prevailing parents, it ruled that the "legislative history is simply not enough" to change the actual statutory language used (Source: *The Akins Group*, ScotUSblog, June 2006). **V**

Judge-Schools must reimburse autistic boy's back tuition

Henrico County's (Richmond, Virginia) school system must reimburse the private-school tuition expenses of an 8-year-old autistic boy even as it challenges his family's claims that he wasn't receiving an adequate public education, a federal judge ruled.

U.S District Judge Robert E. Payne ruled Wednesday that under federal education law, the suburban county is liable for paying Reid Tutwiler's tuition, legal costs and interest from Dec. 29, 2003, when an administrative hearing officer ruled that Henrico wasn't providing the boy with an adequate education, until March 20, 2006, when his parents and the school division agreed on a new individualized education program.

Payne ruled that under the Individuals With Disabilities Education Act, and state law, the school district must assume the child's educational expenses after a state hearing officer determines that the local school division is failing to provide the child with a free and appropriate public education, even while the School Board appeals the officer's decision.

IDEA also requires school divisions to provide disabled students with free public education as a condition of accepting federal funding, Payne wrote. (Source: *Associated Press*, July 2006). **V**

Judge Dismisses Utah Waiting List Lawsuit

A U.S. District Court judge in Utah dismissed a class action waiting list lawsuit in late February because plaintiffs – individuals with developmental disabilities on the waiting list for services – are not in imminent danger of being institutionalized. Also, the funds needed to provide home and community-based services for them are not available and would necessitate cutting other priority-need services. The Division of Services for People with Disabilities (DSPD) would need an additional $8 million in ongoing funding to serve the approximate 1,750 individuals – ages 6 to 77 years old – currently on the waiting list. The Utah Disability Law Center (P&A) filed the original lawsuit December 2002. According to the DSPD Director George Kelner, the class action suit cost "a lot of money, money that could have been spent developing solutions." (Source: *Community Services Reporter*, July 2006: For *CSR* subscription details, visit http://www.nasddds.org/Publications/index.shtml). **V**

How much is a disabled Person's Life Worth?

Over the years, when a person with mental retardation was injured or even killed, wrongdoers were not often held accountable because families were informed that the economic value of the disabled person's life was of little monetary value. The evolving nature of the law, however, may be ushering in a change.

Recently, a $ 1 million dollar settlement was reached concerning the death of a 51 year old woman with profound mental retardation. The woman died of lithium toxicity after a series of related errors committed by the pharmacist, primary physician, psychiatrist, and provider. The series of errors caused the woman significant suffering over a period of time up and until her death.

Her family was awarded $1 million in a legal action against wrongdoers. (Source: *Dever Association Newsletter*, citing Massachusetts *Lawyers Weekly*, June 5, 2006, p. 7). **V**

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State News

Wisconsin: Tracking provision passes

2005 Wisconsin Act 386 (May, 2006) includes a requirement that the state Department of Health and Family Services submit to the legislature an annual report on the status of Medicaid-eligible individuals who have been relocated or diverted from "nursing homes, intermediate care facilities for the mentally retarded, and centers for the developmentally disabled."

The report shall include the impact of the transfer on health and safety, the extent of involvement of guardians and family in the transfer or diversion process, and an accounting of costs and savings (per individual, as well as collectively). The law calls for annual tracking of every individual transferred, regardless of the year transferred:

"[The report shall include] the nature and duration of relocations or diversions that specifies the locations of relocated or diverted individuals every year after home or community placement occurs, so as to keep track of individuals on an ongoing basis." **V**

VOR hosts its Second Annual State of the State Forum in Washington, D.C.

