

Fall 2006

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## President's Message

### Social Security Reform Remains a Concern

by Mary McTernan, President



The headline in the September 9, 2006 *Washington Post* says it all, "**President Aims to Revisit Social Security After Recess.**"

VOR has been monitoring closely the Administration's plans with regard to Social Security Reform. Any revision that substantially alters or slashes Social Security as we know it will potentially leave our loved ones without critical services. Most people with severe and profound mental retardation were born with their disabilities. Many of these individuals also experience physical disabilities, complex medical conditions and/or severe behavioral challenges. They need assistance in every aspect of care, including walking, talking, toileting, dressing, transportation, recreation, and therapies. Any reductions in the benefits they receive from Social Security could seriously harm their care and may cost lives.

VOR has made our concerns clear to Members of Congress and the Administration, including representatives of the President's Social Security Commission:

"Any changes in Social Security must preserve it as **family insurance** for everyone who is eligible regardless of whether they have a disability. Private accounts will not provide the same security: they will cut guaranteed benefits and greatly increase both the budget deficit and national debt. Social Security must continue to provide guaranteed benefits for children and spouses when their spouse or parent retires, dies or becomes disabled." (*VOR letter to the U.S. Senate*, Nov. 2005).

"We are particularly concerned about the potential impact of **personal accounts**. All three models proposed by President Bush's Commission to Strengthen Social Security involve the use of personal accounts to provide future insurance for participants. While we appreciate support for personal responsibility, we recognize that one person's choice to be accountable for his/her future 'social security' could, under Social Security Survivors Insurance, potentially divert funds from another individual who is totally incapable of financially securing his/her own future." (*VOR Position to Congress*, June 2005).

We have also called on Congress to guarantee that a "**beneficiary impact statement**" on every major part of any Social Security proposal be conducted to ensure that we understand the actual impact of the proposed changes on people's daily lives.

Although President Bush has said that Social Security reform will not affect people with disabilities, the absence of a specific legislative proposal leaves us gravely concerned about unintended consequences.

Social Security Reform is an issue that is vital to every VOR member. Be alert to any proposed changes, as reported by VOR, and let VOR know what you hear. Most importantly, let your Congressperson know of the threat to your family member. **V**

### Coming Up

**Oct 7, 2006:** The VOR Board of Directors will meet to set the VOR's short and long-term priorities. Future newsletters will provide details.

**June 10, 2007:** VOR Annual Meeting in Washington, D.C.

**June 11 and week of June 12, 2007:** VOR Washington Initiative Briefing and visits to Capitol Hill.

**Ongoing:** VOR's History Project continues. See page 9 for more details.

**President:**  
**Mary McTernan**  
**Editor: Tamie Hopp**



# Legislative Update

VOR's efforts in Washington, D.C., several action alerts, and coordinated efforts with other state and national organizations have led to significant progress on VOR's legislative priorities for 2006:

## Opposition to Sunset Proposals

Objections from grassroots advocates and moderate Republicans derailed House efforts to pass H.R. 5766, the Government Efficiency Act, and H.R. 3282, the Abolishment of Obsolete Agencies and Federal Sunset Act. A planned vote, scheduled for late-July, was pulled by House leaders after it became clear the measure could not pass. Both bills contained proposals to create federal "Sunset Commissions" – entities with the power to evaluate government funded agencies or specific programs and issue recommendations to Congress on whether those bodies should be consolidated, abolished or otherwise altered. Critical programs for people with mental retardation, including Medicaid, Medicare, and the State Children's Health Insurance Program (SCHIP), would be at risk. The issue could come up during the "lame duck" Congressional session, in November and December. See <http://www.vor.net/SunsetActionAlert.html> for more details. **V**

## Cost Sharing and the Deficit Reduction Act of 2005

The Deficit Reduction Act (DRA) contained an apparent drafting error that, if enforced, would have allowed states to impose unlimited cost sharing obligations on low income Medicaid beneficiaries (See, <http://www.vor.net/DRACorrection.html>). On June 16, 2006, CMS released a letter to State Medicaid Directors, which states in part, that CMS will not enforce the DRA provision relating to cost sharing; regulations will be forthcoming that are consistent with this intent.

In related news, Senator Gordon Smith (R-OR) introduced S. 2409, designed to extend the Part D cost-sharing exemptions now enjoyed by dual-eligibles living in nursing facilities and ICFs/MR to dual-eligible beneficiaries who receive Home and Community Based Services (HCBS) waiver services, and other community living arrangements. In its comments to CMS on the proposed Part D regulations, VOR urged CMS to provide HCBS waiver recipients the same protections as recipients of ICFs/MR care, on the premise that the eligibility criteria for ICF/MR and HCBS are identical. **V**

## Adequate Federal Funding for Programs Serving People With Mental Retardation

Congress left Washington on Sept. 29, leaving most appropriation bills incomplete, including Labor, HHS, and Education. The earliest these bills will be considered is after the November elections, during a "lame-duck" session. The Administration's intent on pursuing additional Medicaid cuts has drawn protests from a bi-partisan group of Congressmen and the Governors. In separate letters, 88 House Republicans, bipartisan group of 44 Senators, and the National Governor's Association urged Michael Leavitt, Secretary of HHS, not to act on administration proposals that would reduce Medicaid payments for providers by \$12.2 billion over five years. A Congressional hearing is planned in November or December, according to the *Washington Post*.