60 VOR members and leaders attended VOR's "State of the State" forum on Friday evening, June 9, in Washington, D.C. Participants reported on happenings in their states, learning from each other's successes and challenges. For more details visit, http://www.cofar-mass.org (link, Newsletters (Summer, p. 5). **V**

Washington, D.C.: Group Home Failures Persist

The District of Columbia continues to provide dangerous, substandard care to disabled residents at some of its group homes and has recently hampered oversight efforts by failing to provide full and timely information on critical operations, a federal court monitor has found. In her latest quarterly report, court monitor Elizabeth Jones describes numerous and chronic problems with the city's Mental Retardation and Developmental Disabilities Administration. She also questions whether she is getting complete reports on death investigations, saying that at least one document she received from the District was edited to remove information critical of the city. A review of five deaths between late 2004 and late 2005 showed that recommendations issued after death investigations weren't always shared with direct care providers, putting group home residents at risk, she said. "The continuing failure to remedy critical systemic issues of substandard care, treatment and oversight means that other clients will experience needless pain, delayed or non-existent attention to high risk situations involving health and safety, and unnecessary threats to their very existence," she wrote. "The urgency to remedy these systemic failures could not be greater." (*The Washington Post*, June 24, 2006). **V**

VOR's Abuse and Neglect document: Updated and online

Visit http://www.vor.net/abuse_neglect to see these and other stories.

Missouri: Families fight to keep state facilities open

Families of Missourians with mental retardation have rallied on the Statehouse steps, produced DVDs and booklets, and staged press conferences for years -- all to try to convince the Governor of one thing: They trust state institutions to take care of their relatives. They say it would be more dangerous for their family members in privately run facilities. They're taking on the courts, researchers and advocates for the disabled who argue the opposite.

Advocates for closing state institutions argue that large institutions breed cultures of mistreatment that can be easily hidden from the public.

But criticism has mounted for more than a decade over how states monitor private homes.

While large, state-run facilities are inspected by federal regulators, the federal government allows the states to oversee most smaller, privately run places. And as early as 1993, a congressional committee complained that states had no idea of problems in private group homes until after tragedies. Ten years later, the Government Accountability Office said the federal government still hadn't forced states to ensure the safety of residents in private facilities (Source: *St. Louis Post-Dispatch*, June 12, 2006).

Confirming that problems in private group homes exist, a recent *Post-Dispatch* investigation found abuse and neglect of mentally retarded residents in state centers and in private facilities the state supervises. Since 2000, there have been more than 2,000 confirmed cases of abuse and neglect with 665 injuries and 21 deaths. The series – "Broken promises, broken lives – can be accessed at http://www.stltoday.com/stltoday/news/special/abuse.nsf/Front?OpenView&Count=2000. **V**

California: Inside Bay Area Investigative Series – Broken Homes

26,000 of California's 200,000 residents with developmental disabilities -- people who are mentally retarded, have Down syndrome, are autistic or have other disabilities -- get some type of community-based care, and many of them are in licensed care homes which are in residential neighborhoods all over the state. Many have been placed in care homes over the past dozen years, as the state emptied its institutions.

continued, next page

The investigation shows a care system whose low standards, poor funding and limited oversight spell trouble for the more severely disabled people it is now expected to serve - people the system was never set up for in the first place. And it shows that the state agency ultimately responsible for the welfare of the developmentally disabled has little direct involvement in their care. (Source: *Inside Bay Area*, July 3 -- 5, 2006, http://www.insidebayarea.com/brokenhomes). **V**

Illinois: Parents slam state over planned disabled cuts

A plan to downsize nine state facilities that care for the developmentally disabled is drawing fire from the parents of some residents. The Illinois League of Advocates for the Developmentally Disabled (IL-ADD), which represents families with residents at each of the state homes, argues that moving residents into smaller group home settings should be based on what is best for each individual, rather than on a quota system. IL-ADD is concerned that the moves, which will be conducted over the next six months, could be a signal that the state is moving to shutter more state facilities. It is challenging the state's decision to move 200 residents out of the nine institutions.

The Illinois Department of Human Services reasons that the transfers, which will reduce facility census to 2,500, will boost staff-to-patient ratios and improve the quality of care for the remaining residents.