VOR continues to watch budget reform proposals, such as Sunset Commission proposals and the Line Item Veto Act (S. 3521), which would enable the President to terminate funding for entire discretionary programs and/or single out Congressional improvements or expansions of entitlement programs, including Medicaid, for termination. In early-Sept. VOR issued an Action Alert and wrote every Senator, strongly opposing S. 3521 (see, <http://vor.net/Sept12006.html>). **V**

## Support For Federal Legislation to Enhanced Access to Health Care by People with MR

On July 25, 2006, Senator Tom Harkin (D-IA), introduced S. 3717, the Promoting Wellness for Individuals with Disabilities Act of 2006. The bill proposes fiscal incentives for health care education programs to provide disability-specific curricula. S. 3717 also includes a provision that will immediately promote good health outcomes, wellness programs, and preventive health screenings. VOR supports this legislation. **V**

## H.R. 1264, the Director Support Professionals Fairness and Security Act of 2005.

More than 75 of Representatives have signed on to H.R. 1264, a bill that its sponsors hope will give people with disabilities the quality workforce they need for their daily long-term supports. For VOR's position on the staffing crisis, see <http://vor.net/staffing.html>. **V**

## Medicaid Commission Hearings

The last Medicaid Commission hearing will be held November 16 and 17. A final Commission report will be issued to HHS Secretary Leavitt in December. The Commission was charged with looking for ways to "modernize the Medicaid program so that it can provide high-quality health care to its beneficiaries in a financially sustainable way."

VOR has participated at Commission meetings in March, May and July, by providing written and public comment focusing on choice, quality and access to a full array of residential options. We will participate in the final Commission hearing in November.

## Senate passes Combating Autism Act

On Aug. 4, the Senate passed S. 843, authorizing almost \$1 billion in federal funding for autism-related research, early detection, and intervention. In the House, however, Commerce Chairman Joe Barton (R-TX) said his Committee will not consider the bill until his own NIH reform bill passes. H.R. 2421 has more than 200 co-sponsors.



# Money Follows the Person May Come to Your State: Be Prepared, Get Involved

36 states file  
"Intent to  
Apply" for  
Money  
Follows the  
Money  
Follows the  
Person grant

Arkansas  
California  
Connecticut  
Delaware  
District of  
Columbia  
Georgia  
Hawaii  
Florida  
Illinois  
Indiana  
Iowa  
Kansas  
Kentucky  
Louisiana  
Maine  
Maryland  
Michigan  
Mississippi  
Montana  
Nevada  
New  
Hampshire  
New Jersey  
New Mexico  
New York  
North Carolina  
North Dakota  
Ohio  
Oklahoma  
Pennsylvania  
Tennessee  
Missouri  
Texas  
Virginia  
West Virginia  
Wisconsin  
Wyoming

## Money Follows the Person Law - Background

The Centers for Medicare & Medicaid Services (CMS) is requesting proposals from States to participate in the Money Follows the Person Rebalancing Demonstration. This demonstration, created by section 6071 of the Deficit Reduction Act of 2005 (DRA), supports State efforts to "rebalance" their long-term support systems by offering \$1.75 billion in over 5 years in competitive grants (January 1, 2007 – September 30, 2011). The demonstration provides for 100% federal financing of the program (instead of the standard state/federal Medicaid match) for 1 year for the transition of facility residents to qualified home and community-based service (HCBS) settings. The following criteria, as outlined in the law, are fundamental to a successful grant application—

- Increase the use of community-base, rather than institutional, long-term care services;
- Eliminate barriers or mechanisms that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive support for appropriate and necessary long-term services in the settings of their choice;
- 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 transition from an institution to a community setting; and
- Ensure that procedures are in place to provide quality assurance for eligible individuals receiving Medicaid home and community-based long term care services and to provide for continuous quality improvement in such services.

CMS will accept one proposal from each State interested in participating in the demonstration program. For the upcoming year, the deadline for grant applications is November 1, 2006 (Source: CMS MFP guidance to states, July 26, 2006).

## VOR Call to Action -- Be Prepared, Get Involved

36 states have filed their voluntary "Notice of Intent to Apply" for MFP grants (see sidebar). According to the MFP law, "States must engage in a public process for the design, development and evaluation of the MFP demonstration project." The grant must detail the public development process that was used to develop the application as well as ongoing processes to "allow for input from eligible individuals, their families, authorized representatives and other key stakeholders" (CMS, July 2006).