IL-ADD argues that the state needs a mix of smaller, group homes and institutions in order to adequately serve residents who have different levels of impairments. The families hope to convince Gov. Rod Blagojevich to abandon the downsizing plan, but Burke acknowledges that it could be an uphill battle. Still, says Burke, "We have nothing at stake except the lives of our children. And that's quite a motivator. We believe that our message is one that will prevail."

Organizations advocating in favor of closing the state facilities have won a number of rounds in recent fights over the future of the state's policies toward caring for developmentally disabled residents. For example, Blagojevich last month expressed doubt about reopening a portion of the old Lincoln Developmental Center, which was closed in 2002 by former Gov. George Ryan. (Source: *The Pantagraph*, June 2006). **V**

Kansas: DD Council calls for closing state developmental center

According to the Kansas Council on Developmental Disabilities, Kansas no longer needs two state hospitals for the developmentally disabled. Currently, individuals are served at Parsons State Hospital and Training Center and the Kansas Neurological Institute in Topeka.

Later this summer, state welfare officials will begin a lengthy assessment of the hospitals' future. "At this point, there's not enough capacity in the community to support the kind of medical needs and behavioral issues we're talking about here," said Ray Dalton, who oversees the hospital for the Kansas Department of Social and Rehabilitation Services. Neither hospital, he said, is designed to take the other's residents. "Parsons is set up for people with severe behavioral issues," said Dalton, a former superintendent at KNI. "At KNI the emphasis is more on medical conditions."

Legislators also have balked at expanding community-based programs for the developmentally disabled, most of which are operating at or near capacity.

"Any reduction in the state hospital populations has to be coupled with additional supports in the community," said Peggy Wallert, director of community relations and development at Cottonwood, Inc., in Lawrence.

Interhab, a state association representing community-based programs, opposes closing another state hospital without a clear understanding of the costs and how the openings will be paid for.

State Rep. Barbara Ballard, D-Lawrence, doubts that either hospital will close anytime soon. "I just don't see it happening until we can identify how we can provide the same – or better – services in the community," she said. "We need to guarantee that the funding will follow the individual out of the hospital and into the community," and "we have a long way to go before we can make that guarantee, "said Ballard, who serves on a budget subcommittee that oversees the SRS budget. (*The Lawrence Journal-World*, June 29, 2006). **V**

The importance of guardianship: A State example

According to the Maryland Governor's Access Steering Committee Report (2001), "ultimately, the individual's choice or team recommendation for community placement would supercede family's preference, **unless a family member is guardian for the individual**" (Source: *MCAR Newsletter,* June 2006; emphasis added by VOR).

It doesn't get any clearer than that. Your status as a parent or sibling or other relation is not the same as being a legally-appointed guardian. For more information visit, www.vor.net/guardianship.htm.

AN HISTORIC OPPORTUNITY: Your stories needed for VOR's History

Accomplished author Deb Gilbert will be writing, for publication, VOR's history. This is an exciting project that will help preserve and honor the important work of early advocates, while also speaking to VOR's past and future successes.

Ms. Gilbert, writes:

"No amount of detail is too small: Your first visits to school, to see the doctor, to a movie theatre, to a park, to a grocery store, to a restaurant, or to a birthday party; experienced at home, in a group home setting, or in an institution; experiences of inclusion, exclusion, segregation and/or discrimination – all the adversities, the inconveniences, the difficulties that mobilized you to become an activist: not the generalized things you obviously opposed, but the specific dated incidents you experienced with all the sequential detail you can remember. We want the readers to see and hear and feel and re-live through your eyes and memories what you went through (the good, the grey, and the bad).

"We need the issues of living with and advocating for a relative with disabilities to come to life for the reader.

"We hope that the conclusion of this work delivers to readers a vibrant living testimony for all the hard work done by all of you have labored so long on your relatives' behalf."