VOR members and other choice advocates, especially organization representatives, are strongly urged to request the opportunity to participate in the grant writing process. Being involved can ensure you are informed, as well as provide an opportunity to influence the future direction of your state's MFP program. For example, one state is considering using its MFP funding, if received, to help implement its already state-approved expansion of community resource centers. Another state will use its grant, if awarded, to transition individuals from nursing homes; that particular grant request expressly excludes MR/DD state-facility residents. This information is known only because VOR members were proactive and secured "seats at the planning table" on behalf of their statewide organizations (VOR affiliates).

To assure that your choice perspective is represented, **contact your state Medicaid office** and request an opportunity to be involved. Being part of the planning also provides you the opportunity to be sure that the MFP law's requirements with regard to quality and continuity of care are adequately considered. **V**

### Tip! Community Resource Centers and MFP Grants

MFP law and CMS guidance to states emphasize that states must ensure that individuals transferred from facilities benefit from continuity of care and quality assurance in their new residential settings. **Community Resource Centers**, which utilize the existing services at state and private facilities, could help support individuals transferred to community residential settings, by providing continued access to facility-based health care, day programming, recreation, respite, and/or other services. By getting involved, you can help persuade your state to include a CRC-component within the MFP grant request. **V**



AL (69.51)  
AK (50.16)  
AZ (66.98)  
AR (73.77)  
CA (50.00)  
CO (50.00)  
CT (50.00)  
DE (50.09)  
DC (70.00)  
FL (58.89)  
GA (60.60)  
HI (58.81)  
ID (69.91)  
IL (50.00)  
IN (62.98)  
IA (63.61)  
KS (60.41)  
KY (69.26)  
LA (69.79)  
ME (62.90)  
MD (50.00)  
MA (50.00)  
MI (56.59)  
MN (50.00)  
MS (76.00)  
MO (61.93)  
MT (70.54)  
NE (59.68)  
NV (54.76)  
NH (50.00)  
NJ (50.00)  
NM (71.15)  
NY (50.00)  
NC (63.49)  
ND (65.85)  
OH (59.88)  
OK (67.91)  
OR (61.57)  
PA (55.05)  
RI (54.45)  
SC (69.32)  
SD (65.07)  
TN (63.99)  
TX (60.66)  
UT (70.76)  
VT (58.49)  
VA (50.00)  
WA (50.00)  
WV (72.99)  
WI (57.65)  
WY (54.23)



## Donor's Forum

By Tony Padgett  
VOR Director of Resource Development

### The Federal Connection: Why organizations and their individual members should join VOR

VOR is a national organization that advocates for a full array of residential services and supports for the full continuum of people with mental retardation, through all stages of life. We advocate for the provision of services based on choice and need, with full family involvement in the decisionmaking.

#### ***VOR is needed!***

While your statewide family/guardian organization and your local facility-based family associations play crucial roles, these organizations are not dedicated to tracking on a regular basis what is happening at the national level, especially with regard to Medicaid.

***What Congress and the Administration do to Medicaid will impact the services your family member receives, for better or worse. Nationally, the FEDERAL government pays between 50 and 76% of every Medicaid bill, depending on what state you live in.***

Without FEDERAL funds, Medicaid programs would not exist in any state. When FEDERAL funds are cut, or when the FEDERAL government changes the rules as to how federal Medicaid funds can be spent, the result is felt by Medicaid beneficiaries all across the country, including your family members.

VOR reliably lets its members know when Medicaid faces a cut or is poised for reform. We directly communicate with Members of Congress and officials within the U.S. Department of Health and Human Services. We also call upon our members to contact their elected officials by fax, phone, e-mail and mail. Help from VOR's members is what ultimately has the most significant impact – after all, elected officials will be thinking about votes, and numbers count.

VOR needs your membership support. New members increase our numbers and our collective strength. Financial contributions also help VOR grow and enhance all of our programs aiming to enhance choice and empower families, including our Congressional advocacy in Washington, D.C.

VOR has its role at the national level. Your state organization has its role at the state level. Facility-Based Family Associations have their role at the local levels. We are all interconnected and mutually dependent on one another to achieve success.

Please help complete the circle. Join VOR today and be assured your national voice will be represented and heard.

#### **We can adapt this letter for your individuals in your state!**

Some of VOR's State organization affiliates have sent a state-specific version of this article to their individual members, encouraging VOR membership. We would welcome your support in this way. Contact Tony Padgett, VOR Director of Resource Development at 847-253-6020; [anthonypadgett@sbcglobal.net](mailto:anthonypadgett@sbcglobal.net), for a state-specific version of this article.  
**Numbers Count!** Thank you!



## House Subcommittee holds hearings on Americans with Disabilities Act (ADA)

On Sept. 13, 2006, the House Judiciary Committee's Subcommittee on the Constitution examined the ADA.

Subcommittee members heard from witnesses who provided an historical perspective, focusing on Congress' intent 16 years ago, when the law was enacted.

Recognizing that the ADA has resulted in making some communities more accessible, the Subcommittee expressed concern that the law has not received the "broad support by the Federal Courts that Congress intended," noting that the Supreme Court has significantly limited the reach of the ADA's protections in recent years. Noting the Supreme Court's "competing interpretations" of these provisions, Subcommittee Chairman Rep. Steve Chabot said, "This hearing, I believe, takes the first step toward resolving some of this uncertainty to help ensure all individuals who fall within the intended reach of the ADA are covered and are sufficiently protected." (Source: *Opening Statement*, Chairman Chabot, September 13, 2006). **V**

## Legal Briefs

### Ohio: *Martin v. Taft* – Settlement Reached for Additional Medicaid Community Services

An agreement between parties to settle the long-standing *Martin v. Taft* class action lawsuit has been reached. If endorsed by the next Governor and General Assembly, it will provide opportunities for an additional 1,500 Ohioans with mental retardation and other developmental disabilities to be served through Medicaid-funded home- and community-based waivers; and allow for the funding and safeguards needed to assure these services.

The Ohio Legal Rights Service (OLRS), Ohio's P&A, originally filed the case in 1989 on behalf of citizens with disabilities seeking to expand community residential services. The agreement offers new residential choices, including alternatives for individuals who currently reside in institutional settings, but **does not require the closure of any public or private facilities**. The settlement is conditional upon funding approval in Ohio's next biennial budget.

The *Martin v. Taft* agreement was negotiated among representatives of OLRS on behalf of plaintiffs, the Governor's Office, ODMRDD, the Ohio Department of Job and Family Services, and the Attorney General's Office. A fairness hearing for public comment by interested parties will be scheduled in the U.S. District Court for the Southern District of Ohio. (Source: *Ohio Department of MR/DD Press Release*, September 25, 2006, *emphasis added*).

The current settlement represents a major shift by OLRS and the state, no doubt in response to intense grassroots opposition to an earlier proposal to eliminate entirely the ICF/MR option from Ohio's Medicaid plan. More than 31,000 advocates, providers and other stakeholders joined a petition to object to this provision in a 2005 proposed settlement agreement. Months after Judge Robert Sargus denied the 2005 proposed settlement, he issued an opinion and order adopting a Special Master's report and recommendations in the 16 year old *Martin* litigation. Judge Sargus agreed with the Klein Objectors (formerly represented by the late-Bill Burke), that individuals with mental retardation and other developmental disabilities who are not, nor will not be in "need of community housing and services," are not members of the *Martin* Class and cannot be bound by any decision in this case. Judge Sargus' decision also stated, "individuals have the right to decline community-based treatment," citing the Supreme Court's *Olmstead* decision. As now defined, the class does not include anyone who is satisfied with their current care and opts not to be transferred from their facility home [Source: *The Advocate*, Winter 2005]. **V**

### South Carolina: State responsible for contracted patient care

The state Supreme Court has reversed a lower court decision, ruling that the state is still responsible for providing reasonable care to patients even when it contracts work out to private vendors. In 1997, Lexington County resident Brenda Bryant sued the Babcock Center, a community program serving people with developmental disabilities, and the state Department of Disabilities and Special Needs, claiming that her 21-year-old mentally retarded daughter was raped by at least one man after she left a Babcock home with him in 1995. Babcock Center officials said the sex was consensual. According to court papers, Madison left Babcock Center in April 1996 to live with her mother. The state had claimed it had no duty of care to Madison because she voluntarily admitted herself to state care. Justices disagreed. (Source: *AP*, July 2006). **V**

#### Update on key cases

*Ligas v. Maram* (Illinois): Oral argument in the appeal of the denial of intervention by private ICFs/MR residents is scheduled for October 30.

*Brown v. Bush* (Florida): An effort by families to overturn a district court ruling denying intervention was unsuccessful. A recent appellate court ruling upheld the denial of intervention, calling the attempt to intervene untimely. Families and guardians are considering options for their next legal maneuver.



### Florida: Group home closed for violations

Rodents and roaches. State chemicals left in unlocked cabinets. Electrical cords with wires exposed. A syringe in a kitchen drawer. Florida state inspections turned up those problems and others over nine months at 10 Professional Group Home, Inc. residences. The deaths of four residents and health and safety violations prompted the Florida Agency on Persons with Disabilities to shut down the Miami-based chain. The agency is required by law to monitor group homes once a year, but it does so at least once a month, officials report.

Group homes are licensed by the agency and receive money through reimbursements from a Medicaid program for people with disabilities. There are 1,263 providers statewide. The homes are part of the state's emphasis on deinstitutionalization, taking people out of large institutions such as Gulf Coast Center. In one case, a Professional Group Home resident died just six weeks after he was moved from Gulf Coast center, where he had lived since 1994." (Source: *The News-Press*, Sept. 20, 2006).

### State and Florida P&A plan to close facilities

The State of Florida and the Florida Advocacy Center (P&A), have settled Brown v. Bush, calling for the transfer of clients from large institutions to community settings by 2010. Statewide, 981 people are in institutions. Reportedly, between 12 – 15,000 Floridians are waiting for services. Families of facility residents are challenging the settlement.