To see Ms. Gilbert's complete letter, visit: http://vor.net/HistoryProject.html

There is no required format, except that the author, Ms. Gilbert prefers any written submission be double spaced. You are encouraged to be informal, relaxed and comfortable as you share your recollections. You may share your experiences in writing or by speaking into a tape recorder (which VOR will provide upon request). Consider nothing to be irrelevant; be detailed in your account.

Within 60 days (by Oct. 31), please send your history and the signed release form (below) to:
Deb Gilbert * 1436 Elmwood * Lakewood, Ohio 44107-3902 * dwistargilbert@sbcglobal.net

If you have any questions or concerns, feel free to contact VOR directly at 847-253-6020. All of us at VOR are sincerely grateful for your contribution to this important project.

Story contribution examples

- ✓ Your families' personal story - what motivated you to go beyond caring for your loved one to advocacy for all people with mental retardation;
- ✓ When did get involved with, or even form, your local and state advocacy organizations;
- ✓ The "kitchen table" anecdotes -- meetings and mailings;
  The trips to state capitals and Washington, D.C.;
  Key meetings with notable state and federal policymakers;
- ✓ Your mentors;
  Realizing your concerns were national eve before VOR was founded;
- ✓ Your work today; and
- ✓ All of the above and more!

For complete details, visit: http://vor.net/HistoryProject.html

RELEASE

I, the undersigned, agree to submit my personal story about my loved one with mental retardation and my involvement in VOR for a book tentatively entitled Voices for the Voiceless. As guardian of this individual, I allow disclosure of personal and historical information regarding my loved one for publication. I understand that my story will be edited for grammar, mechanics, and style. None of the facts will be changed. I will have the opportunity to review the edited version for my comments and suggestions. I will submit my story to Deb Gilbert at her e-mail address, by mail, or by tape recording to:

Deb Gilbert * 1436 Elmwood * Lakewood, Ohio 44107-3902 * dwistargilbert@sbcglobal.net

PRINT NAME: ____________________

SIGNATURE: ____________________

I would like my story to be told under a pen name. Check at the following line if this is so_____.
The pen name I would like to use is --____________________.

Donor's Forum

Teamwork: Growing VOR Together

By Tony Padgett
VOR Director of Resource Development

Attending our 2006 Annual Meeting in Washington was very exciting. This was my first time visiting congressional representatives and state senators advocating for VOR's issues. So much is dependent on strong Medicaid funding. The most rewarding part of this year's imitative for me was the opportunity I had to meet many of you for the first time. The stories of family victories and struggles many of you shared with me reinforced my resolve and commitment to my fund raising efforts for VOR.

Our 2006/07 fiscal year fundraising goal is an aggressive one. To help achieve this goal, a Major Gifts Committee, chaired by long-time VOR Board Member, Jane Anthony, has been created. The Committee implemented new major gift giving levels. A major gift appeal to VOR's Board of Directors has already yielded over $9,000!

Your help is needed to reach our 2006/07 goal. The key to successful fundraising is through establishing relationships. As I cannot be everywhere and meet everyone, your personal contacts can greatly strengthen our fundraising efforts. For example, in 2005, VOR received a $20,000 grant. This grant was made possible through a contact one of our members has with the foundation. Moreover, most of our sponsorship dollars for our Washington Initiative came from companies and organizations where our members have personal contacts. This is an area we would like to grow for next year's Initiative!

Taking this theme further, several fundraising and new member acquisition ideas proved to be successful. Two examples come to mind - one produced increased funding and another helped to grow our membership base. A Virginia couple sent a personalized appeal letter to former college friends asking for "significant" donations to VOR in honor of their son who currently resides at a residential facility. They included a photo to make it even more personal. Another member sent a "gift membership" letter to members of her parent group, sponsoring their VOR membership for a year. Jane and I walked both people through the writing of the letters to achieve the best results. These appeals have brought in substantial revenue and are excellent opportunities to use as a template for our upcoming VOR AWARENESS Month in October. With the help of our members implementing ideas like these, we will meet our fundraising goals.