## State News

### Mary McTernan, Ph.D., VOR President, responds to news of abuse in Florida group homes

(published, *Miami Herald*, October, 2006).

VOR, a national organization speaking up for people with mental retardation and their families, has long been concerned about the ability of Florida to provide safe community homes to people with profound mental retardation. We appreciate the recent articles regarding group home abuses (*News-Press*, September 19 and 20, 2006).

Questions remain. How can the State boast about monthly monitoring of all 1,263 group home providers and yet miss visible evidence of poor care such as rodent feces, badly soiled pillowcases, black mold, and dead roaches? These problems materialized over time; not from one month's "monitoring" to the next. Just what does Florida's Agency for Persons with Disabilities consider 'monitoring?' Is it a phone call to the group home's owner or supervisor asking if all is OK? What does the State really know about the people being "cared for" by the remaining 1,262 providers still in business?

Rather than pat itself on the back for removing one bad apple, the State would be better advised to address the effectiveness of its community "monitoring" practices; consider reversing its plan to close specialized, federally-monitored, facilities ("DSIs"); and work to provide programs for the 12,000 or more Floridians waiting for services. **V**

### Kentucky ousts company running center for mentally retarded adults

A regional mental health agency has taken over management and treatment at Kentucky's largest and most troubled center for mentally retarded adults in a \$56 million contract, state officials announced Tuesday.

The Cabinet for Health and Family Services has been negotiating with the Bluegrass Regional Mental Health-Mental Retardation board for nearly a month after federal officials threatened to withhold some \$43 million in funding when Oakwood couldn't ensure the safety of patients.

The agreement with Bluegrass pushes out Liberty Healthcare, a Bala Cynwyd Pa.-based provider that entered into an \$18 million, 12-month contract last year to manage the facility and try to improve conditions.

Bluegrass already has a contract with the cabinet to manage Eastern State Hospital, the cabinet's regional psychiatric hospital in Lexington. State officials credit Bluegrass for drastically improving patient care and safety at Eastern.

Parents and patient advocates said Oakwood's switch to Bluegrass is a welcome change. "We think it will be a good thing," said Marjorie Keegan, of Louisville, whose 50-year-old son has been a patient at Oakwood since the facility opened in Somerset in 1972. "It appears Bluegrass has done a good job with the other hospital."

Louise Underwood, former VOR Board Member, served on the task force that selected Bluegrass and supports the state's decision. She has long consulted with families of Oakwood, serving with others a strong advocate for high quality and choice at Oakwood and other facilities in Kentucky (Source: *Associated Press*, Sept. 12, 2006). **V**

### Illinois: Update on Lincoln Developmental Center

Succumbing to pressure from community advocates, Illinois Gov. Blagojevich has backed away from a prior commitment to re-open Lincoln for people with mental retardation. Instead, State Rep. Bill Mitchell has introduced a bill to use the newly-renovated facility as a home for veterans with Alzheimer's. Apparently, what is defined as inappropriate segregation for one disabled population is acceptable for another. **V**



## Utah's oldest care center thrust into fight of its life

The Disability Law Center, Utah's P&A, recently called for the closure of the Utah State Developmental Center before a Medicaid task force. The attack shocked and angered families whose loved ones receive care at the Utah County institution.

Supporters of the developmental center argue that the center handles the most severe cases, including medically fragile residents who need around-the-clock monitoring and people with behavioral problems too difficult to control in private group homes. The center also operates a forensic unit behind a 20-foot security fence that houses half a dozen residents remanded by the courts because they are not mentally competent to stand trial on violent-crime and sex-related charges.

Parents of residents like to compare the center to a hospital intensive care unit, a concentration of cutting-edge services for critical cases. And like an ICU, they say, the center's residents use a disproportionate amount of resources simply because their needs are the most extreme.

But disability activist Andrew Wriggle says the majority of the residents in American Fork could be cared for in the community. He and other critics want profiles on the residents' disabilities. They also would like an audit on the amount of money the sprawling center sucks from various state budgets, including funding for maintenance and new buildings. "With that money, the state could provide care for many more people in the community," Wriggle said.

George Kelner, state director of services for people with disabilities, says moving the residents to community-based programs would cost from \$180 to \$490 per day, with additional expenses for medical or psychiatric services. "It would cost close to what it costs at the developmental center." And, he says, some patients with severe behavior problems would require invasive supervision at all times. "Is that a better quality of life than at the developmental center?" he asks.

Rep. John Dougall, whose district encompasses the developmental center, is also a supporter of the facility. Still, he wants the task force to take a close look at costs. He also wants investigated arguments that the center's concentration of resources may deprive rural areas of services. "I'd like to see the total cost structure of providing those services," he says. He doubts lawmakers will seriously consider closing the developmental center in the short term. "There are lots of dynamics involved. Many families think it's the best resource for their loved ones." (Source: *The Salt Lake Tribune*, Aug. 21, 2006). V

## Virginia News

### SWVTC Community Resource Center celebrates first year

A new system for providing services for citizens with mental retardation and those caring for them was established in southwest Virginia thanks to a bill that established Southwestern Virginia Training Center (SWVTC) as a Regional Community Support Center (RCSC), one of two started in the state in July 2005. This resource center is designed after a model started at Northern Virginia Training Center. The new program allows the center to serve as a hub to provide a range of services throughout the greater community.

"This new program represents a real opportunity for SWVTC to have a positive impact not just on the lives of persons with mental retardation who live at our facility but also to provide assistance to persons who live in our region of the state," said facility Director Dr. Dale Woods, Ed.D.

"We planned to provide outreach services for consumers through behavioral/psychiatric consultations, dental services, training for community providers, community services board staff, parents and teachers, and assistance with mobility/balance training in coordination with engineering departments at Virginia Tech," said Dr. Dale Woods, E.D.

The first year, SWVTC's RCSC provided 1,851.25 hours of technical assistance to over 135 different clients. The biggest success of the RCSC the first year was the dental clinic. In the first year, 42 clinics were held for 126 clients for a total of 365 visits. Day camps for children with autism and disabilities were also held at SWVTC, as part of the RCSC program (Source: *SWVTC Press Release*, Aug. 16, 2006). V

### Families of CVTC residents set sights on expansion, not downsizing

Planning for the new Central Virginia Training Center took a step toward 'partnering' Monday, as stakeholders began working with a consultant who specializes in using diversity in opinion rather than allowing factions to tear apart a construction project. Parents and the State agree that CVTC should be rebuilt; but they disagree strongly on the size of the new facility. Families want at least capacity for the present census of 519, preferably more to accommodate expansion. The facility is presently licensed for 731 people, including 97 skilled nursing beds. With a 24-bed acute care hospital and residents with significant cognitive, physical, medical and behavioral needs, parents worry that a smaller facility will mean some very vulnerable Virginians will be without a critical safety net. The State is pushing for a facility for 300 residents.

Even after a session with consultant William Ronco, size continues to be an issue, but some families felt that communication had improved and that those with the most severe needs won't be transferred. Other parents vow to continue to pursue the issue of size. Randy Lassiter, a parent of an adult child at CVTC, for example, is among one group of families that has successfully sought the introduction of a Virginia Senate bill that will require CVTC continue to accommodate at least 550 residents (Source: *News-Advance*, Sept. 11, 2006 (portions of article)). V



## Colorado: Funding change costly to developmentally disabled programs

### Report shows community living on the rise

Between 1977 and 2005, persons with intellectual disabilities living in settings of 6 or fewer increased 20,400 to 291,100 persons, including an estimated growth from 8,700 to 184,000 of people living in settings of 3 or fewer. Persons living in state and non-state institutions of 16 or more residents decreased 207,400 to 67,100 (68%) between 1977 and 2005, including a decrease from 154,600 to 40,100 (74%) in the number of people residing in state institutions.

Download "Changing Patterns in Size of Residential Settings for Persons With Intellectual and Developmental Disability, 1977-2005" at [http://www.aamr.org/reading\\_Room/pdf/LakinMR0806.pdf](http://www.aamr.org/reading_Room/pdf/LakinMR0806.pdf). (Source: AAMR F.Y.I., September 2006), Vol. 6, No. 9). **V**

### ANCOR Releases New State Disability and Medicaid Fact Sheets

ANCOR, a nonprofit trade association representing private providers who provide supports and services to people with disabilities, in partnership with H&W Independent Solutions, has created 51 individual state fact sheets. The state-specific fact sheets provide MR/DD demographic and Medicaid funding statistics. See <http://www.ancor.org/issues/medicaid/MedicaidFactSheets.html>.

The Arc of Pueblo said the planned state cuts violate the law requiring services for the developmentally disabled and friends and relatives of those clients should submit formal appeals to the state and federal governments.

The state has moved to a fee-for-services payment system, dropping the old flat rate for day-program services. Day program providers say that means if a developmentally disabled client doesn't come to day program on a given day, the day program doesn't get paid for serving them. The fee is based on each 15 minutes a client is at the program.

The problem, providers say, is that developmentally disabled clients are not consistent, due to behavioral or other problems. Yet, they must pay staff and have the program ready to serve the maximum number of clients who may come. If funding fluctuates with each day's attendance, it makes it hard to budget and plan for staff and services.

Providers argue that funding rates are supposed to be set according to the needs of each client. Clients that have more needs, such as those who can't speak or who need hygienic services, are supposed to be funded at a higher level for the provider.

Garcia said she's asked for a state audit of the funding levels, hoping it will show the disparity between client needs and the funding level selected for them. (Source: *The Pueblo Chieftain*, August 23, 2006). **V**

## California spends millions helping the mentally retarded live independently. But who protects them from being ripped off?

The state spends hundreds of millions of dollars for services to people with mental retardation and then does an insufficient job monitoring the private contractors who actually take care of these relatively helpless people. Despite these disabled people's vulnerability to abuse, there appears to be no direct, systematic government regulation of the private companies and individuals who take care of people with MR living on their own.