As your new Director of Resource Development for VOR I stand ready and able to assist you with fundraising efforts in your State. Feel free to contact me and let's make it happen for VOR! 1-847-253-6020; anthonypadgett@sbcglobal.net.

The more funding we have, the louder our VOR voice.

October 2006 is VOR Awareness Month
Please participate!

This successful annual event provides VOR members, including individuals, family organizations and facilities, the opportunity to collaborate for the benefit of persons with mental retardation everywhere!

The purpose of VOR Awareness Month is to make more people aware of VOR and generate a case for financial support of our organization. VOR Awareness Month activities will help educate individuals about the important national role that VOR has and the absolutely critical and direct impact on state and local trends. This education is carried out collectively by the grassroots efforts of VOR members, like you, at the state and local levels.

As an **active VOR member** you are fully aware of VOR's impact, and the vital need to continue to disseminate our shared message. We want to help you make more people aware of all of the things VOR members are doing together to protect all of our loved ones with mental retardation.

To begin our planning of the 2006/07 fiscal year, **we want to hear from you!** Flexibility is the cornerstone of planning for VOR Awareness Month. **We welcome new ideas from you** -- events that you know will work in your state or locale -- so we can share those with other members wanting to help but not exactly sure where to start.

To help you, VOR stands ready to provide the background materials and other support that will be needed, including materials and speakers at organization meetings. We will come and speak to your organization to share information on VOR activities and developing trends in services and policies affecting persons with mental retardation. Or we will provide literature for you to share. Please tell us when your family meetings are held. Together we can accomplish much.

Please contact Tony Padgett at 847-253-6020 or anthonypadgett@sbcglobal.net for assistance or more information.

Thank you very much in advance for your participation and support.

VOR Welcomes Tribute Donations

Gifts have been received

In Memory of

John Bracken, Sr.
William Whetham

In Honor of

Danny Dubrowsky
Jeffrey Gans
Dolores Keipert for Mother's Day
Jason Kinzler
Benny and Heather Sims

In Celebration of

Tony Pederzani's 50th Birthday

VOR Tribute Donations

Your Name ______________________________

Your Address

____

City ______________ State ________ Zip ____________

In Memory of ______________________________

In Honor of ______________________________

Anniversary ______________ Get Well Wish ______________

Other Occasion ______________ Birthday ______________

Amount ______________________________

Please send acknowledgment to:

Name ______________________________

Address ______________________________

City ______________________ Zip ______________

Please make checks payable to VOR and mail to:

Voice of the Retarded
5005 Newport Drive, Suite 108
Rolling Meadows, IL 60008

Membership Form: Please send dues to VOR, 5005 Newport Dr., Ste. 108, Rolling Meadows, IL 60008

____
ame

____
Address

____
City State Zip

____
Telephone

____
Fax E-mail

Please check as appropriate:

____ I am a new member

____ I am current member and my record needs updating (i.e., new address, name, phone, etc.). I have circled the changes needed on this form.

____ No changes are needed

Membership Categories:

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

A additional gift/pledge is enclosed for

___$5,000 ___$1,000 ___$500 ___$250 ___$100 $__ Other

Payable:

☐ **Quarterly** ☐ **Semi-Annually**

☐ **Other (please indicate)** ________

A check made payable to VOR is enclosed.

Or please charge to my ☐ **Visa** ☐ **MasterCard**

Card Number: ______________________________

Expires: ______________________________

Amount to charge: $ ______________________________

Signature: ______________________________

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence. It is in our best interest that u receive VOR's information, so please call if $25 per year poses a financial hardship. **Jul06**

This newsletter is sponsored by our good friends at Harris Bank

HARRIS™

with whom VOR has been banking with for over a decade.

Thank you Harris Bank!!!

VOR
Speaking Out for People
with Mental Retardation

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Rolling Meadows, IL 60008
847-253-6020 headquarters
847-253-6054 fax
vor@compuserve.com; http://www.vor.net

A national, non-profit 501(c)(3) volunteer association of individuals and families working for persons with mental retardation