Here's how it works: A private company receives taxpayer money to send caretakers to the homes of people with mental retardation and other disabilities who live alone. The state then delegates oversight of these private companies to private, nonprofit corporations, dubbed "regional centers," which have the dual responsibilities of funneling state money to contractors who care for people, and checking in periodically on the "consumers" who receive the services. In the event a complaint arises, regional center personnel have the option of ceasing to do business with the provider, contacting the Developmental Disabilities Board, or in unusual cases, informing law enforcement or adult protective services. There is no official way, however, for a guardian or a member of the public to obtain information about possible complaints against a company. It's not even clear whether the "regional centers" systematically keep track of complaints for their own private use. (Source: *San Francisco Weekly*, September 6, 2006). **V**

## Louisiana: Housing battle centers on money

As the state prepares to dole out roughly \$100 million in tax credits to foster development of affordable housing in areas devastated by Hurricanes Katrina and Rita, advocates for the disabled and developers are battling over the kinds of projects that should be embraced. The advocates for the disabled are pushing a plan backed by the Louisiana Recovery Authority to emphasize the creation of mixed-income developments, with credits to include units for developmentally disabled people who would get supportive services paid for by the state. But many developers have been skeptical of those concepts in the post-storm environment, saying the first priority should be the rehabilitation of flooded buildings and construction of new ones for desperately needed workers. Overshadowing the debate about how the Louisiana Housing Finance Agency should spend the federal tax credits is the need to hand them out quickly, both to get redevelopment under way and to make sure projects are completed by the time the credits expire at the end of 2008. (Source: *The Times Picayune*, August 23, 2006). **V**



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

In the last issue of *The Voice*, VOR shared with members our exciting, "historic" opportunity. Accomplished author Deb Gilbert is writing, for publication, VOR's organizational history. To help tell VOR's story, we really need to hear from the families that make up our organizational fabric. For example,

- ✓ 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. and key meetings with notable state and federal policymakers;
- ✓ Your mentors;
- ✓ Realizing your concerns were national even before VOR was founded;
- ✓ Your work today; and
- ✓ more!

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 reports that she has received some submissions, but needs many more families to step forward to share their personal accounts. She can receive your written submission by mail or e-mail, or she would welcome speaking with you on the phone. VOR can also provide tape recorders for those who prefer to give oral account of their personal situation.

To help with this process, and provide motivation for others, VOR will be posting 2 stories that have been received, with the permission of the authors. These personal accounts are compelling and contain the sort of background detail that Deb needs to write our history. You can read these examples, as well as access full details about the project at <http://vor.net/HistoryProject.html>. **V**

"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 who have labored so long on your relatives' behalf." ~

Author Deb Gilbert

## Send stories to:

Deb Gilbert  
1436 Elmwood  
Lakewood, OH 44107-3902

Before publication, your permission to share your story and use your name will be required. For a copy of the Release Form, visit <http://www.vor.net/HistoryProject.html>.

## Odds and Ends

### What has VOR done for you?

Over the years, VOR has received testimonials from members who have been helped by VOR's advocacy. We would love to hear from you as to how VOR has supported you in your advocacy on behalf of your loved one. To share your story, please contact Tony Padgett:

Tony Padgett – VOR  
5005 Newport Dr., Ste. 108  
Rolling Meadows, IL 60008  
847-253-6020 ph  
847-253-6054 fax  
[anthonypadgett@sbcglobal.net](mailto:anthonypadgett@sbcglobal.net)

### In Autism's Grip

For six days, beginning Sept. 24, *The Record* ran a special report on autism. [http://northjersey.com/autism/autism\\_page.html](http://northjersey.com/autism/autism_page.html)

VOR's First Vice President, Robin Sims, and her daughter, Heather (a resident at Hunterdon Developmental), were interviewed by reporter Bob Irvy. The entire series, including the Sims' family feature, is at [http://northjersey.com/autism/autism\\_page.html](http://northjersey.com/autism/autism_page.html).

An interview with Bob Irvy, who effectively dispels myths about "institutional" care is available at: <http://www.autismpodcast.org>.

### Families USA Health Action Conference

Every January, Families USA, in conjunction with a wide range of national organizations, organizes a grassroots health advocacy conference in Washington, D.C. It's a great place to learn and share strategies with other advocates around the country and to recharge for the year ahead.

Next year's conference, Health Action 2007, will be held January 25-27, 2007 at the Renaissance Mayflower Hotel. The opening speaker will be Senator Barack Obama. Visit [www.familiesusa.org](http://www.familiesusa.org)/conference for more details.



## Lead Charitable Trusts: A unique way to benefit VOR

By George Mavridis  
Massachusetts State Coordinator

You have read articles in *The Voice* and other VOR publications urging you to include VOR as a beneficiary in your will or revocable family trust.

A lead charitable trust is a lesser known financial instrument that gives more immediate financial benefits to you and VOR, if you designate VOR as one of your designated 501(c) 3 charities. A lead charity trust is irrevocable and can be opened by anyone, anytime as long as they have some disposable assets that they want to donate to a charity. One example is a portion of a stock position that, if sold, would result in a very large long-term capital gain.

Most brokerage firms or mutual fund companies offer lead charitable trusts. These companies will (a) require a tax deductible minimum deposit to serve as the trust principle (e.g., \$10,000 - \$25,000); (b) one additional minimum deposit to the trust in the future (e.g., \$1,000); and (c) a minimum grant to a 501(c)(3) charity, like VOR (e.g., \$500).

By way of example, let me share my personal example. I opened my lead charitable trust by transferring to the irrevocable trust some shares of stock that, if cashed, would have resulted in a sizeable long-term capital gain tax penalty. Instead, I was able to take a one time charitable gift deduction (IRS Form 1040, Schedule A) because the stock was "given" to my irrevocable charitable trust. Because the IRS does not allow two bites from the same apple, I cannot deduct my gift to VOR or any other charity from the trust, but any future gifts to the trust are tax deductible. The donation(s) to VOR can be issued in my name, anonymously, as single gift, or on a regular schedule. You can also restrict VOR's use of the grant by designating the grant's purpose.

Remember, the lead charitable trust is irrevocable. You should check with your personal tax consultant to be sure that this money will not be needed to fund your retirement or other family obligations. The advantage to VOR is that you can designate VOR to receive some immediate or periodic grants rather than be a beneficiary of your estate plan later. The advantage to you is that you receive an immediate tax deduction when you open the lead charitable trust or make an additional gift to the trust. In the case of a gift of stock, you may also be able to avoid sizeable capital gain tax consequences. V

## Planning for the Future: Have you had "The Talk?"

Many of our loved ones with mental retardation are aging, and so are their families. In some instances, a mother, dad or sibling has served as the court appointed guardian of the individual with mental retardation for many years. However, that guardian's health is now diminishing. What should guardians and families do? It's time to do some planning.

Many families have avoided having "The Talk" – meaning, who will be the successor guardian or co-guardian to manage the disabled loved one's care after the current guardian passes on? This discussion is hard to initiate.

VOR strongly urges families to view successor guardianship planning as an act of empowerment. Planning for a successor guardian is a proactive, constructive step for ensuring that your loved one's future health, safety and happiness are protected. Without a guardian in place, the disabled person's fate is left to bureaucrats, who do not have a singular duty of loyalty to the person with mental retardation. Parents, siblings, and other family members should discuss who within the family is best suited for this role.

Families also should keep in mind that guardianships can be crafted to meet the unique needs of not only the person with a disability, but the individuals who are willing to serve. For example, co-guardians can be established whereby the current guardian is joined by the newer or younger successor guardian. With co-guardianship, the responsibilities can be shared and, in the event that one co-guardian is not available to make a decision, the other co-guardian is ready and available to act. Alternatively, a limited guardianship of the person only might be a good option when the guardian prefers to deal with personal, medical and/or legal matters. Guardianship of the estate is another option where there is a need for decisionmaker to handle finance. To assist you in deciding the type of guardianship that is best, families should seek the advice of experienced attorney, who is knowledgeable about guardianship law and skilled in moving you through the sensitive family dynamics for implementing change.

For some families, the guardian is ready to plan for a successor, but there is a lack of family members available or willing to serve. In this circumstance, guardians should begin the search for a professional guardian to act in partnership with the existing guardian or in a successor capacity. With the expanding numbers of elderly, there are more professional guardians and, thus, greater choice in finding a successor guardian with similar values and talents.

Ultimately, it is critical to the long-term well-being of your loved one with mental retardation that the family have "The Talk." Without this important planning in place, a guardian could die and the person with a disability could be without an immediate guardian to act on his behalf. Probably the saddest testimonial to a guardian's years of devotion would be to leave your loved one with mental retardation without a ready, court-appointed protector.

Have "The Talk" today. (Source: *Newsline*, The Dever Association (Massachusetts), October 23, 2005). V

**"There can be no greater symbol of commitment and love than for a family to decide who will serve as the guardian of a loved one."**



## VOR Welcomes Tribute Donations

Gifts have been received

### In Memory of

Carlys Crile  
Dickie Gayheart

### In Honor of

Jeffrey Gans

Gerald Cukierski, CPA and Peter Sharp, CPA  
Cukierski & Kowal, LLC

### In Celebration of

The Marriage of Jennifer and Sean O'Brien  
Benny Sims 20<sup>th</sup> Birthday

## VOR Tribute Donations

Your Name \_\_\_\_\_

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Please send acknowledgment to:

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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**

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_ E-mail \_\_\_\_\_

Please check \_\_\_\_\_ I am a new member  
as appropriate: \_\_\_\_\_ 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 you receive VOR's information, so please call if \$25 per year poses a financial hardship.

**Oct06**



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Speaking Out for People  
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